

# Truth and Citizenship

## Towards an ecology of human rights

Simon Duffy

Editors: John O'Brien and Simon Duffy

THE NEED FOR ROOTS





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## About the Author

### **Simon Duffy**

Dr Simon Duffy is Director of the Citizen Network Research and President of Citizen Network Coop. He is a co-founder of UBI Lab Network, the Neighbourhood Democracy Movement and the Self-Directed Support Network. In 2008 he was awarded the RSA's Prince Albert Medal for his development of self-directed support in social care.

## About the Editors

### **Simon Duffy**

see above

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John is a leading thinker in human services. He is affiliated with the Center on Human Policy, Law and Disability at Syracuse University in the US and the Marsha Forest Centre in Canada.



# Foreword

Professor David Abbott

Norah Fry Centre for Disability Studies, University of Bristol, May 2020

Simon Duffy came to give the annual Norah Fry Centre Annual Lecture in January 2020 when, at the time of writing at least, the world felt like a very different pre-coronavirus place. Our annual lecture has been graced with the insights and wisdoms of folks such as Jenny Morris, Tom Shakespeare, Sheila Hollins and Alan Roulstone to name just a few. Each speaker has had something unique to say but always foregrounded disability justice, social action and the links between academia and activism.

Simon's lecture and the focus of this paper makes a choice not to rehearse the harms done to disabled people by the current and recent governments. In these days of pandemic, we have seen something ugly and explicit about the eugenics underpinning responses to the virus (Liddiard 2020). Instead citizenship, rights and love are the tenants of the paper that I found and find most compelling.

Two of my academic heroes, Jenny Morris and Ruth Lister, have both written persuasively and powerfully about citizenship. Both feminist scholars, they highlight the way that access to citizenship can be heavily mediated and restricted by those with more power at the expense of those with less power. In Lister's (2007) discussion of 'inclusive citizenship', she reminds us that much of the debate about citizenship has been theoretical and abstract and rarely been enlivened by empirical exploration or lived experience – a challenge that remains real. Morris (2016) unpacked how and why the UK government was systematically undermining access to the category and reality of citizen and citizenship for disabled people. Her paper seeks, as Simon's does here I think, to link citizenship (and rights) with questions of values, collectivism and community. She wrote:




*...we have to recognise what are the fundamental causes of the problems we face. A denial of the common good; an attack on the idea that we can pool resources to promote the common good; a removal of democratic accountability from government and local government and their replacement by the accountability of the market.*

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In the paper here, Simon suggests that rights on their own are perhaps a little ‘cold-hearted’, distant, to be bargained for and won or lost. Again, we have seen some of this in relation to current, so-called ethical dilemmas about rights to the full range of treatment options for those who contract coronavirus. The right to health care quickly became politicised with disabled people fearing that their rights would quickly be put to one side in favour of more deserving (productive) folks (Hastie 2020). Gerard Quinn (2009) who argues for the potentially transformative power of rights, recognises that the work to be done is to understand the value systems underpinning rights and to translate words into action and the abstract to the everyday, “... the text alone does not guarantee that its values will be transposed into the worldview of policy and law-makers”. One way of doing this he suggests is to support minority voices to become more prominent and to, “put the person back in the frame”, to mitigate against their relative powerlessness.

This brings me neatly onto love. It’s more than a decade ago since I was involved in research with LGBT people with learning disabilities – the first study of its kind (Abbott & Howarth 2005, Abbott & Burns 2007). Amidst the accounts of pain and discrimination, what stood out were unassailable tales of wanting to love and be loved. This seems obvious but somehow, at the time, was not obvious at all. Something of the instantly recognisable and near universal stories about love that we were told proved a crucial part in changing hearts, minds, some policy, some practice and some lives. The work and the bravery of people who shared their stories with us put people “back in the frame”.

Simon’s paper then is a fruitful reflection on the intersection of rights, values, citizenship and community and on the night the audience had a range of positions and responses to it. Afterwards there were stories and music from father and son Fionn and Jonathan Angus, activists



and musicians (<https://www.fionnathan.com>). There was wine, song, community and love.

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# 1. The end of our illusions

When I began to prepare this talk I thought I might try and present some of the work we and others have done to highlight the policy attacks on disabled people; and in particular the way in which the UK Government seems to be intentionally ignoring or manipulating evidence, promoting stigma and, as the United Nations has clearly stated, breaching the human rights of disabled people.<sup>1</sup>

In particular, I thought about running through my effort to carry out a cumulative impact assessment of Government policy on disabled people, at a time when the Government claims - paradoxically - that it is impossible to evaluate the impact of its multiple policies, but that it is confident that they will be positive.<sup>2</sup> I also wanted to talk about the dreadful Troubled Families Programme that abuses families (often families of disabled people) by blaming them for problems they did not cause - adding insult on top of disadvantage.<sup>3</sup>

I wanted to discuss the work of my colleagues Catherine Hale, Claudia Gillberg and George Faulkner, who have each described the ways in which prejudice against people with so-called invisible disabilities, like ME, has been exploited to promote damaging welfare reforms, often abusing medical research.<sup>4</sup> Or the work of Mo Stewart, who has shown how many of these policies have evolved from an ideological commitment to undermine the welfare state with the financial assistance of US private insurance companies. I also wanted to cover the collapse in funding for social care for adults and children and the increased rates of suicide and mental illness associated with the roll out of the Work Capability Assessment.<sup>5</sup> Many of these facts are described in detail in our recent publication - *Second Class Citizens* - by Stef Benstead.<sup>6</sup>

I also thought about the lessons we could draw from all the different campaigns that we have been part of to resist these injustices. The creation of the Campaign for a Fair Society, Pat's Petition, the Spartacus Network, the WOW Petition, the Learning Disability Alliance, Learning Disability England, the various campaigns against ATUs, the ongoing efforts of Disabled People Against the Cuts (DPAC) and the emerging Reclaim Social Care campaigns.<sup>7</sup>

In particular, given the limited success of all these campaigns, I thought it would be useful to discuss why it is so difficult to get the media, politicians, the big charities and the general public to take these problems seriously. Why do so many groups seem unwilling or unable to resist these injustice - often becoming, by their silence, complicit?

But then I began to doubt myself. We have just elected as our Prime Minister a man who has been sacked twice for lying.<sup>8</sup> I am sure I do not need to persuade anyone in this audience that current disability policy is largely bad, that our leaders don't really care and that we can no longer expect evidence or rationality to lead automatically to good policy. Having promised to talk about Truth and Citizenship, I feared I would spend my whole time talking about Lies and Injustice. This would be depressing and self-defeating.

Perhaps - at a time when it's hard to see the light - it is best to seek the light and focus on Truth and Citizenship. For there are certainly some positive things to think about and there is certainly no excuse for giving up hope in ourselves - even if it is hard to have hope in our current crop of political leaders.



## 2. Truth matters

*Conceptually, we may call truth what we cannot change; metaphorically, it is the ground on which we stand and the sky that stretches above us.*

**Truth and Politics in Arendt H (1956) *Between Past and Future*.**  
New York: Penguin. p. 264

It is no explanation of our current crisis, but it is surely more than coincidental, that we have been worrying about Truth for many decades. In particular academics tend to be very cautious about claims to truth. You won't get published in your average journal without hedging all your claims with significant caveats. Even if we do accept the truth of logic or the need for data we certainly become very worried about claims to moral truth.

There are some good reasons for this; but also some very bad reasons for this.

If we are not careful we end up conceding far too much ground to the enemies of truth. If we treat every position as valid - then some will exploit this fact and poison public discourse with lies and dangerous claims. If we are not careful we might be like those journalists who counter-balance a climate scientist with the claims of Donald Trump or become like whoever it is who puts Nigel Farage on the television at every opportunity. Balance means exercising moral judgement - there is no escape - not every claim should be given equal weight.

There are also very good reasons for treating morality and justice as matters of truth - not as opinions or as some kind of social construct. My doctorate was an argument for the existence of moral truth, and through the centuries philosophers, theologians and ordinary people have typically lived by the assumption that morality is real and that there is nothing dubious about ethical

truth.<sup>9</sup> The tendency today to treat morality as a set of pick-n-mix values is certainly very modern, but it's also pretty stupid.

Moreover – even if you don't believe me, or the many better thinkers who came before me – isn't this a little like the issue of climate change denial. I am no expert in climate science and I can't be sure that every claim that is made about the impending crisis is valid. But if the experts are wrong, yet I believe them, the worse that can happen is I waste some energy doing things I didn't need to; but if I ignore them when they are right, then I will have contributed to the cataclysmic destruction of the natural world and of humanity itself.

This is a version of what in philosophy is called Pascal's Wager. Pascal said – if the cost of refusing to believe in God is an eternity of torment – then we'd be much better off believing in God, even if God's existence was extremely improbable. Having faith costs us nothing we cannot afford to lose, but it offers us much. Too much doubt may risk absolute destruction.

Just as there are perhaps better arguments for God's existence than Pascal's Wager, so there are better arguments for the reality of morality than the one I'm making here – but I still think it's an important starting point for us. Why are you doing disability studies, campaigning for human rights, training as a social worker, creating new organisations, campaigning, or doing whatever it is that you do that led you here tonight? It is surely because you believe that this work really matters – you want to do the right thing – not the wrong thing. You were not making some random career choice.

Interestingly, sometimes people's unwillingness to accept the reality of morality has a moral motive. For sometimes people confuse moral realism with moral dogmatism: they think that if someone is claiming there is a truth about morality then they are also claiming that they know what the truth is. But this does not follow. It is quite possible for me to think that there is moral truth without thinking I am the one who knows it. In fact it is precisely this combination of truth and uncertainty that makes humility, moral enquiry and rational debate possible.

It is only the relativist who can be dogmatic. If I make up my own moral truths then my claims are as justified as anyone's.



Whatever I choose to believe in I am always right – and whatever you believe in you are right too.

We need to leave this relativism behind us. If we are going to try and make some real progress the first thing we should do is have faith in the value of what we are doing. For instance, when we claim that every human being has human rights let's assume that this is true and not let ourselves have the rug pulled from under our feet by those who claim that rights are just social constructs.

In fact the existence of disability rights – which are one kind of human right – is the central claim around which my talk has been constructed. I want to defend disability rights, but also to suggest ways in which we need to look beyond rights and see the value of other moral perspectives, many of which I think are essential to the viability of disability rights themselves. Rights can be real without being independent of other moral realities.



### 3. Fragile ideologies

My second claim is that not only should we assert the truth of morality, but that we also need to think a bit of a harder think about what moral reality actually demands. Perhaps the rather sceptical and relativistic twentieth century has left us ill equipped to know what we should be standing up for. In fact if we push aside the curtain of relativism and examine the ideals that rule the world today, we will find that we are living in a world which is dominated by nineteenth century values, and rather dubious values at that.

The dominant ideals - lurking behind most government policy or research in social science - are the assumptions of utilitarianism, liberalism and Marxism.<sup>10</sup> These are each very limited, dangerous and often self-contradictory philosophies. Moreover, in broad historical terms, they have often devolved and turned into the bastard ideologies of the twentieth century: meritocracy, eugenics, racism, fascism and communism.

This may all seem too sweeping. But think about what those competing nineteenth century ideas have in common. In a sense they all see human beings as broken happiness machines; and they each offer to provide the happiness that disordered reality denies us, whether through technocratic control, the mindless operation of the market or via the inevitable revolutionary process of historical materialism. We are broken - and they will fix us. They are inhuman philosophies, heartless and hollow.

Of course, in the second half of the twentieth century - after the horrors of the Holocaust, World War II and the emergence of totalitarianism - we saw important efforts to rebalance things and to find a more human understanding of how we might live together as equals. The welfare state was developed to provide

people with the security people need to thrive and live without fear – protecting people from the forces that created totalitarianism.

*“All our experiences - as distinguished from theories and ideologies - tell us that the process of expropriation, which started with the rise of capitalism, does not stop with the expropriation of the means of production; only legal and political institutions that are independent of the economic forces and automatism can control and check the inherently monstrous potentialities of this process. Such political controls seem to function best in the so-called welfare states whether they call themselves socialist or capitalist. What protects freedom is the division between governmental and economic power, or to put it in Marxian language, the fact that the state and its constitution are not superstructures.”*

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**Hannah Arendt from Arendt H (2013) The Last Interview and Other Conversations.** Brooklyn: Melville House.

Human rights – a full set of rights not just a limited set of political and property rights – were asserted to counterbalance the destructive ideologies of central control. More specifically when it comes to protecting the interests of people with disabilities we have seen human rights develop into a powerful framework of disability rights. This increased focus on human rights has been transformational and positive. Deinstitutionalisation, independent living and the right to be a free and equal member of society are now widely accepted as hallmarks of a civilised society. Disability rights – to some degree – are now essential elements of progressive social policy. <sup>11</sup>

## 4. The limitations of rights

But my fear is that human rights, on their own, will never be enough to bring about the kinds of changes we want to see. For rights also have their limitations and, in the UK at least, we are learning that Governments have equipped themselves quite well with the means to blunt the impact of human rights. For example, highly regressive welfare policies, like the Employment and Support Allowance, have also been defended as advancing people's right to work. At the same time efforts to defend disabled people from attack on the basis of human rights have also failed to get the backing of the general public. Damning human rights reports from the United Nations barely merit a mention in the UK's mainstream media.

There are a number of problems with human rights if we try to rely on them as the only guide to moral behaviour or if we think that they can be the only foundation of a just society.

The first problem is that rights can seem very negative. Rights are things we claim or demand from others. Some rights (negative rights) seek to place restrictions on what others do to us - don't hurt me, don't steal from me, don't treat me unfairly. Other rights (positive rights) demand that others do something for us - give me money, food, housing, education. Although it may seem unfair to put it this way, the problem is that focusing only rights can seem almost selfish, the opposite of being virtuous. To insist on our rights is to demand that others change what they are doing, and it is also an expression of our weakness and vulnerability.



The second problem is that rights can also seem very legalistic and threatening. We don't tend to use the language of rights within loving families, friendships or community life. We only start talking about rights when things aren't working and there is always a hint of the courts and legal process about the use of the language of rights.<sup>12</sup>

The third problem is that claims to rights can feel unsustainable. For instance, there seems to be a tension between saying we all have the same rights, while also pointing out that some of us are different, that we face extra barriers, that we need more support, more money and that society should be changed in some other way to make it accessible to us.

Increasingly some groups are saying that they cannot afford to respect our human rights, that we do not even have the right to demand such rights and that if we were really equal then we wouldn't need these special rights in the first place. As the saying goes:

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*"You can't have rights without responsibilities."*

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Now this is ambiguous. It is true that no right can exist without a corresponding duty. Rights without duties are just empty shells. But it doesn't – logically follow – that one person must have the same set of rights as another – rights and duties only need to balance out across a whole community.

But this solution to the problem of unequal need is only partial; for we are not always clear why some people are entitled to receive something extra while others must be forced to provide that something extra. At times of social and financial anxiety, like today, it is very easy for those defending injustice to exploit the sense that the rights of special groups are not real and that those right claims are excessive and that they are being exploited by groups who should not really qualify for special treatment.

In fact modern politics seems to oscillate around such disputed boundaries. One of my favourite social movements is Acorn (which came to the UK from the USA and started here in Bristol) and they have a great slogan:

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*“Take back what’s ours.”*

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This slogan makes perfect sense in the context of more than 40 years of growing inequality and neoliberal expropriation. But it is also clearly a threat to those who have benefited from this state sanctioned redistribution to the wealthy and in long-run it raises big questions. What is ours? What is yours? Whose rights matter most? Where does my security lie – with the state and social rights or with my family and the right to private property?

Every society needs to find a balance between what is privately owned and what is public and shared.<sup>13</sup> Given the inevitable inequality created by social structures, redistribution is an essential feature of a just society – but that redistribution must feel fair if it is to be sustainable. If our only approach is to advocate for rights we will find ourselves unable to create a vision of an attractive and sustainable community that can bring people together and build wider social support. Worse, we may come across as selfish or threatening – this may not inspire the social change we want to see.

## 5. The role of rhetoric

My temptation at this point is to address the deeper philosophical questions at stake here and try to argue for my own preferred moral and political theory – one that embraces the existence of rights – but situates those rights within a broader context.<sup>14</sup> But I don't want to do that, in fact I think that approach can actually be rather unhelpful and may reinforce our current problems.

Academic and theoretical debate is interesting and valuable – but do we really need another theory just now? If we are committed to disability rights, as I am, I think what we really need to do is think about how we persuade other people of the value of disability rights. The challenge we face is not theoretical, but rhetorical.

For instance, much of the initial advocacy around people with learning difficulties exploited the rhetoric of pity. I am old enough to remember the time when Mencap's logo was the teary Little Stephen – an image killed off in 1992.<sup>15</sup> Pity does get an emotional reaction; but not only is pity patronising it is also exhausting. And, when the well of pity runs dry, humans often do even worse things than patronise each other. There is only a short step between seeing someone as a pitiful and seeing them as a menace.<sup>16</sup> This is clearly not the way forward.

We are entering a new period and we will need to find new ways of defining what is important and what we must protect. This means persuading others and we need to find a rhetoric that is truthful, ethical and persuasive – in particular we need to persuade people who are not in our core group to understand the benefits of our values.

Rhetoric gets a bad name; if we see that something is designed to persuade someone then we may think it rather transparent and crude: 'Get Brexit Done!' for instance. But I think we need to learn from our classical and medieval forebears. Rhetoric is not

some dark art, practiced only by dangerous extremists. Rhetoric is the highest form of rational expression; rhetoric is our ability to persuade others, in order to find agreement for shared action. Rhetoric is the speech act of citizens.

Of course rhetoric can be misused – as can all good things – but it is better to learn how to use rhetoric than to invest all our time in mindless chatter or unloved and unread research. At best rhetoric is communication, connection and the creation of community. It should always be truthful, and at its best it is truth honoured by clear and persuasive expression.

Rhetoric – like truth – is three dimensional.

**First**, there is the logical or organisational aspect of rhetoric. Good rhetoric helps us see how different ideas can be combined in a way that is compelling. It clears away confusion and obstacles to our assent. Good rhetoric maps out a journey that we might want to take.

**Second**, rhetoric is representational, it offers us a vision of what is, what was or what might be, that connects the real world to our emotional life. It rings true with what we see and with what we feel. Good rhetoric makes us feel the journey is worth taking.

**Third**, rhetoric is performative, it calls us to action by inviting us into community with the speaker. Good rhetoric creates connection, trust and a space for us to define our own role. Good rhetoric pulls into fellowship on the journey itself.

Of course good rhetoric here means effective rhetoric – not rhetoric for the good. Good rhetoric is just as likely to serve bad ends as good – perhaps even more likely – because those with bad intentions need to focus even more on persuading people than those who assume that the right choice is the obvious choice.

A recent piece of very effective rhetoric was ‘Get Brexit Done’ a phrase which was repeated again and again, sometimes with the additional phrase ‘Unleash Britain’s Potential.’ In terms of its logic you couldn’t get a simpler argument and this was part of its charm. After three years of confusion to assert a simple idea, in a simple way, with no caveats and no context made perfect sense.

The cogency of the message was reinforced by the the nightly misery that the British public had undergone as Parliament failed – again and again – to agree a way forward. The idea that Brexit

might unleash Britain's potential suggests that there will be a release in energy as cease to bang our head against the Brexit wall. The simplicity of its message also helped the Government avoid any discussion of the multiple failings of the previous Conservative Governments and implied that we would now move on afresh.

The simple message was combined with an almost clownish performance by the Prime Minister, who presented himself as the kind of person who was quite happy to push on through and do the deed – however stupid the consequences.

Contrast this with the rhetorical strategy employed by Greta Thunberg. Her actions and words are designed to provoke a sense of crisis, to challenge the powerful, but also to pull people into global collective action. Her directness, her humility and her integrity are communicated at every stage. She behaves as if we are in a state of crisis that we are refusing to acknowledge and everything she does makes sense of that truth.

Rhetoric may be used for positive and negative ends. But rhetoric is certainly required if you hope to bring people with you; and if we think disability rights are important then we need to develop a rhetorical strategy that persuades people that such rights are important.



## 6. Rhetoric for rights

The good news is that collectively we have already done much of the necessary thinking; but where we may have failed is to take our own values and ideals seriously enough and to advanced those ideas outside of our own communities. I am thinking in particular of the ideas developed by thinkers like John O'Brien, Judith Snow, Beth Mount, Marsha Forrest and Jack Pearpoint and many others.<sup>17</sup> As you may know, these thinkers are part of a movement to advance the interests people with learning difficulties in particular - but much else besides - and they have led what I would call the Inclusion Movement.

My proposal is that Inclusion Movement offers us the ideals we need in order to sustain and support disability rights. Inclusion is not a threat to disability rights, but it helps us understand what it will take to bring those rights to life. Rights are essential - but we must think ecologically - we must identify the conditions that will help them to thrive. Inclusion without human rights is near impossible; human rights without the values of inclusion may be unsustainable.

There are three aspects of the Inclusion Movement that I particularly want to stress here: community, love and citizenship. These are all interconnected realities - but they each offer slightly different support to the notion of disability rights.

As we discussed above, one of the problems with the idea of rights on their own is that they seem to generate selfish demands which those outside the right-claiming group can interpret as burdens, possibly unsustainable burdens, on themselves. This is not helpful and the more the listener sees themselves as on the other side of these rights - always the giver, never the receiver - then

the more the listener will switch off. Part of the solution to this problem is to focus on the universal benefit of being a member of a community that takes care of each other, that honours its obligations to each other.

Community makes sense. We are hungry for community and many other problems in the modern world are created by our refusal to pay attention to the conditions necessary for communities to thrive. If we advance disability rights as universal rights – there to protect everyone in the community – and there to support everyone’s contribution back into the community then we turn everyone into a beneficiary and everyone into a contributor.

This also raises of the question of whether we should re-examine the boundary between who is a disabled person and who is not a disabled person. Perhaps non-disabled people are just potentially disabled people or previously disabled people. Perhaps we need a bigger we.<sup>18</sup>

We also need to start talking about love, and in particular to take a much more positive approach to the idea of family. When all is said and done it is primarily families who do much of the work of community life. It is families that many of us want to go home to, and as we grow up it is a good family, above everything else, that we want to create. Families can get screwed up – just like everything else – but the kind of love that families create and inspire can never be replaced. The battles between family advocates and disability advocates are very damaging to our cause; and understanding what it takes to value families is a ticket to connecting to the hearts and minds of millions of ordinary people.

A greater focus on love and family may help us avoid some of the heartlessness that creep in if we only talk about rights. Currently many families struggle, barely coping with minimal support. Even if they are aware of their rights those rights can often feel very risky. The exercise of disability rights may seem to threaten the wellbeing of a loved one with institutionalisation, poor quality care, social isolation or abuse. Families also need rights, including the right to be respected as a family. Families create support – the most powerful source of support in the world – and families often need the support of their community to carry on or to change when they need to change. Families need to be



put at the heart of the story of disability rights. Do not families have rights too? <sup>19</sup>

Finally we must assert our citizenship and invite others into citizenship. People with learning difficulties understand the everyday value of equal citizenship better than most. In my experience they are also amongst the first to recognise the value of the responsibilities citizenship brings. We cannot build a better world by waiting for 'them' to do 'it' for 'us'. Especially as any better world must be egalitarian and democratic. We begin to build a better world the day we go out and behave like a citizen.

Rights serve citizenship - they enable us to live a life of meaning, to contribute to the community and to build relationships of love and friendship. Rights are also created by citizens - because it is citizens who fulfil the duties that rights create, whether that's paying our taxes, respecting the law or - more importantly - by building the kinds of inclusive communities that nurture the diverse talents of all their members.





## 7. Citizen Network

I began by running through some of the work of the Centre for Welfare Reform over the past ten, difficult years. At the end of 2019 I agreed with the over 100 Fellows of the Centre to begin the process of turning the Centre into a sustainable cooperative and citizen think tank. This will be an ongoing challenge, especially when the Centre's ethical position remains in conflict with many of the principles of the UK Government and the Centre has maintained a commitment to tell the truth which often brings it into conflict with those who have power and money.

However I want to end by saying something about a newer project, which several of us began in 2016 - Citizen Network. Citizen Network is still in its infancy, but it is an exciting project which is very relevant to what I have been exploring today. Fundamentally Citizen Network is committed to the notion that every single human being matters and that in order to properly value each other we need to ensure everyone can live a life of citizenship.

What is bold - even outrageous - about this project is that we are committed to take ideas that have been developed by people with learning difficulties and their allies and to treat them as if they really do apply to everyone. We assume everyone is different - and that's a good thing - as Judith Snow puts it "Our differences are a gift."

Moreover this gift is not just the gift of human uniqueness - the fact that I am me, and that you are you - but it is also the basis of human community and equality. I can only be me if you can be you. Defining our value by reference to some external meritocratic scale where some people score higher than others does not just

do an injustice to those who will score lower, it undermines the whole value of humanity itself:

*Someone once told Rabbi Mendel that a certain person was greater than another whom he also mentioned by name. Rabbi Mendel replied: "If I am I because I am I, and you are you because you are you, then I am I, and you are you. But if I am I because you are you, and you are you because I am I, then I am not I, and you are not you."*

**Buber M (1991) Tales of the Hasidim.** New York: Schocken Books. p. 283

And it is only through this earthly appreciation of our mutual differences, our gifts and our needs – and our needs are a gift – that we can create the communities by which we create the only kind of equality that really matters – the equality that comes through equal membership of community. As Arendt puts it:

*Aristotle explains that a community is not made out of equals, but on the contrary of people who are different and unequal. The community comes into being through equalising, isathenai.*

**Arendt H (2005) The Promise of Politics.** New York: Schocken Books. p. 17

But how do we take these ideas seriously?

Well one way seems to be by building a community that openly values them and which communicates them and which helps people develop collective, collaborative and cooperative forms of action to live by these ideals.

My friend Marilyn Wilson told me many years ago – “people with learning difficulties will save the world” – and I still see no reason not to believe her. At the moment it seems to me the world faces a triple crisis of citizenship and it needs people with learning difficulties more than ever before.

We have become anxious about including people who seem too different. Will disabled people be included in communities when we seem prepared to allow children to be drowned in the Mediterranean or in the Rio Grande?

We seem willing to accept growing levels of inequality, oppression and exploitation. Will disabled people be treated with

respect when we allow our welfare system to become increasingly punitive, controlling and impoverishing?

We seem willing to accept the cataclysmic destruction of the planet and the diversity of plant and animal life and the prospect of making the world increasingly uninhabitable. Will we respect our own human diversity if we seem to care so little about natural diversity?

But flip this round. What may seem a dispiriting challenge is also full of potential. Disabled people and families are working to welcome refugees. Disabled people are working to challenge the crazy benefit system. Disabled people are part of the campaign to save the planet.

These challenges help us find common cause, and not just with other oppressed groups, not just with different people in different countries but with everyone.

Is not citizenship the thing we all strive for – just as the ancient Greeks noticed two and half thousand years ago? Is not citizenship – active citizenship – both the end and the means of a just society?

Citizenship offers a life of meaning – connection, community, contribution – with freedom – and the means to live with others without exploitation or control. Aren't these fundamental features of any human life? They are certainly all within the realm of possibility – to save ourselves we must save the planet, to save the planet we must save ourselves, and to do this we must each wake up to the challenge of being a citizen.



# Conclusion

*Citizens are people who can say “I belong to this place and it’s people and I am willing to act from responsibility for my belonging.” People with disabilities are among those who are vulnerable to social exclusion: being pushed to the edges of society and deprived of what they require to participate actively. Citizenship creates a framework for understanding what it is that we’re really trying to do when we become allies with people with disabilities who are seeking a life that makes sense.*

**O’Brien in O’Brien J and Blessing C (eds) (2011) *Citizenship & Person-Centred Work*. Toronto: Inclusion Press. p. 110**

To defend human and disability rights we need to understand the conditions in which these rights thrive. We need an ecology of human rights. The seed of human rights – in order to be more than an idea – needs the water of citizenship, the earth of community and the light of love. Law – on its own – does no work.

In fact rhetoric is not mere rhetoric. The ideas that inspire and motivate us are the ideas upon which must be build and no useful theory can afford to reject.

“The Truth is out there” said Mulder to Scully. It is. But it is also within us. What we really seek is a life of meaning, contribution and love – which together also go by the name of citizenship. In the UK we are learning that the existing systems cannot be trusted – relying on the establishment and established patterns of behaviour risks destruction.

Change is necessary.

But that change starts within. We must wake up our inner citizen, ask ourselves whether what we are doing is really helping – not just others – but ourselves – are we becoming the person we need to be, the best version of ourselves. This is demanding, but truth is demanding. Let’s accept that challenge.



# Notes


1. There have been several UN committee reports outlining the persistent failure of the UK Government to respect human rights, including disability rights. See, for example *UN Committee on the Rights of Persons with Disabilities* (CRPD) (2016) *Inquiry* concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention.
2. In 2010 I facilitated two meetings of leaders from the early period of deinstitutionalisation, to look backwards in order to think about what future strategies might be helpful. The first meeting was held just as the Coalition was being formed and at the time many of us were hopeful that ideas like the Big Society might reflect our hope for a more inclusive community orientated society - how naïve that seems now.

At the second meeting Ritchard Brazil argued forcibly that we all need to go and look at the Government's spending plans and we'd understand that we were in store for the most severe attack on the welfare state we'd ever seen. He was right and this meeting led to the creation of the *Campaign for a Fair Society* which tried to alert people to the severity of what was happening and eventually morphed into the *Learning Disability Alliance* in 2015 ahead of the General Election, and which then became *Learning Disability England* after the election. Over those years we published three distinct and increasingly sophisticated analyses of the cuts, the last of which was called *Counting the Cuts* (2014).

We also worked to support two petitions which aimed to get this issue discussed in Parliament. The first of these was called *Pat's Petition*, named after its originator Pat Onions, and the second - backed by the comedian Francesca Martinez - the *WOW Petition*. Our research was cited by John McDonnell in the subsequent parliamentary debate and this led to a commitment by the Minister of State for Disabled People, Rt. Hon Mike Penning MP to contact me and my "team" (sadly there was no team, it was just me, a computer and the internet).

I never did meet the Mike Penning's team as they refused to meet my requests: (a) to explain what was wrong with my methodology, (b) to explain how my data sources could be improved and (c) to include representatives from the relevant Government departments. Of course I know that it was very likely that they would refuse these requests, because I knew that the goal of Government was to neutralise the impact of my criticisms by being able to say they had met me but had been unable to make any progress. How could they possibly do anything else? I saw my goal as simply drawing the discussion out and trying to force as much of their refusal to deal with this matter in an open and rational manner into the public domain. Hence I published all of my correspondence with the DWP officers here: <https://citizen-network.org/library/next-steps-on-a-cia.html>

In the subsequent correspondence the civil servant who acted for the Minister explained that:




“...the main reasons why we do not believe that such analysis can be conducted accurately are that: (a) our survey data is limited, particularly in terms of the capturing of the severity of disability; (b) there are a number of overlapping reforms coming in at different points up to 2017/18 and that the order of reforms is important to capture; (c) the caseloads are dynamic, so changes in one benefit will affect eligibility to others and this is necessary to capture in any analysis; and restrictive assumptions are needed around how income is shared within households.

“I would just like to reiterate that the Government expects its reforms to taxes, welfare, and public service spending to have a long term positive impact, in particular helping to get more people into work by making work pay and providing greater support for those who cannot work by targeting resources more effectively. We can expect to see people moving into work and taking more hours.”

In other words we don't know how to calculate the likely impact of multiple 'reforms' and the fact that we are doing many different things at the same time makes it even more difficult to know what will happen; nevertheless we are confident that the outcomes will be positive. Of course we now know even more about the very negative impact of these 'reforms' on mental health, suicide rates, poverty rates for disabled people and the increased death rates. Yet none of these facts has changed the course of Government policy. Extreme cuts in social care continue, cuts in Housing Benefit and the cuts to benefits are also entwined with increasing levels of micro-management, scrutiny, sanctions and a climate of fear. Films like *I, Daniel Blake* demonstrate the almost absurdist reality of Government policy.

3. See for example the forensic analysis of this dreadful policy in GREGG D P (2017) *The Great Troubled Families Fraud: State Lies & Failed Policies*. Spital, Wirral: Green Man Books.
4. The various groups who are sometimes labelled as having chronic illnesses have been particularly hard hit by government policy. These policies are often functions of what can be called epistemic injustices, where often academia itself seems to play an important role by disguising or distorting an injustice, often to serve professional interests. See for example, FAULKNER G (2016) *'In the Expectation of Recovery' Misleading Medical Research and Welfare Reform*. Sheffield: Centre for Welfare Reform. HALE C (ed.) (2019) *Stories of Our Lives: Case studies from the Chronic Illness Inclusion Project's emancipatory research on benefits and work*. Sheffield: Centre for Welfare Reform. GILLBERG C (2016) *A Troubling Truth: Chronic illness, participation and learning for change*. Sheffield: Centre for Welfare Reform.
5. STEWART M (2017) *A sense of betrayal*. JOURNAL OF PUBLIC MENTAL HEALTH, Vol. 16 No. 1, pp. 6-8. <https://doi.org/10.1108/JPMH-05-2016-0023>.
6. BENSTEAD S (2019) *Second Class Citizens: The treatment of disabled people in austerity Britain*. Sheffield: Centre for Welfare Reform.
7. My own personal journey during this period began with the utterly naïve assumption that if the facts were made clear then the public's sense of outrage would lead to revulsion with the Government's policies. The painful lesson I had to learn was that it is not enough to just publish something and to hope that people's natural sense of justice would take over. There seem to be a series of institutional or social blockages



which mean that just telling people bad news does not lead to change. Hopefully we will see justice eventually, although this will do nothing for the lives harmed or lost. Certainly there is a strong case for arguing that disability rights are far from safe and that only a more organised and independent form of advocacy and social pressure can provide some guarantees in the future. However, to date, efforts to coordinate such an effort have proved fruitless.

8. OBORNE P (2021) *The Assault on Truth: Boris Johnson, Donald Trump and the emergence of a new moral barbarism*. London: Simon & Schuster.
9. DUFFY S J (2001) *An Intuitionist Response to Moral Scepticism: A critique of Mackie's scepticism, and an alternative proposal combining Ross's intuitionism with a Kantian epistemology*. PhD Thesis, Edinburgh University.
10. DUFFY S (2013) *The Unmaking of Man: Disability and the Holocaust*. Sheffield: Centre for Welfare Reform.
11. UNITED NATIONS (2006) *Convention on the Rights of Persons with Disabilities* (UNCRPD)
12. Kant argues that we refer to concepts of duty and rights when natural good will is missing. See for example, Kant, I *Groundwork of the Metaphysic of Morals* in PATON, H. J. (ed.) *The Moral Law*. London: Hutchinson, 1948. [2]
13. An excellent discussion of the basic human need for both public and private property can be found in WEIL S (1987) *The Need for Roots: Prelude to a Declaration of Duties Towards Mankind*. London: Ark.
14. Jeremy Waldron provides an excellent discussion of rights in context. See for example WALDRON J (1983) *Liberal Rights*. Cambridge: Cambridge University Press.
15. My friend Simon Cramp discusses his experience of the battle to change this identity when he was working as a self-advocate at Mencap. CRAMP S (2017) *Don't Cramp My Style: a campaigning life*. Sheffield: Centre for Welfare Reform.
16. I have discussed this phenomenon in my *The Unmaking of Man*. DUFFY S (2013) *The Unmaking of Man: Disability and the Holocaust*. Sheffield: Centre for Welfare Reform.
17. Key references for the Inclusion movement. There are several important documents outlining the values and the practical wisdom of the Inclusion Movement. Most are published by Inclusion Press in Canada. It is hard to do justice to all of these writings but I would pick out:  
O'BRIEN J AND BLESSING C (eds.) (2011) *Citizenship & Person-Centred Work*. Toronto, Inclusion Press.  
O'BRIEN J & MOUNT B (2015) *Pathfinders: people with developmental disabilities and the allies building communities that work better for everyone*. Toronto, Inclusion Press.  
SNOW J (1994) *What's Really Worth Doing And How To Do It*. Toronto, Inclusion Press.



18. This is an important if contentious issue for disability politics. It seems to me that hopeful campaigns, like the campaign *Every Australian Counts*, have succeeded partially because they helped all Australians to identify with the needs and rights of disabled people. Casting rights in ways that are more universal helps people see that a special right is not exclusive, it is just a universal right which applies in special circumstances. current debates about Universal Basic Income seem likely to replay some of these debates. See for example, RICHARDSON C & DUFFY S (2020) *An Introduction to Basic Income Plus*. Sheffield: Citizen Network Research.
19. The work of Pippa Murray is important in demonstrating the possibility of linking together the rights of families and disabled people, see for example MURRAY P (2010) *A Fair Start*. Sheffield: Centre for Welfare Reform.





# The Need for Roots Series

The Need for Roots is a series of publications from Citizen Network that explores the purpose, values and principles that ground and nourish the changes in relationship, practice and policy necessary to creatively support full citizenship for all people. Our aim is to foster the sort of inquiry that will lead to a deeper understanding of core words like person, community, citizenship, justice, rights and service, as well as newer terms emerging from efforts to reform social policy such as inclusion, self-direction and personalisation. Proceeding as if the meaning of these key words is obvious risks them becoming hollow and spineless, functioning as rhetorical filler or tools of propaganda and fit only for reports and mission statements.

## THE NEED FOR ROOTS

We have named the series after the title of the English translation of a book by Simone Weil, a philosopher and activist. She wrote in 1943, at the request of the Free French Resistance, to chart a way her native France could renew itself and its citizens after victory over the Nazis. Far more than her specific conclusions we admire her willingness to search deeply in history for the distinctive strengths of her people and their communities, to think in a disciplined and critical way about human obligations and rights and the conditions necessary for their expression, and to risk mapping out in detail how her ideas might be realized in practice (a meaningful effort even though few if any of these specific recommendations were judged practical enough to attempt). As well, we are awed by her courage, throughout her short life, to struggle to live in a way that coherently expressed her beliefs and the insights generated by that effort.

We offer this series because we think it timely. Real progress reveals powerful ways that people at risk of social exclusion, because they need some extra help, can contribute to our common life in important ways. But there are substantial threats to sustaining and broadening this progress to include more people.

We want this series to benefit from the experience of all disabled people, of people who require additional support as they grow old, of people in recovery from mental ill health and trauma. We invite them to consider this series as a way to speak for themselves. In describing its social context we will speak from our experience of the people who have taught us the most, people with learning difficulties and other developmental disabilities, their families and allies.

In the span of two generations the life chances of people with learning difficulties and other developmental disabilities have markedly improved. Family organising and advocacy have redefined private troubles as public issues



and attracted political support and rising public investment in services. The growing cultural and political influence of the disabled people's movement has established the social model of disability as a corrective to an individualistic medical model, declared the collective and individual right to be heard and determine one's own life course and the direction of public policy, and struggled with increasing success for the access and adjustments that open the way to meaningful civic and economic roles. People with learning difficulties have found allies and organised to make their own voices heard, increasingly in concert with the disabled people's movement. Discrimination on the basis of disability is illegal in more and more jurisdictions and the *UN Convention on the Rights of Persons with Disabilities* asserts the right to full citizenship and the assistance necessary to exercise that citizenship. The population confined in publicly operated institutions has fallen dramatically and institutions in any form are losing legitimacy. Social innovators have created effective practices and approaches that assist people to develop their capacities, exercise meaningful direction of their own lives, and participate fully in their communities. More and more people with learning difficulties enjoy life in their own homes with chosen friends or partners, are employed in good jobs, join in civic life, and use generally available public services and benefits.

These improvements in life chances merit celebration, but the journey to citizenship for all is far from over. Governments' responses to fiscal crises have cut public expenditures in ways that fall disproportionately and harshly on disabled people and their families. Scandalous mistreatment, hate crime, neglect, and abuse continue to plague everyday life for far too many disabled people. People whose impairments call for assistance that is thoughtfully designed and offered in a sustained way by trustworthy, capable, committed people are particularly vulnerable to exclusion and deprivation of opportunity. The thrust to self-direction is blunted by rationing, restrictions on people's discretion, and risk management. Authorities turn aside people's claims on control of funding and family requests for inclusive school experiences for their children or entangle them in labyrinthine procedures. Far too few people with intellectual disabilities and their families hold the expectation of full citizenship and too many straightforward desires for access to work and a real home are trapped in bureaucratic activities adorned with progressive sounding labels; so rates of employment and household formation remain low.

There are even deeper shadows than those cast by inept or dishonourable implementation of good policies or clumsy bureaucracies nervous about scarcity and risk. Powerful as the social model of disability and the language of rights has been in shaping public discussion, individual-blaming and controlling practices thrive. Authorities typically moved from unquestioned control of disabled people's lives in the name of medical or professional prerogative to the unquestioned control of disabled people's lives in the name of a gift-model of



clienthood, which assigns authorities responsibility for certifying and disciplining those eligible for publicly funded assistance. As the numbers of people diagnosed with autism increases, more and more families organize to seek public investment in discovering or implementing cures. Most worrying, lives are at risk in the hands of medical professionals. Even in the area of appropriate medical competence, people with learning difficulties are at a disadvantage, experiencing a higher rate of premature death than the general population. The growing power of testing during pregnancy enables what many researchers and medical practitioners call “secondary prevention through therapeutic abortion,” framed as an option that growing numbers of parents accept as a way to avoid what they imagine to be the burdens of life with a disabled person. Medical researchers seek even more ways detect and terminate disabling conditions. Some defences of euthanasia seem to assume that disability makes life an intolerable burden - despite all the evidence to the contrary.

An adequate response to the mixture of light and shadow that constitutes current reality has at least three parts. Two of these are more commonly practiced and the third is the focus of this series of publications. First, keep building on what works to develop, refine and broaden the practices necessary to support full citizenship. This will involve negotiating new boundaries and roles in ordinary economic and civil life and generating social innovations that offer people the capacities to live a life that they value. Second, intensify and sustain organizing and advocacy efforts: build activist groups; strengthen alliances; publicly name problems in ways that encourage positive action; agitate to assure adequate public investment, protect and improve positive policies and get rid of practices that support exclusion and unfair treatment; and educate to increase public awareness of the possibilities, gifts and rights of all disabled people. Recognize that both of these initiatives will need to be sustained for at least another generation and probably as long as humankind endures.

These two initiatives - building on what's working and organising for social change - have two advantages over the third. They both encourage immediate practical actions that concerned people can take today and don't demand making time for study and reflection. Neither questions a commonsense view of history as steady progress: we may suffer setbacks at the hands of today's opponents but our trajectory is upwards and we can act free of the backward ideas of the past. Our culture offers few resources for sober consideration of the shadows that haunt our efforts, the ways we are ensnared by history and enduring human potentials for indifference, tragedy and evil. So it is understandable that we take refuge in the idea that progress is inevitable if we are smart enough, indifference can be enlightened by proper marketing, and tragedy and evil discarded as superstitions.



## TRUTH AND CITIZENSHIP

The third initiative, growing deeper roots, is a call for a different kind of action. *L'Enracinement*, the French title of Simon Weil's book, means something closer to "rooting"—actively putting down roots rather than just acknowledging that roots are needed. Deepening the roots of our work is a matter of conversation, with the words written down by the authors in this series, with one's self in reflection, with friends and colleagues in discussion, with a wider public in debate and political action. We hope that time spent in study will add meaning to our current efforts, foster a better understanding of challenges and possibilities, and generate and refine creative actions.

**John O'Brien and Simon Duffy**

# Publishing information

## Citizen Network

Citizen Network is a global community working to create a world where everyone matters. It was established in 2016, but was developed by the independent citizen think tank the Centre for Welfare Reform. In 2022 the Centre changed its name to Citizen Network Research and it now acts as the research and publications hub for Citizen Network.

[www.citizen-network.org](http://www.citizen-network.org)

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## The Need for Roots Series

Citizen Network is publishing a series of papers that explore the underlying features of a fair society. The series aims to engage different thinkers from many different traditions in celebrating human diversity and ensuring its survival.

