

## AUSTERITY AS DISABLING: THE STATE AND UNCERTAINTY IN THE FUTURES OF CHILDREN WITH DISABILITIES

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This paper draws upon interviews conducted with parents to explore daily experiences of raising a child with disabilities. In particular, it looks at the cultural consequences of disability and the uncertainty that comes with raising a child with disabilities. In doing so, this paper follows existing literature in the field of the anthropology of disability in considering disability as culturally constructed. It also explores how the relationship with state services plays a significant role in shaping the extent to which parents feel that they are able to hope, and plan for the future. Past and current interactions, as well as dominant political and social discourses, leave many parents overwhelmed by feelings of worry and uncertainty, not just because they cannot imagine what the future will look like, but also because they do not trust that the welfare state will sufficiently provide for their child once they reach adulthood. This paper examines how parents manage these uncertainties. Through examining these manifestations of uncertainty and worry stemming from failures of state services I argue that, for these families, austerity is disabling.

**Keywords:** Disability, austerity, uncertainty, the state

### Introduction

I first met Matthew's family as an undergraduate student at university. We were connected through a charity based in Oxford - me as a volunteer and Matthew as a participant with a rare chromosomal disorder and autism -and over the past few years we have built a close relationship. During this time, I learnt so much about the importance of family and friendships, but I also gained first-hand insights into life as a family with a disabled member, and the unique challenges that come with it.

One of these insights arises from a conversation I had with Matthew's parents in May 2021. They had just come from a phone call with Motability, a national scheme which works

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to provide transport solutions for disabled people in the UK. Ever since I had known Matthew, he had required walking aids for mobility within their home, and whenever we had gone outside, he had been using a wheelchair that his dad had pushed for him. However, as Matthew had grown (he was now 16 years old), this had presented more of a challenge, as the chair had become harder for his dad to push.

They explained that, following a lengthy application process, their request for a state-provided motorised chair had been denied. I was stunned. I knew the difficulties that mobility posed every day for Matthew and his parents, but, given that specialist wheelchairs can cost up to £25,000, for now Matthew they would have to wait.

Matthew's family, as it turns out, are not alone in this struggle. In 2018, the *Health Service Journal* reported that over 5,000 children in England waited over the four-month target for their equipment to be delivered — and this was those with approved applications (Ryan 2020: 100). Moreover, changes to the process, notably the introduction of the Personal Independence Payment (PIP) in 2013, meant that by 2018 over 40% of Motability clients had lost motorised equipment (Ryan 2020: 95).

Luckily for Matthew's family, however, the story does not end there. In July 2021, I received a WhatsApp message from Matthew's mum- a photograph of a beaming Matthew outside the Motability centre in his brand-new motorised wheelchair. My shock, as it turns out, was shared by his parents; they had only gone in expecting an assessment but, as Matthew had demonstrated sufficient skill, they had finally been able to take a chair home. We were thrilled. But this moment was also bittersweet; Matthew's parents should not have had to fight for this wheelchair.

Whilst all of us in the UK will at some stage rely on state-provided services, for disabled families this dependence is much greater. As a result, since 2010, austerity measures have hit the disabled community the hardest, with the state failing to provide some of the most basic of public services. To address these failures, the first step is to listen to disabled people and their families, to understand what their everyday struggles may be, and what they need to face them.

This article draws upon data collected through fieldwork carried out during Autumn 2021, and February 2022. This fieldwork consisted of semi-structured interviews with parents of disabled children<sup>2</sup>. Of the 8 interviews carried out, 2 went ahead in-person, and the rest via Microsoft Teams. Whilst I had predicted that conducting the interviews virtually might impact the kinds of conversations that we were able to have, especially considering that we were covering sensitive topics, I found this not to be the case. In reality, each interview proved insightful and highly valuable. In the interviews, we discussed the joys and barriers of everyday lives for these families, both in terms of practical difficulties, as well as social ones. We also

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<sup>2</sup> The participants of this study are Karen, and her 16-year old daughter Sophie who has cerebellar hypoplasia, Nick, and his 11-year old son Noah who has Down's syndrome, Lucy, and her 17-year old son Ollie who has Duchenne muscular dystrophy, Abigail, and her 15-year old daughter Freya who has a chromosome disorder, autism, epilepsy, and learning disabilities, Kate, and her 12-year old son Tommy who has autism, learning disabilities, and mild cerebral palsy, Naomi, and her 11-year old son Ciaran who has autism and ADHD, Phillipa, and her 16-year old son Joe who has Down's syndrome, and Olivia, and her 17-year old son Matthew who has a chromosome disorder and autism. All of the names used in this article are pseudonyms. All of the participants of this study live in the UK.

discussed participants hopes and worries for the future, and the ways in which they realistically saw the future for themselves and their children. Throughout the process, I was aware that the topics we were discussing were highly personal, and often emotional. Of course, the methods employed in the collection of data are not without their limitations. Given the relatively small number of people interviewed, it makes no wider claim to represent any given population and is instead a reflection of the experiences of those interviewed.

Of the eight people interviewed, seven identified as female, and one as male, and all of those interviewed identified themselves as the primary carer for their child. Six of the females and the one male interviewed were married, with partners who had continued to work, whilst one of the interview participants was a single mother. However, several of the participants did describe part-time work which they were involved in, which included volunteering in a charity shop, as well as creating educational resources for other parents, and care professionals. It seemed as though this work which did not involve directly caring for their child, was very important to the parents.

## **Becoming the parent of a child with a disability**

The experience of parenting a child with a disability is marked by constant uncertainty. Although the diagnosis of a disability is, on one level, a medical one which brings about questions of health and treatment, it is also a social one. The idea that disability should be understood using a social model first emerged in the 1980s in response to approaches which were overly medicalised (Hughes and Paterson 1997). Medical models of disability were inadequate as they implied the problems faced by disabled people arose from a physiological origin, which could be corrected through physical therapy.

What it means to be disabled, and how this is impacted by social and cultural contexts is something which anthropologists are uniquely placed to examine. This is partly due to anthropology's focus on the Other, and the utility of the anthropological lens of culture. As argued by Reid-Cunningham (2009), consideration of the cultural barriers through which disabilities can be constructed provides a useful way of understanding disability as a cultural construct. She asserts that 'disability may be considered a culture, culture may be considered a disability, and cultural norms and values influence conceptions of disability' (Reid-Cunningham 2009: 99). An outcome of these social models of disability is the explicit argument that culture itself is disabling, exemplified by the fact that across different cultural contexts, some disabilities (for example, deafness) are not considered as such at all (McDermott and Varenne 1995). In a discussion of disability and uncertainty in the context of austerity, a separation of disability from its status as a bodily condition is important, as it encourages a consideration of the influences of cultural, social and political attitudes in shaping the disabled experience.

A key text in the field of disability anthropology is anthropologist Robert Murphy's 1987 book *The body silent*. When he was in his late 40s, working as an anthropologist, Murphy discovered that he had a tumour in his spine, one which would eventually irreversibly progress into quadriplegia. He uses an anthropological lens to explore themes of independence and

disability, and the cultural devaluation of disability in the US. A key observation that he made is the somewhat awkward relationship between the disabled and non-disabled, resulting from a cultural emphasis placed on physical perfection. Thus, he argues that discrimination against the disabled community stems from a kind of fear; ‘we are subverters of the American Ideal, just as the poor are betrayers of the American Dream’ (Murphy 1987: 116). His insights are illuminating for any kind of study of disability as he shares experiences of what it is like to be disabled: ‘disability is not simply a physical affair for us; it is our ontology, a condition of our being in the world’ (Murphy 1987: 90), whilst also articulating why disabled people face discrimination and alienation in American society: ‘they are afflicted with a malady of the body that is translated into a cancer within the self and a disease of social relations’ (Murphy 1987: 111).

## Diagnosis: confronting the unexpected

Everybody says, when you’re pregnant, is that, ‘what do you want, a boy or a girl?’. And everybody goes, ‘oh, I don’t really mind. So long as their healthy.’ (Abigail)

A turning point in the journey of a parent of a child with a disability comes with the diagnosis. One thing that is common amongst parents is that, often, disability is entirely unexpected. When describing how they envisaged parenthood before having children, parents overwhelmingly described expecting ordinariness; their child is healthy and happy— and normal. Disability problematises narratives of perfectibility, rooted in developments in obstetric medicine and reproductive technologies (Rapp and Ginsburg 2001: 544). A key anthropological insight into these issues is provided by scholars, such as Kittay, Rapp, and Ginsburg, who have written openly about their personal experiences of parenting children with disabilities. A common experience shared by parents is how their child’s diagnosis led to a kind of reconceptualisation of what it means to be a parent; ‘the birth of anomalous children is an occasion for meaning-making’ (Rapp and Ginsburg 2001: 536).

This is also explored by Landsman in her work looking at what it means to be the mother of a disabled child within a cultural climate of perfection, and a new age of reproductive technologies (Landsman 1998). Similarly, she argues that mothers feel a sense of responsibility and guilt for not producing a ‘normal’ child, which results in deliberate attempts to recognise and assert the personhood of their child, ‘advocacy for one’s disabled child becomes part of the identity of the mother, but it is born of the recognition of the child’s humanity and of one’s fear that the full value of the child is missed by others’ (Landsman 1998: 87). As a result, the birth of a child with a disability is often highly anxiety-inducing for parents and families.

My first reaction was, ‘he just can’t have muscular dystrophy, because that doesn’t happen to us, that happens to other people.’ (Lucy)

The treatment of the disabled as the 'Other' has been explored within anthropological literature on disability. As argued by many scholars, disability is no less a social diagnosis than it is a medical one; to be disabled is in many ways a social condition (Murphy 1987: 4). Thus, for a parent, diagnosis also brings about a total reconfiguration of what both their own and their children's lives will look like.

Mothers frequently tell stories of, upon giving birth to a disabled child, being commiserated instead of congratulated; one participant was advised by a healthcare worker to take time to grieve for the child she thought she was going to have. Responses such as this mean that sharing the news of disability, alongside the news of the birth, can present a unique challenge. Phillipa's son was diagnosed just a few days after he was born. She felt that it was important to share the news of his diagnosis with news of his birth, and she did so in cards which she sent to close friends and family.

I felt like a bit of a fraud, because I thought, they're sending all these flowers and nice messages, and congratulations on your new baby. And you think, at some point, I've got to tell them that he's got Down's syndrome, and he's not the perfect baby. (Phillipa)

Phillipa's experience is reflective of the responsibility that mothers often feel upon not producing a 'normal' child, a narrative which is, again, reproduced within dominant perceptions of personhood. Furthermore, the responsibility that mothers feel to share the news of diagnosis alongside birth is reflective of the inextricable link made between the child and their disability. One of the cultural consequences of disability is that an individual's very identity as a 'full person' is called into question, and this is clearly something which can begin at birth (Luborsky 1994: 240).

## **Uncertainty: milestones and development**

My eldest stepson has got three children, and I remember him saying, 'Oh, well, they do this at such and such a stage.' And I remember biting my tongue, just because I wanted to say, 'if they're lucky'. (Karen)

The idea that personhood is linked with the development into 'normal' adulthood had been explored extensively in the anthropological literature. Understanding attitudes towards disability and independence in the UK also requires an analysis of how such perceptions intersect with dominant discourses surrounding personhood. Developments in the anthropology of personhood have sought to problematise the dichotomy between the Western individual and the 'dividual' of 'the rest' (Busby 1997; LiPuma 1998; Spiro 1993; Amit and Dyck 2006; Walker 2013). Whilst there is now a wealth of ethnographic evidence which illustrates the extent to which interdependence and relationality are highly important also for people in the West (McKearney 2021; Hollan 1992), the narrative of independence and personal autonomy still persists in the UK. However, one area in which this cultural conception is clearly problematised is the case of disability. For many disabled people, so-called 'full independence' is

neither possible nor desirable, and thus the dominant personhood discourse in the UK can be highly damaging and stigmatising.

Adulthood and personhood are often considered synonymously, and one achieves full personhood by completing certain prescribed stages of development; moving out of your home, finding employment, getting into relationships (Luborsky 1994). Parents of disabled children must therefore confront the fact that, in many cases, such milestones will not be reached by their children.

At that period- at around a year - when babies are becoming toddlers, I remember all the time friends would say 'so is she walking?' and how that felt. And I look back, and I wish I could have had enough self-possession and lack of fear for it not to matter, but of course it matters. (Karen)

The assumed link between developmental milestones (walking, talking, reading) and growing up into a 'normal' person serves as a constant reminder of a child's difference. For parents, what this often means is that they are at every stage being told that their child falls outside of normality.

For parents, not only do narratives of personhood, dependence and care leave their child's very identity as a person questioned, but also what their future will look like as an overarching question. Uncertainty is derived from the question of what a child will be capable of in the future, as their development does not always align with that of the average child. Further, with complex disability comes non-linear development; a child may take their first steps at age four, but not be able to walk fully until eight. Therefore, families' ability to plan for the future is largely impacted by the extent to which they know what kinds of provisions will be necessary for their child once they reach adulthood.

It's difficult, in Freya's case, to think about the future, because we don't know how she's going to develop. I mean, when she was ten, there was, 'she's never going to learn to read fluently.' And now she can read. (Abigail)

Throughout conversations about development and ability, parents find themselves occupying the difficult position of wanting to show how their child can overcome the odds of their diagnosis (Landsman 1998), whilst also learning to be measured about celebrating breakthroughs. Worry is therefore compounded by the unknown of what a child may actually want, and need, when they reach the adult stages of their lives.

Such discussions surrounding autonomy and dependence necessarily draw upon the emerging field of the anthropology of care, which explores how care, although a universal, is also highly culturally variable. In this context, care is understood as a relationship of dependence and support through which human lives are sustained (McKearney and Amrith 2021: 1). In discussions of parenthood, personhood, the welfare state, and disability, an exploration into who is providing care and how is of key importance. The value of autonomy, and how this is incorporated in the care of people with impaired cognitive function, is an important consideration to be made (Kittay 2010; Pols, Althoff and Bransen 2017; Pols et al. 2017). While dependence is importance, caring relationships necessarily involve the

consideration of personal autonomy too; 'it is not the caregivers' job to avoid hindering people from enacting autonomy but to support them to achieve a good life' (Pols et al. 2017: 781).

It is clear that there is a complex relationship between autonomy and dependence, arising largely from a cultural situation in which such a large value is placed on independence and personal responsibility. In reality, however, as argued by many anthropologists, the idea that people are able to live completely independently of each other is an illusion, largely born out of the dominant narratives of liberalism.

## **Austerity and the welfare state**

The modern welfare state in Britain was established in the period following WWII to address growing inequalities across the country. However, since this post-war boom, there has been a steady decrease in funding of such services, as the UK economy has shifted towards the 'liberal market economy', in which the values of neoliberalism and minimal welfare protection have been implemented (Koch and James 2020).

The far-reaching impact of neoliberal policies internationally has been studied and written about extensively. What is of particular importance here is the impact that such policies have had both politically and socially on those who are unable to conform to the neoliberal ideal of economic and social independence, and therefore depend heavily on state provisions. Welfare reforms since the 1970s have led to the intensification of liberal claims of individual freedom and state restraint, despite increased calls for equality and state moral obligation (Staeheli and Brown 2003).

Further, while in theory, neoliberal ideology promises the rolling back of the state, in reality this has often led to non-governmental and private entities taking on governmental responsibilities. This has led to logic of the market percolating into state activities, so that even those state institutions which have not been privatised, including schools and the police service, must operate within this enterprise framework (Ferguson and Gupta 2002: 989). As there is an increased emphasis on self-governance and individual responsibility, anthropologists have repeatedly highlighted how some groups, particularly the poor, are less prepared to do this (Koch 2012; Patrick 2017; Bear 2015; Knight 2015). Such criticisms can then also be extended when considering issues of disability and the welfare state as, again, liberal political theory assumes the subject to be an autonomous individual. Because many disabled people will expect to be supported by the state, financially and socially, the issue of personal responsibility cannot be applied here.

On top of this, social benefits in the UK have faced serious cuts following the implementation of austerity measures since 2010. Austerity was presented to governments as a solution to the financial crisis in 2008. Cuts have subsequently been implemented across the public sector, but in the years following 2010, it has become increasingly clear not only that austerity measures have had devastating effects for the most vulnerable, but also that they have had major adverse economic effects.

Based on a macroeconomic analysis of the three years that followed 2010, influential economist Paul Krugman argued that the implementation of austerity policies was done so on the

basis of flawed economic data. This data was used to justify cuts to public funding based on the advice that debt stalled growth. However, Krugman disputed these claims and demonstrated that, during this three-year period, there was evidence to show that many countries experienced severe economic downturns which were more or less proportional to the austerity measures themselves (Krugman 2013).

Therefore, Krugman argued that global economies have suffered as a direct result of the implementation of austerity policies. Beginning in 2010 in the UK, these cuts hit those who rely on the welfare state the hardest and have fundamentally transformed the state of social care in the country.

It is well documented that austerity and welfare cuts have a disproportionate impact on the disabled community. Since the introduction of austerity measures in 2010, disability advocates have repeatedly highlighted the devastating impacts that they have had on people with disabilities. By 2013, the Centre for Welfare Reform predicted that disabled people would endure 9 times the burden of cuts that the average person would, while those with severe disabilities would be hit up to 19 times harder (Ryan 2020: 3). However, in the past 12 years the situation has continued to worsen, with a 2019 UN report finding that families with disabilities were projected to lose on average more than 30% of their annual net income in the next 2-3 years (Alston 2019: 16).

As such, families who care for disabled children are acutely aware of their inherent vulnerability to cuts to welfare spending. The political rhetoric that emerged throughout the 2010s made it clear to many people dependent on welfare services that not only were their needs not prioritised but, worryingly, that as recipients of state benefits, that they were somehow responsible for their own situation. The image of the ‘benefits scrounger’ was prevalent in popular media throughout the 2010s, depicting those who relied on the state as lazy and deceptive.

## **Dependence: realising the importance of the welfare state in your life**

The austerity programme came in, and what was very clear to us was how absolutely dependent we were on the NHS and on public services. (Lucy)

For many parents of disabled children, there is an acute awareness of their dependence on state services. However, given the fact that this dependence is much greater than that of the average person, and the political rhetoric surrounding the provision of financial support to those unable to work, this dependence is often felt as a kind of vulnerability. While in theory the state is supposed to be the ‘safety net’ for those in need, such as the ill or disabled, in reality many people feel as though the welfare state is not a reliable source of support for them or their families.

I am very aware – and became aware, really, as soon as he was diagnosed – of our vulnerability. And that’s what really worries me, particularly in the in the climate of austerity. (Lucy)



This is a dependence which intersects with so many aspects of the daily lives of parents and their families.

Despite the increased implementation of neoliberal policies, which push towards an ethics of self-governance and personal responsibility, many people in the disabled community will continue to rely on the support of the welfare state. In work such as that of Koch (2012), Patrick (2017) and Bear (2015), anthropological approaches have turned to focus on how people are forced to continue facing the problems of daily life under the conditions of austerity. In her ethnographic work, Patrick compiles accounts of the benefits system to explore lived experiences of the British welfare state. Specifically, she explored how claimants are stigmatised and stereotyped as benefits 'scroungers' (2017).

These notions are especially interesting when considering the place of disabled people. Much of the rhetoric surrounding people who rely on benefits invokes class-based arguments, in which there is an association of being poor with being undisciplined and irresponsible. However, such constructions can be problematised in the case of disability. As highlighted by Murphy (1987), disability discrimination is unique in the fact that it as a social category is so permeable; anyone at any time could become disabled, and by extension so could a close family member or friend. Thus, an ethnographic exploration into the experiences with the state of largely middle-class families with disabled members provides a useful new insight into the workings of the current UK welfare state.

In Koch's ethnography on a British council estate, she observes how mothers turn to a more localised, collective understanding of care and kinship in which larger groups support each other. For many parents of disabled children, the creation of connections with other parents of disabled children has become an essential source of support, as many described parenthood as an experience marked by a sense of loneliness.

I remember moments really marking that loneliness. I felt marked out all the time as a parent. I had different preoccupations; I couldn't take things for granted. (Karen)

Of the parents who experienced this, most attributed this loneliness to the separation which they see as naturally occurring as their friends raise their own children. The experiences of raising a child with disabilities is so different, and causes such profound changes in a parent's life, that parents described feeling as though they were no longer able to relate to friends' experiences.

Sometimes they're saying, 'I'm really worried what Hubert's going to do for his GCSEs', and you're thinking, 'I'm really worried my child's never going to feed himself'. And you think, your world is just so different. (Olivia)

I'm not able to be the friend that they're all being to each other, and all the things they do together, I can't do them. I can't afford them. I don't have time to do them. And they have got very different lives to me now. (Kate)

It's always been painful, looking at other families going off on trips together, that almost natural exclusion that happens. (Karen)

For those who had access to friendships within the disabled community, sharing experiences with other parents created a vital sense of community. As with the mothers Koch (2012) worked with, these relationships became more than just friendships, but important sources of support and advice. In particular, given the ways in which many parents felt left behind by the system that was supposed to provide for them, being a part of a wider community of parents facing the same issues became crucial for the sharing of advice on how to navigate the complex and opaque system.

Using the framework of survivance, we can begin to analyse the techniques deployed by parents to help each other and resist the label of victimhood. The concept of survivance originates from Native American studies, and it has been used to describe how Native American people used narratives of an active presence to overcome a colonial view of them as mere victims (Vizenor 2008). Applying this framework within the context of this ethnography, we can analyse the use of survivance techniques in the context of the social and economic uncertainties present in the experiences of parenthood. As with the women in Koch's (2012) ethnography, community and support from other parents is of great importance to many parents. This involves the sharing of frustrations, joys, and stories. However, this support goes beyond informal conversation and the sharing of similar stories, to in many cases manifesting in the organisation of peer-run support groups, in which parents of older children guide parents of younger children on navigating the complex state bureaucracy.

I set up a support group, because I was so cross that these families couldn't fill in those forms. (Olivia)

The passing of advice for those who receive it can be crucial in knowing how to access the resources they need. However, it is also a source of empowerment and pride for those who are able to share the knowledge they have gained over the years to help others. For Olivia, setting up her support group was a way of mobilising her skills to help others access resources that may not be obviously available. For many parents, the experience of accessing state-provided services is one marked by a series of barriers formed by a lack of information, a lack of governmental support, and a lack of clarity by the government. The sharing of advice, building of communities, and creation of spaces such as parental support groups are a kind of resistance to this, and thus can be understood as a kind of survivance technique. They provide a means through which parents can not only find an outlet for stresses and uncertainties, but also to resist bureaucratic barriers to restate their active role as agents living under the state. Parents feel as though much of the information they are able to share in these circles is deliberately obscured by government providers, especially with regards to information about claiming resources or financial aid that they are entitled to. As such, through being able to spread the word about techniques that they have themselves used, parents are able to regain some kind of control and power against the force (state bureaucracy) which they feel is not working to help them.

## **Faith in the future: how austerity impacts the capacity for hope**

You realise slowly over time that these people [working in the local council] absolutely don't care; they almost detest them. It's, 'how little can we get away with spending on your child?'. (Olivia)

We're finding ourselves reliant on kindness, and kindness has no place in a democracy. You shouldn't have so-called equal citizens who are reliant on kindness in order to have their basic needs met. (Lucy)

The experiences of the participants interviewed, particularly those which are marked by feelings of vulnerability and helplessness, indicate that they have very little faith in the ability of welfare services to provide for their children in the future.

How people spoke about the welfare state was revealing both in terms of the extent to which they had faith in it, but also exactly how austerity policies have impacted this. For those who know that their child will always, in some way or another, rely heavily on state services in their day-to-day lives, austerity is therefore understood, amongst other things, as an attitude. This is then reflected in the actual interactions that parents have with state actors, who they feel are not working to serve their needs, but instead the money-saving, corner-cutting needs of the state.

They don't do support; they are a barrier, so their job is to not spend money. (Naomi)

As well as in terms of state actors, the state is also spoken about in terms of a system more generally, one which is at its core rigged against the people it is supposed to help. Accessing state services is framed as a kind of fight or battle, in which people are getting support in spite of the system, not because of it.

It's like one of these gladiator battles: just throw you in and whoever is strongest survives. (Naomi)

There's the fight for services, because there's such a shortage of it. (Olivia)

These experiences and perceptions have a profound impact on the faith that parents have in the state. At the same time as acknowledging that, under the current circumstances, the future does not feel hopeful for their children, parents also described a lack of confidence that the situation that welfare services are currently in will improve any time soon.

In his 2013 book *The future as a cultural fact*, Appadurai argued for a greater anthropological attention on the role of imagination in social processes and constructions of the future. This call was echoed in Bryant and Knight's 2019 work *The anthropology of the future*, in which they argued that 'our concept of the present *as present* derives from the future; that without a concept of futurity the present ceases to exist as such' (Bryant and Knight 2019: 16).

Implicit in question about the future for parents and their families was that of uncertainty. In anthropological literature, uncertainty has been understood as a fundamental dimension of risk, concerning the future (Boholm 2003: 167). Berthomé et al. argued for an interactionist approach to uncertainty, that saw it arising as the outcome of interactional dynamics (Berthomé et al. 2012). Such a perspective is reflected in Allard's ethnography which explores the role of bureaucratic anxiety in Warao Amerindian interactions with the state. Here, uncertainty was understood to have resulted from the extended and unfamiliar social relations that bureaucratic processes created (Allard 2012).

With more recent developments in the anthropology of time, anthropologists have become increasingly interested in how past experiences and present precarity or uncertainty impact how people are, or are not, able to imagine their futures. For example, in their work with Palestinian women whose husbands were serving life sentences in Israeli prisons, Segal observed how women were caught in an eternal present (Segal 2013). For them, the future exists as a complete abstraction, and therefore cannot be anticipated or imagined. Similarly, Bryant's ethnography exploring experiences of time in Cyprus during the early 2000s, during the ongoing conflict between the north and south, she argued that present crises bring the 'present-ness of the present into the fore', making the future a complete unknown (Bryant 2016). This orientation towards the future, demonstrates how the present can be understood as 'taking on the burden of gathering the past and projecting it into the unknown future' (Bryant 2016: 24).

Of course, in discussing how they are, or are not, able to plan for their futures, the question of hope arises. When faced with a future where a child will be reliant on a service which has already repeatedly failed to meet their basic needs, many parents described a lack of hope in the future.

I don't think it's going to be great for Ciaran unless something changes in the social care system. (Naomi)

Obviously, I follow what's going on in the government and stuff. And that gives me very, very, very little hope as to how they are looking at the future of social care and looking at the future of disabled people. (Kate)

Hope is an important dimension of future-building, as it is not just an orientation, but a tool through which realities can become constructed. As argued by Bryant and Knight, hope provides momentum to 'facilitate social change by actualizing potentiality' (Bryant and Knight 2019: 143). The potentials that hope provides for social action is explored ethnographically by Novas (2006), in his examination of the political economy of hope in biomedical research. Here, he found that activism driven by the hope of patients and their families demonstrates that hope is not simply a product of the imagination, but actually can materialise through social practice (Novas 2006: 290).

This analysis reveals the significance of hope for those living in uncertainty. Hope is an important tool which can transform futures and drive change. However, the capacity for hope can be limited in the face of constant failures by government services, and pervading narratives surrounding the cutting back of public services.

As illustrated in Novas' ethnography, collective action and group activism can provide the conditions through which hope can be realised. As with the support groups that many parents reported having attended, finding and participating in action with communities of similar people can provide an essential technique within which hope is not just imagined, but used as a tool to improve futures.

## **Austerity as disabling**

We're not limited by Ollie's ability or disability. We're limited by the money that's there to do stuff. (Lucy)

In the context of disability, the idea of vulnerability is a key one. However, when parents spoke of vulnerability and worry, the source could never be traced back simply to their child's disability. Instead, their concerns arose from situations of financial instability, and the worry that other people would not provide sufficient care for their child if they were no longer able to. In this context, therefore, it became increasingly clear that disability could not be reduced to a medical, biological, or bodily condition. Instead, disability is a social condition, as argued by Murphy, who described his disability as 'a disease of social relations no less real than the paralysis of the body' (Murphy 1987: 4).

I believe in him; I believe he has potential. But I don't believe in other circumstances. (Nick)

Further, in the context of austerity, these concerns are heightened. The worry surrounding the social consequences of disability in terms of discrimination and prejudice from peers is compounded by that which materialises in the failures of state services.

We are completely dependent on other people, and on the systems that will pay those people, find those people, and support those people to be here. That's the biggest worry. I think that's a bigger worry than Ollie's condition. Because the condition is what it is. (Lucy)

These ideas are reflected in Frances Ryan's work on the impact of austerity on the lives of disabled people in Britain. As a journalist living with a disability, Ryan explored how policies and attitudes of austerity Britain have consistently worked to strip disabled people of their basic rights. In her book, she argues that vulnerability is not inherent to the condition of disabled people; isolation, desperation and fear are not inevitable. Instead, vulnerability arises when 'politicians choose to pull the support disabled people need in order to live dignified, fulfilling, independent lives' (Ryan 2020: 9). This is very much reflected in the accounts of parents, whose concerns principally arose from a lack of faith that the welfare state would be there to provide for their child in the future. Whilst McDermott and Varenne (1995) argued for a social model of disability which saw culture as disabling, in the context of the lives of disabled people in the UK, it is also clear that, for many families, austerity is disabling.

## **Accessing the welfare state: bureaucracy, forms and complexity**

Bureaucratic processes have been extensively analysed by scholars in political science, who look at how it functions as a tool of the state. Weber was the first to formally approach bureaucracy as a unit of study in its own right, referring to it as an 'iron cage', and an inevitable outcome of capitalist modernity (Weber 2006). In his view, dehumanisation was an essential outcome of bureaucratisation, a fundamental virtue of capitalism, that erased human emotion from official business (Weber 2006: 51).

Such ideas have increased relevance in contemporary society, in which the inefficiency of government and government services has manifested in a proliferation of form-filling. As it has become more difficult to access public services and money, many have found themselves spending increasing time and effort form filling in order to access, or regain access to, benefits (Koch and James 2020).

These ideas have been explored in more recent ethnographies which have directly addressed the role of bureaucratic processes in contemporary society. For example, in his work in Pakistan, Hull explored article documents through the lens of materiality and agency (Hull 2012). Unlike Weber, who characterised documents as passive, Hull approached them as artefacts of sociality, through which relationships with the state are shaped and interpreted (Hull 2012: 18). Such a framework provides a fascinating insight into how people actually engage with documents and forms.

## **Complexity: understanding the system**

The biggest challenge was finding out about, and negotiating with, the local authority to meet your needs, and then finding a place that would have him, who can meet his needs. The hardest by far. (Naomi)

When describing interactions with state services, most parents described being confronted by overwhelming complexity. Rather than being presented with information about the kinds of support available to them, and how to access it, parents are left to find this for themselves. From the perspective of parents as claimants, they see this ambiguity as deliberate, as a measure to prevent them from claiming everything that they are entitled to.

It's knowing what information sources there are and what's out there, and working out how to navigate that. That is actually incredibly complicated; there's all sorts of barbed wire in there...it's very, very complicated. (Karen)

Whilst this complexity therefore has the consequence that some families are simply not able to access resources that should be available to them, it also has huge impacts on the daily lives of those trying to navigate it. For parents who already spend more time than most caring for their child's needs, they must then dedicate another large part of their lives navigating

complicated bureaucratic systems in order to access the support provided through the government. This can have a profound impact on the temporal experience of parenting, as people are unable to put energy into thinking about what the future might look like.

I definitely do just live day to day. And there is also this element of there being so much to do care-wise in a day that I don't really have space for anything else. And people often say to me, 'just get through the day'. (Kate)

This kind of temporality has been studied anthropologically, with scholarship looking at how precarious social situations can leave people stuck in a kind of constant present. For example, in his ethnography of displacement under new development projects in Vietnam, Harms explored how temporal uncertainty restricts capacity for productivity (Harms 2013). Similarly, when confronted with seemingly endless bureaucratic tasks, compounded with the time it takes to care for a child, planning for and imagining the future can become an increasingly difficult task for parents.

### **Becoming an administrator: form filling**

Here are these families, they've been told their child is profoundly disabled, and that they'll get some money to cover these additional costs. But to get it, you've got to fill in this form. (Olivia)

Given the complexity of these bureaucratic processes, many parents find themselves occupying the position of administrator as well as a parent. Whilst many parents were happy to spend time caring for their child, and supporting them to live happy lives, many also expressed annoyance at the form-filling that they were required to do. This related not only to the length and complexity of the forms that they are presented with, but also the nature of the questions themselves. Testimonies from disabled people who endure extensive assessments in order to qualify for government support have repeatedly highlighted the unnecessarily complex and degrading nature of such processes. For example, writing in *The Guardian* about his experiences of the PIP assessment as a disabled man, Rob Crossan described the process as 'intrusive, humiliating, and completely pointless' (Crossan 2017). Similarly, for parents who must complete extensive documentation in order to prove their child's eligibility for government support, they must undergo a difficult, and emotionally challenging, process.

You read the report, and they are so negative about what they can't do, and what help they need. And when you read the EHCP, it's like, 'is this really about my child?' (Abigail)

The questions are a bit soul destroying, because in order to get the money, you're told fill it in on your child's worst day. Can your child walk? No. Can your child talk? No. Is your child up in the night several times? Yes. Does your child wet the bed? Can your child interact? Does your child need help going to

the toilet? Can your child brush their teeth? Can they wash themselves? When they're tiny, it's not so bad. But when they get to 10 and you're writing 'my child needs help going to the bathroom', it becomes really soul destroying that you're having to put all this information into a form. (Olivia)

Parents described the contradictory feelings of, on the one hand, wanting to celebrate their child's achievements, but, on the other, having to fixate on all of the things their child is not able to do through the process of form filling. As a result, bureaucratic processes become charged with emotion. Thus, as argued by Hull, bureaucracy should not be understood as neutral, and studied in terms of simply a means of governance. Anthropological enquiry should also focus on how bureaucratic texts are 'produced, used, and experienced through procedures, techniques, aesthetics, ideologies, cooperation, negotiation, and contestation' (Hull 2012: 4). Parents' engagements with bureaucracy impact their experiences of time, as well as their perceptions of the state as an entity which they do not feel has their best interests at heart.

## **Schools and education**

The process of actually choosing the school, and then stating the argument to get her a place, was the hardest thing I've ever done. (Karen)

He's not being provided with what he should be provided with, and nothing is done about it. And nobody actually cares that laws have been broken. (Olivia)

Naomi's son Ciaran, now 11, began his education in mainstream school. Although he initially coped well academically, demonstrating an advanced reading level, as he got further into his primary education, Naomi and her partner realised that he was not coping well in the school environment. As his teachers began to notice too, Ciaran underwent assessments, and was diagnosed with autism and ADHD. Initially, Naomi was happy for him to stay in mainstream school with some additional support, paid for by extra funding that the school was receiving. However, increasingly, she began to hear stories about Ciaran being treated differently at school. First, it was that he was eating his lunch with a support worker away from the rest of the children, because he could not cope with the noise of the lunch hall. Then, Naomi discovered that Ciaran had been moved out of the classroom into the corridor, sat at a desk alone and isolated from his fellow pupils.

Given that the school clearly was unable to meet Ciaran's needs, Naomi decided that she wanted her son to be provided with an Education Health Care Plan (EHCP). The EHCP is a comprehensive document, compiled by a team of health, social and educational professionals, which details a young person's needs, and how these should be met. It is only with this document that a child can be placed in a specialised school. However, after being told that there was a long waiting list to get this, Naomi and her partner decided to seek help privately, and managed to get Ciaran his EHCP. However, despite having this paperwork,



Naomi was still told that she did not have evidence to prove to the local council that her son needed to be moved.

We had to go to court to change school, because Ciaran was put in a mainstream school- in theory; he would never have attended. The EHCP was inadequate, because there is a tendency to water it down, so then they can meet the needs until the child goes in, has a crisis, and then they go to special school. (Naomi)

Reaching breaking point, Naomi and her partner made the decision to use up the last of their savings to take their case to court. What followed was a long process of gathering paperwork from Ciaran's school, as well as paying for independent professionals to assess him. In addition, through reading through paperwork received from her son's school, Naomi realised the extent to which her son was in distress at school.

A lot of evidence from the school paperwork was really clear that Ciaran was in distress most of the time. (Naomi)

Having gone through this long and expensive process, the judge eventually ruled in Naomi's family's favour, and Ciaran was moved school. However, the process had a huge emotional and financial toll on the family, all in a battle against the state to get their son into a school which would be able to meet his needs.

The biggest regret, really, is that your child is communicating through behaviour and words that things are not working well for them. But we just believed the professionals who said he was fine. (Naomi)

Unfortunately, Naomi's situation is not a unique one. No doubt much of this resistance to moving children into specialist schools arises from the widespread lack of funding provided to the education sector in general, with an 2018 National Association of Head Teachers (NAHT) survey finding that only 2% of institutions reported receiving sufficient extra funding to meet the needs of disabled children (Ryan 2020: 183).

What becomes clear here time and time again is that responsibility is completely placed on the shoulders of parents. These experiences are consistent with recent scholarship exploring the impacts of neoliberal governmentality on the structure of the state, and citizen-state relationships. In their evaluation of the role of the state in shaping community, Ferguson and Gupta argue that 'the logic of the market has been extended to the operation of state functions' (Ferguson and Gupta 2002: 989). State services are not structured in a way in which people are given support; they must prove conclusively that they are deserving enough, that their child is 'disabled enough', to qualify for state provisions. In many cases, this involves a child undergoing severe and visible distress before parents are believed.

It's all illegal, but because everywhere is failing, it's almost like it doesn't matter. (Olivia)

Parents are placed in a unique situation in which those who are breaking the laws are controlled by those who are making them. The example of conflicts with schools is indicative of wider problems associated with navigating state services. Not only are individuals made responsible for accessing state-provided services but, when they fail to provide what they should, they are also responsible for holding local councils to account. Some parents even expressed explicit attitudes of ‘picking their battles’; it is simply impossible for parents to fight back every time something goes wrong, or a service is not provided.

## Conclusion

Drawing upon existing anthropological literature and interview data, in this article I have argued that uncertainty is consistently present in imaginings of the future for parents of disabled children. This is not only in terms of what a child might want or need, but also of what might be provided for families by the state. I have explored how parents understand the role of the state in their lives, and how this impacts their capacity to have faith in the future. Often, this relationship is understood as one of opposition: parents feel as though they access state support in spite of, not because of, interventions of local state services. As such, following existing anthropological scholarship which demonstrates how culture is disabling (Reid-Cunningham 2009; McDermott and Varenne 1995), I argue that for families of disabled children in the UK, austerity is disabling.

This is not to say, however, that parents are left powerless in the face of this uncertainty. Community action and the sharing of knowledge provides a powerful survivance tool through using which parents are able to assert themselves as active agents within a complex and opaque bureaucratic system. Despite this, the state should not function as a barrier to parents; failures of state services impact the capacity for hope, and hope is not just an object of imagination, but crucial for the materialisation of change.

Given this conclusion, we may ask how anthropology can address these issues. The anthropological focus on personhood brings to the fore the illusory nature of human independence through ethnographically demonstrating the extent to which all humans, everywhere, are dependent on one another. A focus on disability further demonstrates this, and also the quality of human interdependence and capacity for care as something which should not be devalued but celebrated. This could have implications not only in terms of the cultural recognition of dependence as a fact of human existence, but also on how ‘welfare dependency’ is understood more broadly as a condition of all citizens in the UK. In addition, by listening to the experiences of families of disabled children themselves, the issues that truly matter to them can be understood. Disability is not a medical condition of the ‘Other’, but a social category which is permeable and culturally constructed.

At the end of every interview, I asked each participant what they were most looking forward to in their future. The answers were strikingly mundane. Nick was looking forward to his son living around the corner from them, visiting at weekends. Kate was looking forward to getting a paid job and finally being able to go on holiday (something she had been unable to do since the birth of her son 12 years ago). Karen was looking forward to, as she put it, ‘being

sacked' by her daughter and watching her face the world without her. Abigail was excited about seeing her daughter get a job one day, hopefully at a nail salon. For the parents that I spoke to, hope was for normality, stability and a future which was not limited by their child's disability. As Naomi put it, 'I want a more boring life'. I hope that she and all the others will be able to achieve this.

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