

## Precarious lives and resistant possibilities: the labour of people with learning disabilities in times of austerity

Keith Bates, Dan Goodley & Katherine Runswick-Cole

To cite this article: Keith Bates, Dan Goodley & Katherine Runswick-Cole (2017) Precarious lives and resistant possibilities: the labour of people with learning disabilities in times of austerity, *Disability & Society*, 32:2, 160-175, DOI: [10.1080/09687599.2017.1281105](https://doi.org/10.1080/09687599.2017.1281105)

To link to this article: <http://dx.doi.org/10.1080/09687599.2017.1281105>



© 2017 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



Published online: 29 Jan 2017.



Submit your article to this journal [↗](#)



Article views: 543



View related articles [↗](#)



View Crossmark data [↗](#)

## Precarious lives and resistant possibilities: the labour of people with learning disabilities in times of austerity

Keith Bates<sup>a</sup>, Dan Goodley<sup>b</sup>  and Katherine Runswick-Cole<sup>c</sup>

<sup>a</sup>Mutually Inclusive Partnerships, Bristol, UK; <sup>b</sup>School of Education, University of Sheffield, Sheffield, UK; <sup>c</sup>Research Institute for Health and Social Change, Manchester Metropolitan University, Manchester, UK

### ABSTRACT

This paper draws on feminist and queer philosophers' discussions of precarity and employment, too often absent from disability studies, to explore the working lives of people with learning disabilities in England in a time of austerity. Recent policy shifts from welfare to work welcome more disabled people into the job market. The reality is that disabled people remain under-represented in labour statistics and are conspicuously absent in cultures of work. We live in neoliberalisable times where we all find ourselves precarious. But, people with learning disabilities experience high levels of uncertainty in every aspect of their lives, including work, relationships and community living. Our research reveals an important analytical finding: that when people with learning disabilities are supported in imaginative and novel ways they are able to work effectively and cohesively participate in their local communities (even in a time of cuts to welfare). We conclude by acknowledging that we are witnessing a global politics of precarity and austerity. Our urgent task is to redress the unequal spread of precaritization across our society that risks leaving people with learning disabilities experiencing disproportionately perilous lives. One of our key recommendations is that it makes no economic sense (never mind moral sense) to pull funding from organisations that support people with intellectual disabilities to work.

### ARTICLE HISTORY

Received 2 June 2016  
Accepted 9 January 2017

### KEYWORDS

Precarity; queer; feminist; learning disability; austerity; employment

### Points of interest

- Disability studies have always engaged with labour.
- Many disabled people want to work but are not allowed.
- The last five years of British political life have made things even worse, with disabled people finding it harder than ever to find work when opportunities for labour are scarce for everyone.
- As work chances decrease, so opportunities for employment support level out.
- People with learning disabilities find themselves in a precarious position in relation to the workforce.

**CONTACT** Dan Goodley  [d.goodley@sheffield.ac.uk](mailto:d.goodley@sheffield.ac.uk)

© 2017 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

- We do know, however, that people with learning disabilities, their representative organisations and their supporters have found innovative ways of supporting people so-labelled into work.
- Financial cuts to these organisations and other services – known as austerity measures – risk undermining these innovative practices.
- We therefore need to urgently address the precarious lives of people with learning disabilities in society.

## Introduction

Disability studies have always engaged with labour. A leitmotif of the British social model of disability is that disabled people want to work but are not allowed (for example, Oliver 1996). These materialist scholars unveiled exclusionary workings of capitalist societies where disabled people are institutionalised as objects of labour (linked to practices of rehabilitative and medical practitioners) or made unemployable (associated with distinctions between those deemed work capable and those deficient). This literature exposed deeply disablist ideas underpinning work as a signifier of valued citizenship (Goodley 2016). The last five years of British political life have made things even worse, with disabled people finding it harder than ever to find work when opportunities for labour are scarce for everyone. As work chances decrease, so opportunities for employment support level out. Welfare interventions (for disabled and non-disabled people) around employment access and support are reduced by austerity. These new human landscapes demand nuanced theoretical responses encapsulated by a critical disability studies approach (Goodley 2014, 2016; Meekosha and Shuttleworth 2009; Shildrick 2012). This position starts with disability but brings in other identities – such as feminist and queer (McRuer 2012; Shildrick 2012) – to strengthen our analytical grip on the shifting sands of late capitalist societies. This approach includes recognising psychological impacts of oppression and the politicisation of emotional life (Goodley 2014). Experiences of discrimination – and incidents of marginalisation in relation to the labour force – are deeply unsettling. One concept that encapsulates this personal and political feeling of uncertainty is precarity, which:

designates that politically induced condition in which certain populations suffer from failing social and economic networks of support and become differentially exposed to injury, violence, and death. Such populations are at heightened risk of disease, poverty, starvation, displacement, and of exposure to violence without protection. (Butler 2009, ii)

Feminist philosophers understand precarity as a core element of the human condition and an organising trope for political action (Puar 2012). Our own take is that we disavow precarity. We are drawn to it as a human quality and attracted to its potential as a politicised phenomenon around which to agitate. Simultaneously, we are repulsed by precarity, especially when some human beings are made more vulnerable than others. Our understanding of the differential spread of precarity is enhanced by our engagement with dis/ability. This split term acknowledges that disability can never exist without implicit reference to its opposite, ability (see Goodley 2014). While our article is interested in the work that is done by disability to the world, we also deploy dis/ability to keep in mind that our social world values ability over disability. Vulnerability is being human. But the marks of ability or disability lead to very different relationships with vulnerability. Dis/ability emerges in our contemporary times:

as a moment of relational ethics: urging us to think again about how we are all made through our connections with others *and* encouraging us to embrace ways of living that are not rigidly framed by humanistic values of independence and autonomy. (Goodley, Lawthom, and Runswick-Cole 2014, 349)

Our article attends to an under-represented consideration; that employment in the lives of people with learning disabilities shines significant light on our precarious lives.<sup>1</sup> The lives and labour of people so-labelled have been sidelined by studies of dis/ability and ignored by mainstream social theories (Goodley 2016). This absence is a human tragedy. But by ignoring disability we are also missing a trick. Our research has demonstrated that not only is the meaning of precarity made coherent by people with learning disabilities but people so-labelled and their supporters have developed many imaginative ways of resisting precarity and working austerity. Turning to the politics of learning disability is not simply being inclusive; it might actually reveal tactics of opposition. In this article we begin by exploring the precaritisation of the lives of the many in neoliberal capitalist Britain. We then go on to consider the ways in which precarity is differentially spread, thinking specifically about the lives of people with learning disabilities. We resist what might be seen as a gloomy prognosis by following Butler (2009) and focusing on the bonds that bind people together to support people into work; bonds that in part emerge as a product of (and response to) precarity. Finally, we celebrate the productive potential that dis/ability displays in demanding us to think creatively and differently about work.

### Theorising precarity and work

We draw on feminist and queer philosophers' theoretical understandings of precarity, including the work of Lauren Berlant, Judith Butler, Bojana Cvejic, Isabell Lorey, Jasbir Puar and Ana Vujanovic in their roundtable discussion *Precarity Talk* (Puar 2012). We agree with Lorey (as quoted in Puar 2012, 165) that we are all precarious: 'all contingent beings, and life proceeds without guarantees just with more or less reliable infrastructures of continuity'. Living in precarity has become normalised as an 'ongoing structural economic problem' (2012, 166). Austere times augment the schism between those who are deemed able enough to work and those who remain jobless (Goodley 2014; Puar 2012). We live in neoliberal-ableism, where the neoliberal imperative for self-sufficiency (fuelled by economic disasters and austerity policies) is enhanced through the valuing of ableism (an ideological position that assumes people are ready, willing and able to labour and consume) (Goodley 2014). Ableism is the love child of individualism and independence: a hidden referent to the kind of citizen we should be. We all fail to live up to ableism's aspirations. Precarity is one psycho-political consequence of this failure. But some are found to be more wanting than others (such as people with learning disabilities). Austerity is a perfect accompaniment to neoliberal-ableist societies; driving forward self-sufficiency through work and shopping in order to make us free. Austerity normalises short-term, insecure and low-wage jobs. The rise in 'zero hours' contracts ensures employers are not obliged to provide employees with any minimum working hours although it is assumed that the worker is always available to labour. Precarious arrangements enable markets to thrive, while bodies and minds are made hazardous as promises of work are held out but denied (Puar 2012; Runswick-Cole and Goodley 2015).

Material attacks on the welfare state, underpinned by a zealous adherence to austerity, make us all vulnerable. But precarity is differentially, rather than equally, spread (Butler as

quoted in Puar 2012, 170). This is the 'special genius' of neoliberal-ableism in which there is wealth for the few and misery for the many (McRuer 2012). Britain has become a '5–75–20 society' (Morton 2015): a 5% elite with access to economic and social capital shielding them from austerity impacts; 20% marginalised, living in poverty; and the remaining 75% characterised as the 'new insecure' living in fear of becoming homeless and destitute. While the white middle-class experience precarity as a new ontology (Lorey as quoted in Puar 2012, 172), precarisation has a long history exposing our fragility as human beings (Butler as quoted in Puar 2012, 160), augmented further when work – and the promise of work – shapes what it means to be a valued global citizen. Paid work is tantalisingly held up as the object of desire but remains obstinately out of reach for many people with learning disabilities (Runswick-Cole and Goodley 2015). Unattainable desires are nourished by neoliberal-ableism.

### Inter/national policy discourses of employment

Work has held much promise for people with learning disabilities. In the 1980s, the Kings Fund (1984) published *An Ordinary Working Life* that built on O'Connor and Tizard's 1950s discussion about the value of employment (Humber 2013, 132). But still we know that less than 10% of people with learning disabilities in the United Kingdom are in paid work, and this figure has stubbornly refused to change for over 20 years (Humber 2013). Many people so-labelled want employment experiences (Sayce 2011). But disabled people are twice as likely to live in poverty (compared with non-disabled people) and live in fear of claiming benefits for being portrayed as 'scroungers' (Sayce 2011, 10). Employment is linked to better health outcomes, higher social status and increased economic well-being (Sayce 2011). Work builds relationships, enables community participation and promotes positive self-identities. As Sayce (2011, 6) reminds us, the right to work is enshrined in the UN Convention on the Rights of Persons with Disabilities as 'the right to work on an equal basis with others in a labour market and work environment that is open, inclusive and accessible'. The United Kingdom is a signatory to the Convention and successive governments have promised work to people with learning disabilities. In 2005 *Improving the Life Chances of Disabled People* (Prime Minister's Strategy Unit's 2005) articulated a vision that by 2025 disabled people should have full opportunities to improve their quality of life, be included as equal members of society and be afforded opportunities for paid work (Purvis et al. 2012, 6). In 2009, *Valuing Employment Now* (Department of Work and Pensions & Department of Health 2009) recognised the marginalisation of people with learning disabilities. The previous Coalition Government endorsed *Valuing Employment Now* in 2010 (Beyer 2012, 187) and the current British government believes that disabled people can and should be supported to work. This aspiration was also reflected in the introduction of the Employment Support Allowance by the then Labour Government – an out-of-work benefit that makes the promise of an employment pathway through a Work Capability Assessment. The Work Choice programme, introduced in 2010, commissioned a small number of prime contractors, reducing the main contracts from around 200 to eight across the United Kingdom, to move disabled people into work. Work Choice providers do not generally provide recognised supported employment provision and it is estimated that only 4.8% of those on the programme have a moderate to severe learning disability and less than 0.5% have 'severe mental health needs' (Beyer 2012 187–188). People with learning disabilities find themselves in a risky position in relation

to the Work Choice programme. Work Choice providers stand accused of cherry picking; focusing resources on disabled people who are already 'close to the labour market' and thus ignoring people with learning disabilities and people with mental health issues who might require more intensive support (Beyer 2012, 192; Department for Work and Pensions 2013, 20).

In addition to Work Choice, Access to Work offers employment funding to support disabled people once they find a job. Access to Work funds up to £25,000 per year on physical adaptation to workplaces, personal aids (e.g. seats, reading machines), job coaches and transport. However, as minority users, people with learning disabilities occupy a perilous position in relation to the scheme (Beyer 2012, 188). Access to Work is not widely known by disabled people or employers, leading Sayce (2011) to describe the programme as the government's best-kept secret. The persistent exclusion of people with learning disabilities from paid work demonstrates their differential precarity. Those failed by these work programmes – who remain unemployed – risk being understood as feckless, idle, benefit-scrouring citizens (Runswick-Cole and Goodley 2015).

Cultural attitudes persist that emphasise the innate incapacity of people with learning disabilities. Despite attempts to change attitudes, many people think those with learning disabilities cannot work; a view strengthened by inadequate transitions from school to adult life. There is no statutory requirement to discuss employment as part of the transition reviews from school to life as an adult. Hence employment 'is not universally considered to be a viable option for these young people by all professionals involved in transition planning' (Beyer et al. 2008, 5).

A lack of urgent commitment to end the precarious position of people with learning disabilities is made evident by the government's failure to set outcome targets by which to measure success or failure (Humber 2013). People so-labelled are offered only the vague promise of moving closer to the labour market. In practice, this has sometimes simply meant moving people from Employment and Support Allowance (a disability and employment-related benefit) to Jobseekers Allowance (an employment benefit) (Humber 2013, 5); seeking rather than doing work.

## Supported employment

The main approach to enable people with learning disabilities to enter employment is supported employment (Wilson 2003, 99); increasingly cited in policy documents as a successful model for work mobility (Beyer, de Borja Jordan de Urries, and Verdugo 2010, 129), replacing traditional day services that offered few paid labour opportunities (Wilson 2003, 99). This approach shifts from segregated sheltered workshops and training schemes to open employment, enabled by personal support workers funded by individual budgets (Wilson 2003, 100). Crucially, support is provided on an individual basis to both employer and employee for as long as it is required (Bryan et al. 2000, iv). A supported employment approach does not subscribe to the view that potential workers have to be 'work-ready' before they can start a job, arguing instead that 'the best place to learn about work is in the workplace' (2000, 2). Supported employment embeds people within their local communities. Sometimes, a job coach<sup>2</sup> works closely with the person and the employer to consider a range of different jobs and identify the opportunities to mark out certain tasks that match an individual's interests and skills.

Support is sometimes offered through job carving, which tailors a job to suit a particular worker. While job carving has been criticised (these jobs are sometimes not thought of as 'real' jobs) it has enabled people with learning disabilities to gain jobs (Wilson 2003). Guidance around setting up their own businesses or social enterprises has also been developed (Bates and MacIntosh 2009). Although one in 10 of the population is self-employed, very few people with learning disabilities run their own business (Foundation for People with Learning Disabilities 2012). The data on work and people with learning disabilities boasts an empirical adequacy to support the view that people so-labelled experience a precarity that is differentiated from their non-disabled peers. Our urgent task is to redress these perilous life chances.

### **Framing our research questions**

Butler (as quoted in Puar 2012, 170) argues that no one 'escapes the precarious dimensions of social life', but it is possible to 'establish the bonds that sustain us'. We are encouraged to evidence the human costs of precarity and to find resistant possibilities. The Equality and Human Rights Commission and Foundation for People with Learning Disabilities (FPLD) found that people with learning disabilities<sup>3</sup>:

- are 2.5 times more likely to have health problems than other people;
- have a much greater propensity to develop physical and mental health problems compared with the general population;
- experience higher rates of hospital admission (76 per 1000 adults) compared with non-disabled people (15 in 1000); and
- are subjected to systematic abuse, dangerous restraint methods and needless suffering in the care of the NHS.

Add these experiences to marginalisation from the labour force and we get a clear sense of the predicaments faced by people with learning disabilities. These analytical guides from the theoretical and policy literature led us to pose the following three questions:

- (1) In what ways are people with learning disabilities experiencing differential precariousness?
- (2) What common bonds sustain people so-labelled in times of austerity?
- (3) In what ways does a consideration of learning disabilities expand our understandings of life and labour?

### **Underpinning research**

This article draws upon qualitative data from the Research Council United Kingdom (RCUK)-funded research project 'Big Society? Disabled People with Learning Disabilities and Civil Society'. This inter-disciplinary, cross-institutional project ran from June 2013 to September 2015 as a partnership between four universities and community partners.<sup>4</sup> Community partners worked as co-researchers at various points in the project as we discovered how disabled people with learning disabilities were participating in their communities, in public services and in social action. The team explored access to networks of interdependence as well as their social emotional well-being in a context of austerity.<sup>5</sup> The research was carried out through seven overlapping and interconnected phases as follows:

- Key stakeholder interviews with people with learning disabilities, the third sector, policy-makers, lawyers and family members ( $n = 11$  stakeholders).
- Longitudinal documentary analysis of academic and policy literature over three years of the project.
- Ethnographic case studies with community partners – observing, talking with and learning from our three partners about self-advocacy, work and community living (in Yorkshire, Lancashire and Bristol respectively) ( $n = 60$  days).
- Analysis of data collected in the first three phases. Impact workshops ( $n = 10$ ) – findings were shared with people with learning disabilities, their supporters, service providers, disability organisations and policy-makers. This included individual feedback with people with learning disabilities ( $n = 15$  participants).
- Researcher in residence – involved Katherine giving her time to the community partners to help promote their good practice to others ( $n = 21$  days).
- Public engagement events – inter/national events to share research and increase the impact of the project ( $n = 18$  events).

Ethical clearance was gained from the University of Sheffield Research Ethics Committee. The research team, including the university and partners, has extensive experience of working with people with learning disabilities in research. This article mainly draws on the findings from the third phase of the research (ethnographic encounters). The participants in the work group were visited three times over a period of 18 months. The ethnographic encounters took the form of interviews that were carried out at a time and place of the participants' choosing. The interviews were supported by workplace tours and the use of Photovoice<sup>6</sup> (Booth and Booth 2003) to support the conversations.

### **Our focus participants**

Ethnographic research invites intimate prolonged engagements with participants. Over 18 months we developed close research relationships with five participants. Their accounts illuminate complex relationships with work and are chosen here because they allow rich qualitative snapshots of the employment experiences of people with learning disabilities in a time of austerity. We provide the following pen portraits:

- Robin is in his thirties. He is very interested in local history and art. He is very active in the self-advocacy movement. He lives with his grandmother and has extended support from other members of his family in a small town in the south-west of England. Robin has two jobs. He works in retail at a local supermarket two days a week. He has worked there for 15 years. Robin is also self-employed and runs a small business. Robin is a talented artist and is a 'conference facilitator'. He uses images to support the spoken word and text at meetings and conferences. He does not simply provide direct representations, but his artwork provides a level of interpretation to support understanding.
- Charlie is in his fifties and lives with his wife in a city in the south of England. He enjoys local amateur dramatics, runs and dances. Charlie works for the city council in their meals service. The meals service provides hot lunches for people in the city who are in need of their support. Charlie works every day and does a range of tasks during the week including recycling, shredding, scanning, filing, cleaning and making teas and coffees. When Charlie applied for the job he was offered a 'working interview' where



he tried out tasks in order to secure the post. He also had the support of a job coach when he started work. The job coach worked with Charlie to make a checklist for daily and weekly tasks that Charlie uses on a day-to-day basis.

- Maria is in her forties, she lives with her mum and dad in a city in the south-west of England. Maria is a keen gardener. She has two jobs. She works two days a week at a drama group running drama workshops with a group of young people with learning disabilities as well as performing herself. She takes part in performances for practitioners teaching them about a range of topics that affect people with learning disabilities, including: how to listen well, independence and sex, relationships and parenting. On Fridays, Maria works at a cleaning company. The company is a social enterprise run by and employing people with learning disabilities. Maria has been involved in the company since it started in 1995. She is a company director.
- Poppy is in her twenties, she lives with her parents in a city in the south-west of England. She enjoys music and dancing and being part of her church community. Poppy has just completed a supported internship<sup>7</sup> with the city council. She is still volunteering at two of her work placements – a café and a baby music session – but she has yet to find paid work. The rest of her week is made up of horse riding and volunteering at the local food bank with her father. She has had three job coaches since she completed her supported internship.
- Sunshine is in her thirties and lives in supported living in a city in the south-west of England. Sunshine arrived in the United Kingdom with her family when she was 15 years old. Sunshine loves buying and selling goods at local markets. Sunshine has two jobs. She works as a cleaner two days a week for a local charity and she works at a café for one day a week. Sunshine is planning to move house so that she can live in her own flat with on-call support. She would like to earn more money and to have one job.

## Analysis

Authors individually and collectively subjected transcripts to thematic analysis and responses were pooled (Snow, Morrill, and Anderson 2004). We reflected on our research questions, connected themes with the broader literature and read for tropes of precarity, common bonds and meanings of work. Theoretical readings of the ethnographic material (led by Dan and Katherine) were supplemented by the policy and practice lens offered by Keith (drawing on 25 years of experience in the field of supported employment). Findings revealed complex engagements with paid work by people with learning disabilities (see Runswick-Cole and Goodley 2015).

### ***In what ways are people with learning disabilities experiencing differential precariousness?***

All of our participants were living with uncertainties in their working and personal lives. The longitudinal nature of the study revealed the ongoing changes in people's circumstances. For Robin, uncertainty about employment was framed in positive ways. He has set up his own business with the help of his business Circle of Support<sup>8</sup> and he is hopeful that it will develop into a bigger enterprise:

One day, I hope that I will run my own business and have a little office. I would like to start employing people who are interested in doing artwork. (Robin)

Nevertheless, for most of the participants, uncertainty was the result of more negative life changes. Charlie had worked at the meals service<sup>9</sup> in his city for a number of years. However, due to local authority funding cuts, the service was moving premises, and the planned move had been delayed, leading to doubts over whether or not the move would go ahead. This was worrying Charlie. He had been told that his job would change after the move but he did not know exactly how:

We were supposed to be moving to new buildings in September but it hasn't happened, it will be February now ... We might have to stand up all day, I don't mind standing up but I don't want to stand up for too long. I want move about a lot and find all the jobs. (Charlie)

Charlie's anxieties were heightened by his manager leaving her position. She had been a key mentor for Charlie in his time at the meals service. More generally, there was an increasing sense of low staff morale and anxiety about the impending move and possible changes to staffing levels and job losses. By 2016, the National Audit Office stated that funding for local authorities will have fallen by 37% in real terms (BBC News Online 2014). Charlie's colleagues were concerned about their own job futures and felt themselves to be at risk. Their continued support for Charlie was being tested. In addition to the uncertainty in Charlie's job, his wife's situation had also changed:

Since I've last seen you, things have changed a bit. My wife isn't working in the café any more, they've closed that down, it's gone. She's going to have a meeting with her job coach. She's still working at the [supermarket] stacking shelves but would like to work a bit more. (Charlie)

Maria's work was also changing:

Since the last time I've seen you, things have changed a bit. I've stepped down as director of [cleaning company] because I was finding it a bit difficult. I was finding it a bit difficult sometimes, like when the new directors were having meetings on a morning I was always here doing drama. And I also felt like it was time to step down because I'd been doing it a long time and I wanted to give other people a chance in the group.

The change of directors prompted Maria to vacate her role. She felt a responsibility to a company she had worked with for 20 years but felt no longer able to carry on. Changes in her family life as a carer for her elderly parents also seemed to play a part in her decision. Life was also uncertain for Poppy. She told us:

I didn't find a job after [supported internship scheme]. I have had three different job coaches since it finished. (Poppy)

The lack of continuity of support to find employment was difficult for Poppy. When we first met her she was enthusiastic about the possibility of a paid job. Later on she told us she had changed her mind and she wanted to stay at the café where she was a volunteer:

I still do the café work but I don't want another [paid] job because I want to stay at my cafes. I like it there. I like wiping up and clearing away. If I could be paid at the café where I work that would be good. (Poppy)

Without the benefit of continued support, the prospect of paid work was perceived as a risk. Leaving the job she loved and people that she liked being with was more important to her than paid work. She valued stability and friendships above the prospect of paid employment. Her desires rested with her friendships rather than salary.

When we first met Sunshine, she too was looking for another job. Sunshine had two part-time jobs, but she wanted one job, and one that paid more money:

I like my jobs but I'm looking for another one. I went looking for another job but they didn't get back to me so I don't know what is going on. I would like to have one job and to earn more money, that would be nice.

But the second time we met Sunshine, she revealed the shaky position which she found herself in and why she had been so keen to get another job:

My Personal Independence Payment (PIP) has come through now, they backdated my money and I'm getting quite a lot of money so I'm fine for money now. Last time you saw me, I was only getting Employment Support Allowance but now my PIP has come through I've got enough money. I had to wait for the money while my PIP came through. It has taken ages to pay me back.

Sunshine's financial position was becoming increasingly unstable as she faced redundancy from her café job at the same time as waiting for her PIP payment to come through. She explained:

I didn't get my assessment in on time so they stopped my money [Disability Living Allowance], but luckily the PIP came through just before my job at the café finished. (Sunshine)

Disabled people are twice as likely to live in poverty as non-disabled people (Office for Disability Issues 2013). Waiting for a benefit to be paid put Sunshine under financial and emotional stress and at risk of personal financial shock.

While all participants faced changes at work, home life too was often shifting. Charlie was living with less money since his wife had been made redundant. Robin hinted that there might be changes to his family life because his grandmother had become 'a bit unwell'. Poppy was about to spend a week with a Shared Lives<sup>10</sup> family while her parents went on holiday, with a view to this becoming a longer-term future placement. Maria's decision to step down from the cleaning company was shaped by her increased caring responsibilities for her older parents:

My dad has been unwell, not himself at all, and that has been adding to it. I'm trying not to be worried about it and to get on with my work because you have to.

Sunshine's move to a flat on her own was on hold but the prospect of change was there for her too as she continued to consider a move. While Sunshine was initiating the change in her home life, the uncertainty experienced by Robin, Charlie, Maria and Poppy was beyond their control. As Maria told us, to live well with precarity means 'you just have to try not to worry and get on'. Robin expressed concerns about cuts to self-advocacy:<sup>11</sup>

Since I last saw you I've been working with the story telling group and the advocacy group. But the advocacy group, there's been cuts there, really fast. And there are only a few people on the partnership board now. They are still have Partnership Board<sup>12</sup> meetings, but they aren't going to have big grand meetings with lots of people there. Lots of jobs have gone, the self advocacy jobs have been taken over by large organisations and they are employing less self advocates now. I'm still on the management group but I don't get paid, I volunteer. People haven't got the money to travel to meetings. People who live in residential places don't really have a choice about whether they can go to a meeting or not. There is no support worker to take them. And the creative arts groups are struggling to get money, there's less people at those meetings.

In times of austerity, the erosion of self-advocacy services denies people a voice, when they most need one. People with learning disabilities experience an unequal distribution of precarity due to complex arrangements associated with inflexible support, experiences of poverty, changes to advocacy and unstable home lives.

### ***What common bonds sustain people so-labelled in times of austerity?***

Thus far we have presented a rather gloomy prognosis for people with learning disabilities. But this reveals only part of the story. Robin, Charlie, Maria, Poppy and Sunshine all talked about the interconnections and bonds that sustained them. Robin described the support from his business circle:

I've got my secretary Claire and Paul my artistic advisor. Rob who is the area coordinator the supported employment team here and Alison, my PA, which is funded through my personal budget.

Charlie was supported in applying for his job at the meals service:

To get this job, I did a 'working interview', I tried out some of the jobs for the interview as well as answering some questions. At first it was very tiring working here, but I didn't give up. I said to myself: 'don't give up, just do it, don't give up'. And I got lots of support from my job coaches from the local Council at first. I needed them a lot at first, but not so much now.

Charlie was sustained in his role, by his job coach. Together they developed a checklist that details tasks to be completed each day and each week:

I have a list of the jobs I need to do each day and the jobs that need to be done once a week and I tick them off so I know what I've done and what I need to do next. (Charlie)

His colleagues offered him support that went beyond the usual boundaries of a workplace. Together Charlie and his manager had agreed that he would be weighed at work each week:

I get weighed at work too. I wanted help to be healthy, I don't want any heart attacks.

For Charlie, rather than this being seen as intrusively overstepping the boundaries of an employer–employee relationship, he enjoyed the 'weigh in' and found it supportive. Work was a place to build mutually beneficial support networks. Maria talked about her work with younger people:

[Place name] is a place where I come to drama every week, and I work in a core group on a Monday, and on a Wednesday I help another lady teach a young group of adults with learning difficulties under the age of 13 to do drama. [Place name] is a place where there are lots of different courses there are lots of people in the community can come too.

She described the ways in which the cleaning company was a supportive community for its members:

We have meetings to talk about whether there are any problems with any of the cleaning – that gets sorted out at the meetings. (Maria)

Maria's work also involved reaching out to the wider community, doing disability equality training and informing professional practice:

One of the things I like about working in the drama group is the training. We work with people who are working with adults with learning difficulties. With doctors, nurses and others. We do plays for them. We've also done plays in schools ... We did one about salt in food. The teachers didn't realise how much salt they was eating in a day, and one even pulled a big sandwich out in front of me and starting eating it. I said 'do you know how much salt is in that?' I've done an animation film with artists.

Participants were supported by their relationships with family members, colleagues, local communities and paid support workers. Indeed, as the debate captured by Puar (2012) acknowledges, in thinking about our vulnerabilities we are asked to consider the kinds of assemblages and interdependencies that are the hallmarks of being human. These relationships enabled our participants to live. But, as we saw earlier, there is also a sense of fragility to these affiliations. Truly recognising precarity alerts us to its liminalities as well as its

possibilities. Moreover, the presence of disability further enhances these limits and opportunities.

***In what ways does a consideration of learning disabilities expand our understandings of life and labour?***

We have written elsewhere about the ways in which dis/ability enlarges, disrupts and expand understandings of labour (Goodley and Runswick-Cole 2014). Critical disability studies illuminates the ways in which dis/ability urges all of us to think again about what it means to be human (for example, Titchkosky 2016). Disability research has emphasised notions of interdependence, community and support – not as markers of deficiency or lack – but as extended notions of what it means to live as a self intimately connected to others. Shakespeare (2000), for example, argued against narrow notions of independence (and its distinction from the socially devalued position of dependency), emphasising instead mutuality and interdependence with one another. Research on families of disabled children has maintained the need to think about parenting and support of disabled children not simply in terms of the actions of parents and family units but instead as products of inclusive communities that recognise and support children and their families (for example, Ryan and Runswick-Cole 2008; Traustadóttir 1995). Furthermore, the political work of disability organisations such as People First – the international activist movement of people associated with the label of intellectual disabilities – has exemplified the ways in which competence, autonomy and self-determination are distributed phenomena (tied to the connections with supportive others) rather than individualised traits (Goodley 2000; Williams and Shoultz 1982).

Even in precarious times, we see the productive potential of the presence of dis/ability in the participants' accounts. Robin's business emerges because of the presence of dis/ability; as he says, 'I offer accessible transcription for all'. What starts as a demand or need associated with dis/ability becomes a form of support to be offered to all. Moving forward he is able to work the dis/ability complex to develop his business and to support other people in understanding new information and ideas. He describes his business circle as being 'a bit like King Arthur's Round Table'. Dis/ability prompts an imaginative response to the need to support Robin in developing his business.

Maria's cleaning company is yet another example of a positive and productive response to dis/ability. The cleaning company opened 20 years ago, and Maria describes the attitudes she faced (that sadly still persist today) that people with learning disabilities cannot work. In challenging these attitudes, Maria reveals the productive presence of dis/ability to spark innovation:

And I felt really horrible by that because just because a person has got a learning disability you can't really say that, because you don't know the person. I mean I didn't even know I could get a job myself, and I did it all by myself because I wanted to and I weren't going to let anybody stand in my way and tell me it's wrong. And when I used to go to a Job Centre with my mum and they used to say 'she can't do any work, she's got a learning disability and she won't be able to work'. And then I met some people on the bus from [day centre] and they said they'd got jobs going, and that's how I started ... people told us we couldn't – and we have. So stick your fingers up at them!

Supporting disabled people into work is not simply a moral argument. In pragmatic terms we have uncovered clear evidence that many people with learning disabilities – co-existing

in their communities with families, job coaches, employers, support workers and friends – have the requisite skill sets to work. We know that when people with learning disabilities are supported well, they can access workplaces and contribute in significant ways. Yet, too often, support is inconsistent. The availability of supported internships, supporting employment methods and access to job coaches is patchy across the country to the extent that a postcode lottery persists (Greig et al. 2014). A national register for job coaches and the rolling out of professional qualifications to develop the job coach might begin to address some of these issues. After all, we have uncovered innovation around work that, well, works. Supporting the work experiences of people with learning disabilities should never be an act of tragedy, pity, calling or guilt. The split term of dis/ability reminds us that successful work experiences are associated with feeling able to participate. These work abilities are crucially tied to the interconnections we have with others who support and enable us.

## Conclusion

Our research invites us to put forward a number of significant recommendations for thinking of precarity and work in a time of austerity. First, we need to address the differential precarity associated with dis/ability. Disabled people are at the foreground of the anti-austerity movement precisely because they are among the first to suffer the cuts of austerity (Goodley 2014, 2016). A review of the economic and policy context in which people with learning disabilities are looking for work reveals a host of broken promises (on the part of successive governments) in relation to promoting work opportunities. This clearly needs to change, not least in raising aspirations and opportunities for young people in the school years. People with learning disabilities are experiencing a form of double disadvantage as welfare cuts threaten their own job opportunities as well as those of their colleagues who provide the support for them to work. These perilous positions experienced in work life are often repeated in home life where uncertainty, often about ageing family member, tends to persist.

Second, we need to tackle different kinds of precarity. We demand new conversations about austerity's impact on cultural, societal and psychological realms. The British government clearly had enough wealth to bail out the banks whilst rendering many poor people destitute by austerity policies. These cuts to essential services risk undermining human networks of competence that people with learning disabilities draw upon and contribute to. Precarity is felt just as acutely at the relational level as it is the economic (Butler 2009).

Third, we need to resource organisations of disabled people to address precarity. The novel ways of working developed by these organisations need to be funded even in a time of austerity (Sayce 2011). We need to see early investment now for long-term gain and policy-makers should turn to disabled people and their allies first when seeking examples of good practice.

Fourth, we must disavow work. We desire employment. Supporting people with learning disabilities into work makes sense economically. Work is a place where people with intellectual disabilities can craft identities that sit in counter-distinction to the passive subject positions afforded by the psychiatric and psychological literature: contrast, for example, 'I work' with 'I go to a day centre'. Labour has the potential to deconstruct intellectual disability. Labouring shows you are doing something: you are able. Work is enabling. But work also debilitates and exploits (Puar 2009). We must always treat work with caution.

Finally, we must ask what does dis/ability do to employment? Dis/ability and work collide in some fascinating, unexpected and frictional ways. How we conceptualise work is refashioned through an encounter with learning disabilities (Goodley, Lawthom, and Runswick-Cole 2014). Care, support and mutuality are key conditions of what it means to be human – illuminated by the presence of dis/ability – and too often are missing from workplaces. Many disabled people permit the labour of others – such as carers and Personal Assistant (PA) – and there is still a body of work to be done on the affirmative possibilities of caring relationships offered by disabled people (Shakespeare 2000).

## Notes

1. We use the term 'learning disability' here to reflect the terminology within current UK policy documents. We acknowledge that this is a highly contested label.
2. A job coach uses matching techniques to identify suitable jobs for individuals and provides on-the-job training, often withdrawing when the person becomes established in their job but offering ongoing support where needed (Bates 2013).
3. See <http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/187705/> and [www.equalityhumanrights.com/EnglandFairer](http://www.equalityhumanrights.com/EnglandFairer) (accessed 1st October 2016).
4. The project involved the University of Sheffield, Manchester Metropolitan University, Northumbria University and The University of Bristol, and the community partners were Speakup Self-advocacy in Rotherham, BOSS Employment in Bristol, Pete and Wendy Crane (inclusive living advisors), Helen Smith and Max Neill (community circles coordinators, Lancashire), Molly Mattingly (Foundation for People with Learning Disabilities) and David Fiddament (MENCAP).
5. See Humanactivism.org (accessed 1st October 2016).
6. Uses photographic methods with participants to document and capture important aspects of their lives.
7. The supported internships scheme helps young disabled people aged 16–24 to find work. The scheme is run by further education colleges who work with employers to find a job that suits the abilities of each intern and to create a person-centred programme. For more information, see: <https://www.gov.uk/government/policies/increasing-options-and-improving-provision-for-children-with-special-educational-needs-sen/supporting-pages/supported-internships-for-young-people-with-sen> (accessed 1st October 2016).
8. A business Circle of Support is a group of people who come together to support a person to run their own business. The business circle will include people with expertise in running their own business and with business-specific knowledge (Bates and MacIntosh 2009).
9. Meals services in the United Kingdom provide hot meals to people living in their own homes, who are unable to cook for themselves. Their clients are often older people and disabled people.
10. Shared Lives is an alternative to home care and care homes for disabled adults and older people, used by around 15,000 people in the United Kingdom. In Shared Lives, a Shared Lives carer and someone who needs support get to know each other and, if they both feel that they will be able to form a long-term bond, they share family and community life. See more at: <http://www.sharedlivesplus.org.uk/what-is-shared-lives/shared-lives#sthash.PiGQBD2Q.dpuf> (accessed 1st October 2016).
11. Self-advocacy is about people with learning disabilities speaking up for themselves (Goodley 2000).
12. Learning Disability Partnership Boards meet in specific local authorities. They are made up of people with learning disabilities, family members and carers and representatives. Partnership Boards intend to give people with a learning disability a say in how local services are delivered.

## Acknowledgements

The authors would like to acknowledge the support of the Economic and Social Research Council's 'Big Society? Disabled People with Learning Disabilities and Civil Society' project.

## Disclosure statement

No potential conflict of interest was reported by the authors.

## Funding

This work was supported by the Economic and Social Research Council [project ES/K004883/1].

## ORCID

Dan Goodley  <http://orcid.org/0000-0002-0660-5671>

## References

- Bates, K. 2013. "Building the Capacity of Job Coaching Support (Sixteen)." <http://www.learningdisabilities.org.uk/our-work/employment-education/building-the-capacity-of-job-coaching-sixteen/>
- Bates, K., and K. MacIntosh 2009. *In Business: Developing a Business Idea*. London: the Foundation for People with Learning Disabilities.
- BBC News Online. 2014. *Auditors' Warning over Council Cuts*. Accessed January 22, 2015. <http://www.bbc.co.uk/news/uk-politics-30108142>
- Beyer, S. 2012. "The Progress towards Integrated Employment in the UK." *Journal of Vocational Rehabilitation* 37: 185–194.
- Beyer, S., A. Kaehne, J. Grey, K. Sheppard, and A. Meek. 2008. *What Works? Transition to Employment for Young People with Learning Disabilities*. Cardiff: Welsh Centre for Learning Disabilities.
- Beyer, S., de Borja Jordan de Urries, F. and Verdugo, M. A. 2010. "A Comparative Study of the Situation of Supported Employment in Europe." *Journal of Policy and Practice in Intellectual Disabilities* 7 (2): 130–136.
- Booth, T., and W. Booth. 2003. "In the Frame: Photovoice and Mothers with Learning Difficulties. (2003)." *Disability and Society* 18 (4): 431–442.
- Bryan, A., K. Simons, S. Beyer, and B. Grove. 2000. *A Framework for Supported Employment*. York: Joseph Rowntree Foundation.
- Butler, J. 2009. "Performativity, Precarity and Sexual Politics." *AIBR. Revista De Antropología Iberoamericana* 4 (3) i–xiii.
- Department for Work and Pensions. 2013. *Evaluation of the Work Choice Specialist Disability Employment Programme Findings from the 2011 Early Implementation and 2012 Steady State Waves of the research* Online at. Accessed January 18, 2015. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/210683/rrep846.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/210683/rrep846.pdf).
- Department of Work and Pensions & Department of Health. 2009. *Valuing Employment Now: Real Jobs for Real People*. London: HMSO.
- Foundation for People with Learning Disabilities. 2012. *Employment*. Accessed January 22, 2015. <http://www.learningdisabilities.org.uk/help-information/learning-disability-a-z/e/employment-careers/>.
- Goodley, D. 2000. *Self-Advocacy in the Lives of People with Learning Disabilities*. Buckingham: Open University Press.
- Goodley, D. 2014. *Dis/Ability Studies: Theorising Disablism and Ableism*. London: Routledge.
- Goodley, D. 2016. *Disability Studies: An Interdisciplinary Introduction*. 2nd ed. London: Sage.
- Goodley, D., and K. Runswick-Cole. 2014. "Becoming Dis/Human: Thinking about the Human through Disability, Discourse." *Studies in the Cultural Politics of Education* 7 (1): 1–15. doi: 10.1080/01596306.2014.930021.
- Goodley, D., R. Lawthom, and K. Runswick-Cole. 2014. "Dis/Ability and Austerity: Beyond Work and Slow Death." *Disability & Society* 29 (6): 980–984. doi:10.1080/09687599.2014.920125.
- Greig, R., P. Chapman, A. Eley, R. Watts, and G. Bourlet. 2014. *The Cost Effectiveness of Employment Support for People with Disabilities Final Detailed Research Report*. Bristol: National Development Team for Inclusion.



- Humber, L. A. 2013. "Social Inclusion through Employment: The Marketisation of Employment Support for People with Learning Disabilities in the United Kingdom." *Disability & Society* 29 (2): 275–289. doi: [10.1080/09687599.2013.776490](https://doi.org/10.1080/09687599.2013.776490).
- Kings Fund. 1984. *An Ordinary Working Life: Vocational Services for People with Mental Handicap*. London: Kings Fund Publications.
- McRuer, R. 2012. *Disability and the Globalisation of Austerity Politics*. Keynote paper presented at the Contact Zone: Disability, Culture, Theory conference, 25–27 October, University of Cologne.
- Meekosha, H., and R. Shuttleworth. 2009. "What's So 'Critical' about Critical Disability Studies?" *Australian Journal of Human Rights* 15 (1): 47–75.
- Morton, M. 2015. *Something's Not Right: Insecurity and an Anxious Nation*. London: Compass.
- Office for Disability Issues (ODI). 2013. *Individuals Living in Persistent Poverty*. Accessed January 29, 2015. <http://webarchive.nationalarchives.gov.uk/20131128110838/http://odi.dwp.gov.uk/disability-statistics-and-research/disability-equality-indicators.php>
- Oliver, M. 1996. *Understanding Disability: From Theory to Practice*. Basingstoke: Macmillan.
- Prime Minister's Strategy Unit. 2005. *Improving the Life Chances of Disabled People*. Accessed January 22, 2015. <http://webarchive.nationalarchives.gov.uk/+http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/disability.pdf>
- Puar, J. K. 2009. "Prognosis Time: Towards a Geopolitics of Affect, Debility and Capacity." *Women & Performance: A Journal of Feminist Theory* 19 (2): 161–172.
- Puar, J. K. 2012. "Precarity Talk: A Virtual Roundtable with Lauren Berlant." *Judith Butler, Bojana Cvejic, Isabell Lorey, Jasbir Puar, and Ana Vujanovic, TDR: The Drama Review* 56 (4): 163–177.
- A. Purvis, L. Small, J. Lowrey, D. Whitehurst, M. Davies. 2012. *Project SEARCH Evaluation: Final Report*, London: Office for Disability Issues.
- Runswick-Cole, K., and D. Goodley. 2015. "Disability, Austerity and Cruel Optimism in Big Society: Resistance and 'the Disability Commons'." *Canadian Journal of Disability Studies* 4 (2): 162–186.
- Ryan, S., and K. Runswick-Cole. 2008. "Repositioning Mothers: Mothers." *Disabled Children and Disability Studies, Disability and Society* 23 (3): 199–210.
- Sayce, L. 2011. *Getting in, Staying in and Getting on: Disability Employment Support for the Future*. London: Department for Work and Pensions.
- Shakespeare, T. 2000. *Help*. Birmingham, AL: Venture Press.
- Shildrick, M. 2012. "Critical Disability Studies: Rethinking the Conventions for the Age of Postmodernity." In *Routledge Handbook of Disability Studies*, edited by N. Watson, A. Roulstone and C. Thomas, 30–41. London: Routledge.
- Snow, D. A., C. Morrill, and L. Anderson. 2004. "Elaborating Analytic Ethnography: Linking Fieldwork and Theory." *Ethnography* 4 (2): 153–155.
- Titchkosky, T. 2016. "Monitoring Disability: The Question of the 'Human' in Human Rights Projects." In *Collection on Disability, Human Rights, and Humanitarianism*, edited by C. Schlund-Vials and M. Gill, 119–136. Publisher Ashgate Press.
- Traustadóttir, R. 1995. "A Mother's Work is Never Done, Constructing a 'Normal' Family Life." In *The Variety of Community Experience: Qualitative Studies of Family and Community Life*, edited by S. J. Taylor, R. Bogdan and Z. M. Lutfiyya, 47–65. Baltimore, MD: Paul H. Brookes.
- Williams, P., and B. Shultz. 1982. *We Can Speak for Ourselves*. London: Souvenir Press.
- Wilson, A. 2003. "'Real Jobs', 'Learning Difficulties' and Supported Employment." *Disability & Society* 18 (2): 99–115.