

**The Care Act 2014: Exploring Capacity
Building and Mediation?**



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Philosophy**

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The dedication of this dissertation is to Brenda Hardaker for
formulating me into the person I am today.

While recognising the support given by Mark and Jacob for their
support over the past six years.

“Disputes take various shapes, follow particular dispute processing paths, and lead to new forms of understanding.”

William Felstiner, Richard Abel and Austin Sarat, ‘The Emergence and Transformation of Disputes: Naming, Blaming, Claiming’
(1980-81) 15(3-4) *Law & Society Review*, 631

DECLARATION

This thesis has not been submitted in support of an application for another degree at this or any other university.

It is the result of independent work and includes nothing that is the outcome of work done in collaboration except where specifically indicated. Many of the ideas in this thesis were the product of discussion with the supervisors Michael Salter, Helen Louise Codd, Kartina Aisha Choong, Kim McGuire.

ABSTRACT

The Care Act 2014 is an Act of the Parliament of the United Kingdom that received Royal Assent on 14 May 2014, after being introduced on 9 May 2013. The Act received the consensus of the three main political parties in the UK during its passage through parliament, and heralded by the Department of Health as the most significant reform of care and support in more than 60 years and which put personalisation at the centre of legislation. This thesis considers whether the principles of the original vision of personalisation were at odds with an increasingly marketised and individualised political vision. It is this context which is vital when considering the existing challenges of personalisation, people with disabilities and law.

The preparatory point is reviewing the approaches to disability and social justice, including the work of Fraser on recognition, redistribution and representation and consideration Rawls and his theory of Justice. Further work is an assessment of the medical and social models and what they have to offer to people with disabilities and their rights. The final review is that of outcome-oriented and sufficientarian approaches with the development of social identity; and reviewing the historical background and the development of the ideals of personalisation, which became the foundation of the Care Act.

Consideration is given to the Care Act 2014, where there is a review and analysis of the pros and cons of the legislation. Starting with a thoughtful consideration of aims of the Act and whether thirty months of its implementation these aims were being addressed; moving to the essential provisions of the Act and early indications of challenges and issues arising. The final chapter is a consideration of a dispute resolution process and whether the remaining status quo was the correct option to take rather than addressing it through an alternative dispute resolution process such as mediation.

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LIST OF ABBREVIATIONS AND GLOSSARY

ADASS – Association of the Directors of Adult Social Services

Adult Social Care - There is no simple definition of adult social care. However, it is agreed it covers a wide range of services provided by local authorities and the independent sector to adults either in their own homes or in a care home. It also includes day centres, which help people with daily living. Services like help with washing, dressing, feeding or assistance in going to the toilet are also included, as are meals-on-wheels and home help for people with disabilities.

Advocacy - Any action or service which: supports, encourages or helps to represent customers; and helps them to understand and communicate their views, needs or rights.

Assessment - A conversation held with a customer, sometimes using a questionnaire, which is used to work out what social care support a customer needs. An assessment takes place when a customer first applies to social care services. The assessment is reviewed at least once a year to make sure that the customer continues to receive the right support, but reviews may happen more frequently depending on an individual customer's circumstances. Please also see Financial Assessment.

Assistive Technology (AT) - The use of technology or equipment by a customer to enable or promote her/him to live independently. It allows people to perform tasks, which, they would otherwise be unable

to do, or increases the ease or safety with which the function can be completed. Telecare is an example of Assistive Technology.

Broker / Brokerage - An organisation or person that helps a customer to arrange the support they need. The brokerage can be done by the Council, a voluntary organisation/charity, a private company, or an individual such as a family member or friend.

Care Funding Calculator (CFC) - A tool to support local authority, health trusts and other public bodies across England and Wales to deliver care services efficiently. It has a similar purpose to a price comparison website, but for social care services. It is used by social care practitioners and people who commission social care services to understand the cost of a person's care package. The practitioner inputs the person's daily support needs into the calculator and based on a range of market costs, it works out a cost range, from which we can negotiate a fair price for the package.

Carers (unpaid) - When I talk about carers, I do not mean someone who is paid to provide care as part of a contract of employment - for example, a care worker or care staff. A carer is someone, who, without payment, provides help and support to a partner, child, relative, friend or neighbour, who could not manage without their help. This could be due to age, physical or mental illness, addiction or disability. A young carer is someone who is under the age of 18 and maybe looking after his/her parents, brother or sister, grandparent or another relative who needs support.

Care Package - A range of community care services, a person will receive for their assessed need.

Care Programme Approach (CPA) - Providing people with severe mental health problems an individual agreed care plan.

Chargeable Services - Chargeable services refer to adult social care services that the Council is allowed to charge for by government legislation. Government legislation may also specify how much we are allowed to charge and if we are not allowed to charge for a service.

Charges for Residential Accommodation Guidance (CRAG) - This document is published by the Department of Health and issues guidelines on how local authorities should determine costs for customers who are in residential care.

Commissioning - Commissioning is the process by which local authorities decide how to get the best possible value for money while providing excellent quality services for local people.

Community Care - Community care enables people to maintain their independence within their own homes wherever possible. Where necessary, i.e. following an assessment or review, assistance is provided to arrange long-term care in residential or nursing establishments.

Complaint - People have a right to complain about a service where they think they have been unfairly treated, or have received poor services.

Continuing Health Care - Continuing healthcare is a package of care arranged and funded solely by the NHS. It is awarded depending on whether a person's primary need is a health need. It can be provided in

a range of settings, including an NHS hospital, a care home or someone's own home.

Direct Payments - Are cash payments made directly to eligible customers who choose to make their care arrangements, rather than receiving services provided by the local authority. Direct Payments are one-way customers can choose to manage a personal budget. They offer greater choice and control.

Discretionary Services - These are services which local authorities are not required to provide by law. They are also sometimes referred to as Non-statutory services.

Domiciliary Care (also known as Home Care) - Domiciliary Care can help people with personal care and some of the practical household tasks that help them to stay at home and be as independent as possible.

Fair Access to Care Services (FACS) - This document is published by the Department of Health and issues guidelines on how local authorities should determine whether a customer is eligible for adult social care services. It covers how local authorities should carry out assessments and reviews and support individuals through the assessment process.

Fairer Charging - Fairer Charging refers to Government guidelines on how local authorities charge for non-residential care services.

Financial Assessment - A conversation, sometimes using a questionnaire, to work out what a customer can pay towards their social care services. A financial assessment will take place after an

assessment has been carried out to determine a customer's social care needs.

Intermediate Care - Intermediate Care is a generic term that covers a wide range of services that help prevent unnecessary admission to hospital or help facilitate early discharge. The term refers to a critical range of services that can help reduce delayed discharges.

Means-tested Contributions - This is a calculation to determine how much customers pay towards the costs of their social care services. This calculation is based on the information provided in the Financial Assessment, and the total is determined by looking at a customer's financial circumstances, (e.g. what income they have if they have any assets such as their own home, etc.).

Mixed Budget - A mixed budget is when a customer wants to arrange and manage some of their Personal Budget for themselves but wants the council to organise the rest in order to get the services they need. Please also see Direct Payments and Managed Personal Budget.

Non-chargeable Services - Non-chargeable services refer to adult social care services that the council is not allowed to charge for by government legislation. Please also see Chargeable Services.

Personal Assistant - A Personal Assistant is a person employed to help someone with his or her daily social care. They can be employed to provide support with activities such as cooking, cleaning and shopping; help with personal care like washing and using the toilet; help with getting around, either by driving or by using public transport; medical tasks; and banking or paying bills

Personal Budget - A Personal Budget is the sum of money, which a customer is assessed as being entitled to receive to help them be independent, safe and well. Personal budgets can be used to pay for any type of service, (not just a social care service) that would help add value to their life as long as it is legal. For example, a person may choose to use some of their money to join a gym or a craft club to help keep them active and allow them to socialise. They must be used to achieve agreed outcomes. A person can choose to receive their Personal Budget as a Direct Payment, Mixed Budget or Personal Managed Budget. These services are chargeable.

Personal Managed Budget (Virtual budgets) - A personal managed budget sometimes called a virtual budget is when a customer wants the Council to manage their Personal Budget for them, rather than receiving a Direct Payment and arranging care themselves.

Personalisation - Personalisation means giving people more choice and control over their own lives. It is the support that fits around the person rather than a person having to fit around the available support.

Promoting Independence - Most people would prefer to look after themselves as much as possible and to remain in their own home. Recent guidance has challenged statutory agencies to promote such independence by ensuring that people have access to the information and services that they need. It also places increased emphasis on rehabilitation and the associated services.

Provider of Care Services - is an independent or statutory organisation that may provide a whole range of care services

Purchaser of Care Services - Maybe the local authority or individuals with their own private financial means or direct payments who purchase care services for others or themselves.

Putting People First - This is a Government agreement to transform public services. The aim of this agreement is to help people to live their own lives as they wish, confident that services are of high quality, are safe and promote their individual needs for independence, well-being and dignity.

Reablement - Specialised help for people to regain the skills and confidence they need to continue living independently at home. Reablement services are currently available to people leaving hospital and people requesting social care support for the first time. The aim is to open up these services to all people who might benefit. This is currently free of charge for up to six weeks.

Resource Allocation System (RAS) - When a customer applies for social care, services they are assessed to work out what their support needs are. Once the needs have been identified, the Resource Allocation System is used to estimate how much these needs might cost. The final amount may change, as the cost of a service may depend on things such as a customer's location.

Respite Services - These services are available for customers to give their partners or family carer a break or holiday. These are Chargeable Services.

Self-Directed Support - Self-Directed Support puts eligible customers in control of the care and support they receive. With self-directed

support, the council does not make choices for the customer but instead supports the customer to: Identify what they need to make their life better; Know how much money they may get to spend on support; Decide what support they receive; Decide when and how they receive it.

Self-funders are people who organise their own care services, with or without assessment by, or assistance from a local authority.

Support Plan - This is the plan agreed by the customer and social care practitioner to meet the customer's care and support needs. A customer will always have a support plan even if they choose to receive a Direct Payment, Personal Managed Budget, an individual service fund or a combination.

Suitable Person - A Suitable Person can be appointed if someone lacks the capacity to consent to direct payments. The appointed person will receive and manage the payment for those people. The law tells the council who can act as this person.

Trust - A Trust can be a group of people made up of friends and family, or a private or voluntary organisation, who can look after a person's Personal Budget on their behalf.

1 GENERAL INTRODUCTION

1.1 Introduction

As a Practicing Solicitor in the UK for many years, specialising in Community Care, Disability Discrimination and Public Law. Having worked in both Community Legal Services and Private Law Firms, gave a unique perspective on some of the requirements that were the prerequisite for the most vulnerable such as advocacy, information and alternative dispute resolution services.

Because of this background, keen interest has developed in mediation both in community care, disability and family law; this is where the interest in doing this research originated. As a person with disabilities, having had to struggle for services to be provided and later on the right to be able to manage the 'care' budget to provide the best services to meet my needs/requirements in both care and employment services. I became involved with a group of parents and like-minded individuals, who operate as an extensive network and 'community for change'. The aims were to work directly with people who need support, and with their families to provide them with the knowledge, power and tools to take control of their lives and test

new innovative ways for people to be in control of their lives — later becoming Legal Advisor and Company Secretary. This became the foundation for In Control Partnership.¹

In 2008 the government announced the Consultation into the ‘new’ care act and welcomed ideas and considerations². There was the development of the ideas of the use of mediation to solve disputes between local authorities and persons with disability. The Draft Consultation (2010) paper gave no mention or consideration to either Alternative Dispute Resolution (ADR) or mediation³. After individual presentations to the Law Commissioners – Frances Patterson QC and Tim Spencer-Lane – they concluded that they thought that the present Complaints Procedure would be adequate under the ‘radical’ and ‘new’ Care Act. Therefore, the embarkation on a research journey to find out whether the Law Commissioner was correct or whether there could be some ‘ethical’ alternative to meet the requirements of the Care Act and the rights of people with disabilities.

1 In Control 2019 <http://www.in-control.org.uk/what-we-do.aspx> Accessed 20/08/2019

2 Law Commission, Adult Social Care: Scoping Report (2008) Part 2.

3 The Law Commission 2010 ADULT SOCIAL CARE A Consultation Paper No 192 viewed 21st August 2019 <
http://www.lawcom.gov.uk/app/uploads/2015/03/cp192_Adult_Social_Care_consultation.pdf>

1.2 Background

April 1st, 2015, the care system landscape in the United Kingdom changed with the implementation of the Care Act 2014 ('the Care Act')⁴. The Department of Health heralded it as the 'most significant reform of care and support in more than 60 years' and regarded as the most systematic and complete set of changes to adult social care legislation since the Beveridge Reforms of the 1940s⁵.

Over the last 70 years, however, the legislative wing of the care system has been added to piece by piece, become fragmentary, out of date and confusing. The Government envisaged that the Care Act would create a 'single, modern law that makes it clear what kind of care people should expect'. For once, a politician cannot be accused of exaggeration. There is no question that the Act heralds significant change.

4 The Care Act however is not applicable in Wales. The equivalent Welsh legislation, the Social Services and Well-Being (Wales) Act 2014, came into force in 2016.

5 For example, it was then that the National Health Service Act 1946 created the NHS in England and Wales whilst the National Assistance Act 1948 formally abolished the entrenched Poor Law system.

Norman Lamb, the Cameron / Clegg Government's Minister for Care and Support, said that the act would put "people and their carers in control of their care and support"⁶. There is indeed a lot in the care act and its guidance about choice and control, involvement, partnership, empowerment and co-production⁷. However, this seems a big ask at a time when hundreds of thousands of people with disabilities have been losing state social care support when welfare reform has restricted access to benefits, and mainstream services that people with disabilities as service users are particularly reliant on have seen cuts year after year in the name of austerity.

Therefore, Norman Lamb's claim demands closer examination. The guidance⁸ confirms that when considering a person's wellbeing, local authorities must begin "with the assumption that the individual is best-placed to judge the individual's wellbeing"⁹. Seemingly, the service user is in a powerful position at the outset

6 Department of Health. 2014a. "Care Bill Becomes Care Act 2014." Accessed 19 July, 2014.<https://www.gov.uk/government/speeches/care-bill-becomes-care-act-2014>

7 Government guidance for the Care Act: undermining ambitions for change? Colin Slasberg & Peter Beresford Disability & Society Vol. 29, Iss. 10, 2014

8 Department of Health, 2014. Care and Support Statutory Guidance: Issued Under the Care Act 2014.

9 Care Act. 2014. London: The Stationery Office.
www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga_20140023_en.pdf

of an assessment, but it is the endpoint of the assessment that determines what support the person will get. The guidance on assessment and eligibility makes clear that the final decisions about what a disabled person's needs are will remain with the council¹⁰. The local authority is in a dominant position at the point that matters most, although of course, this is also dependent on the level of funding from central government. Local authority funding has been decreasing year on year, and we are informed that this is set to continue. The guidance does not explain how local authorities will move from the person's views to their views other than "an assessment must be person-centred, involving the individual". These are concepts which are interpreted at the council's discretion.

Given that the local authority has an obligation not to overspend, how will the present situation of finances trumping needs be changed? It is difficult to see people with disabilities as service users and carers being able to exert more control in the context of severe funding limitations. This question will undoubtedly lead to conflict and challenges, to complaints, appeals and legal reviews,

10 Department of Health. 2014c. "Care Act 2014: How Should Local Authorities Deliver the Care and Support Reforms? Please Give Us Your Views: Eligibility." Accessed 19 July, 2014.
<http://careandsupportregs.dh.gov.uk/category/eligibility/>

as statutory guidance accompanying the Act acknowledges, local authorities can and sometimes do continue to exact a considerable degree of control over people's day-to-day lives¹¹.

1.3 Aims of the Thesis

Central to the Care Act 2014 is the golden thread principle of well-being. At the heart of this principle is 'control by the individual over day-to-day life, including over care and support and the way it is provided.'¹² The choice and control are fundamental to the core purpose of adult care and support which the Care Act guidance sees as being to 'help people to achieve the outcomes that matter to them in their life.'¹³

The aim of the thesis is to demonstrate whether The Care Act 2014 and its Statutory Guidance (hereafter called the Act") fulfils its obligations of providing real choice and control, whilst reviewing the provisions to resolve disputes for people with disabilities as

11 Department for Health (2015) Care Act 2014 Statutory Guidance. Local authorities sometimes actively restrict people's ability to exercise choice and control, employing arbitrary spending limits on particular care and support options, placing undue restrictions on how money can be spent or by imposing burdensome monitoring to restrict choice and impede flexibility. The statutory guidance on the Care Act 2015 is clear: such practices are wholly at odds with both the spirit and letter of the Care Act 2014.

12 Care Act 2014, S1 (2) (d) Promoting individual well-being

13 Care Act 2014 statutory guidance Section 1.1

service users and suggest of any new /existing pathways for remedies and resolution.

1.4 Literature Review

There have been rapid developments in Personalisation of health and social care in the UK over the past five years to develop a more flexible model of provision based upon greater choice and control for people with disabilities as service users. It is important for people with disabilities who are often dependent on others such as social workers to support their autonomy and independence.

A scoping review of the UK literature from the early 1990s through to 2018 was researched. Some studies, such as three reports by InControl - 2005¹⁴, 2008¹⁵ and 2010¹⁶ have suggested

14 Poll, C., Duffy, S., Hatton, C., Sanderson, H. and Routledge, M., 2006. A report on in Control's first phase, 2003-2005. Control; London. transition to personalised budgets showed a marked increase in satisfaction in services and provisions, as well as lifestyle, between time 1 and time 2.

15 Hatton C., Waters J., Duffy S., Senker J, Crosby N., Poll C., Tyson A., O'Brien J., Towell D. A Report on In Control's Second Phase: Evaluation and Learning 2005–2007 2008 London In Control Publications Despite the authors' positive interpretations within the report, there was limited satisfaction in the changes instigated by personalisation in individuals' quality of life and livelihood.

16 Tyson A., Brewis R., Crosby N., Hatton C., Stansfield J., Tomlinson C., Waters J., Wood A., A Report on In Control's Third Phase: Evaluation and

that when implemented well, Personalisation can have a positive impact on the lives of people with disabilities. Other literature highlighted the limitations and critiques of Personalisation.¹⁷ Without the right support to manage budgets and autonomy, people with disabilities could be left vulnerable. In respect of the social workers, the finding of the review was that there was a lack of guidance on how to implement personalisation and a perceived threat to their traditional practice role, resulting in barriers to implementation¹⁸. Although the literature emphasises the need for choice, control and autonomy for the person with disabilities as a service user, this study concludes that more research needs to be carried out into local authorities can support this process.

Both the manual and electronic searches of the literature revealed several critical texts¹⁹, which deconstructed some of the issues related to personalisation, particularly for people with disabilities²⁰

Learning, 2008–2009 2010 London In Control Publications This report focussed on re-assessing the findings of previous studies and conclusions.

17 Roulstone, A. and Morgan, H., 2009. Neo-liberal individualism or self-directed support: are we all speaking the same language on modernising adult social care?. *Social Policy and Society*, 8(3), pp.333-345.

18 Leece, J. and Leece, D., 2010. Personalisation: Perceptions of the role of social work in a world of brokers and budgets. *The British Journal of Social Work*, 41(2), pp.204-223.

19 Clements, L., 2008. Individual budgets and irrational exuberance. *Community care law reports*, 11, pp.413-430.

20 Ferguson, I., 2012. Personalisation, social justice and social work: a reply to Simon Duffy. *Journal of social work practice*, 26(1), pp.55-73.

²¹. As the novelty of this new approach wore off, critical papers regarding personalisation started to emerge²². The literature search found that the main issues that arose regarding personalisation and people with disabilities fell into the following three categories: ‘choice and control’; ‘self-management’ and, ‘autonomy and independence’.

1.4.1 Choice and control

The literature suggests that a critical concern regarding personalisation has been the issue of choice, and the question of whose choice it is ²³. Sowerby ²⁴ indicates that people with disabilities can rely heavily on their families, friends and personal assistants to support them and to highlight what is available and what choices they have. Hence, these people act as a buffer between the person with disabilities and the outside world. Studies have shown that most people have someone else managing their

21 Dodd, S., 2013. Personalisation, individualism and the politics of disablement. *Disability & Society*, 28(2), pp.260-273.

22 West, K., 2013. The grip of personalization in adult social care: Between managerial domination and fantasy. *Critical Social Policy*, 33(4), pp.638-657.

23 Pearson, C. and Ridley, J., 2014. *Self-directed support: personalisation, choice and control* (Vol. 19). Dunedin Academic Press.

24 Sowerby, D., 2010. What sort of helping relationships are needed to make personalisation happen and how can organisations be developed to support this?. *Journal of Social Work Practice*, 24(3), pp.269-282.

budgets (Hatton et al.²⁵, Mansell²⁶), suggesting that they may have limited control themselves. Also, having a personal budget requires a certain level of budget management expertise that not everyone will have²⁷.

Here the issue of mental capacity emerges in respect of choice and control and the degree of competency required to exercise these. Braye & Brammer²⁸ give some useful examples of the dilemmas, which can arise where the wishes and feelings of people who lack capacity cannot presume to be invalid just because of this fact but that best interests must prevail²⁹. A recent case in Northern Ireland has illustrated the importance of establishing clearly in law the

25 Emerson, E. and Hatton, C., 2008. CEDR Research Report 2008 (1): People with Learning Disabilities in England.

26 Mansell, J. and Beadle-Brown, J., 2010. Deinstitutionalisation and community living: Position statement of the comparative policy and practice special interest research group of the international association for the scientific study of intellectual disabilities. *Journal of Intellectual Disability Research*, 54(2), pp.104-112.

27 McConkey, R., Keogh, F., Bunting, B., Garcia Iriarte, E. and Watson, S.F., 2016. Relocating people with intellectual disability to new accommodation and support settings: Contrasts between personalized arrangements and group home placements. *Journal of Intellectual Disabilities*, 20(2), pp.109-120.

28 Braye, S. and Brammer, A., 2012. Law on personalisation.

29 Braye, S., Orr, D. and Preston-Shoot, M., 2017. Autonomy and protection in self-neglect work: the ethical complexity of decision-making. *Ethics and Social Welfare*, pp.1-12 and Preston-Shoot, M., 2014. *Making good decisions: law for social work practice*. Palgrave Macmillan.

right of carers to receive payments on behalf of a relative with learning disabilities³⁰. Here the family carers challenged the amount of payments made by the Health and Social Care Trust as being insufficient and the judicial review³¹ which followed revealed that there was no legal basis for the payments, because in law in Northern Ireland consent was still required to be given by the person with disabilities as a service user to allow their relatives to manage the payments³².

One study has suggested that the central change or choice that people with disabilities wanted was control over choosing their own personal assistants (PAs) (Poll et al.³³). However, this area of choice has raised many concerns regarding the safety and well-being of people with disabilities and the employment of personal assistants³⁴. As personal assistance is not a regulated profession,

30 [2017] 1 FLR 237, [2016] EWFC 1, [2016] Fam Law 272, [2017] 4 WLR 55

31 Bridgeman, J., 2017. The Provision of Healthcare to Young and Dependent Children: The Principles, Concepts, and Utility of the Children Act 1989. *Medical Law Review*.

32 Carr, H. and Goosey, D., 2017. *Law for Social Workers*. Oxford University Press.

33 Kennedy, J., Poll, C. and Sanderson, H., 2007. 13 Creating community inclusion. *Person Centred Practice for Professionals*, p.280.

34 Woolham, J., Daly, G., Steils, N. and Ritters, K., 2015. The evolution of person-centred care to personalised care, personal budgets and direct

and personal assistants employed privately, this can create tensions and dilemmas. For example, by employing a personal assistant, a person with disabilities becomes an employer, a role that has certain exacting requirements such as knowledge of employment law³⁵. Besides, this led several Trade Unions, such as UNISON criticising Personalisation as a method for driving down wages and working conditions³⁶.

1.4.2 Self-management

Many people with disabilities have welcomed the promise of increased choice and control. However, the speed and nature of the Acts implementation and its coupling with the marketisation of the disability service sector has produced well documented, but still unresolved tensions. These are located in broader debates regarding the strain between the disabled rights and neoliberal market narratives upon which the broader personalisation agenda is grounded (Needham 2011³⁷; Kendall & Cameron 2013³⁸;

payments in England: some implications for older users of social care services. *Sociologia e Politiche Sociali*.

35 Meltzer, A., Bates, S. and Robinson, S., 2016. What do people with intellectual disability think about their jobs and the support they receive at work?: a comparative study of three employment support models.

36 Glasby, J., 2011. Whose risk is it anyway? Risk and regulation in an era of personalisation. *Journal of Care Services Management*, 5(4), pp.173-183.

37 Needham, C. (2011) *Personalising public services: Understanding the Personalisation Narrative*, Bristol, Policy Press.

Lymbery 2014³⁹; Mladenov et al. 2015⁴⁰). The conflation of marketisation and self-directed approaches change the nature of relationships between people with disabilities, the state and the market yet the consequences of these shifting accountabilities and the inherent risk, as well as opportunity that sit within these new frameworks, have yet to be fully unpacked (Dickinson et al. 2014⁴¹). The “citizen consumer” construct that places the person with disabilities and their choices at the centre of service delivery systems reflects neoliberal governments’ values and priorities (Clarke et al. 2007⁴²). However, the assumptions underpinning the notion of the person with disabilities as a service user as a key player in, and shaper of a human services market, have been critiqued as problematic and contradictory. Many are

38 Kendall, S. and Cameron, C. (2013) ‘Personalisation of adult social care: self-directed support and the choice and control agenda’, *British Journal of Learning Disabilities*, 42, 264–71.

39 Lymbery, M. (2014) ‘Understanding personalisation: implications for social work’, *Journal of Social Work*, 14 (3), 295–312.

40 Mladenov, T., Owens, J. and Cribbs, A. (2015) ‘Personalisation in disability services and healthcare: a critical comparative analysis’, *Critical Social Policy*, 35 (3), 1–20.

41 Dickinson, H., Needham, C. and Sullivan, H. (2014) ‘Individual funding for disability support: what are the implications for accountability?’, *Australian Journal of Public Administration*, 73 (4), 417–25.

42 Clarke, J., Newman, J., Smith, N., Vidler, E. and Westmarland, L. (2007) *Creating Citizen-Consumers: Changing Publics and Changing Public Services*, London, Paul Chapman Publishing

concerned that true market forces may not operate well in a human service context and that the “profit motive” associated with market competition is “antithetical” to human services values and purpose (Meagher & Goodwin 2015⁴³; Quiggan 2016⁴⁴).

Despite these concerns, the market is developing and responding to the opportunities triggered by the personalisation, through the self-management options. These include the emergence of new service and business models such as online Uber-style⁴⁵ service platforms that provide personalisation people with disabilities with direct access to support workers via the “gig” economy and direct employment initiatives (Rold 2014⁴⁶). These innovations have the potential to offer some people with disabilities as service users

43 Meagher, G. and Goodwin, S. (2015) ‘Introduction: capturing marketization in Australian social policy’. In G. Meagher and S. Goodwin (eds) *Markets, Rights and Power in Australian Social Policy*, Sydney, University Press, pp. 1–27

44 Quiggan, J. (2016) ‘Face the facts: competition and profit don't work in health, education or prisons’, *The Guardian*, <https://www.theguardian.com/commentisfree/2016/sep/12/face-the-facts-competition-and-profit-dont-work-in-health-education-or-prisons>(accessed 9 November 2017).

45 The term “uber” is used to describe any person or thing that is outstanding, supreme, cool or edgy. In this case, the term is used to describe the newly emerging online disability service platforms which mirror the uber taxi model and have the potential to disrupt the traditional disability service provider market. i.e. shop4support, PlanMyCare and slivers of care.

46 Rold, A. (2014) ‘The Gig Economy’, *Diplomatic Courier*, 8 (1), 6.

unprecedented levels of flexibility and autonomy in their support service choices.

These new enterprises are delivering new possibilities for people using and providing services; however, the implications for different personalisation stakeholders have yet to be adequately thought through. While online recruitment platforms exemplify ideas of choice and control for support workers and personalisation people with disabilities, there are inherent risks in these innovations. These relate to central tensions between individual gain and empowerment on the one hand and a “strong social contract”, robust institutions and “collective identity” on the other (Williams & Dickinson 2015⁴⁷). It has been suggested that individualised and market-driven approaches may be fundamentally flawed in the context of public and social services and may constitute “regressive individualisation and narrowing of collective democratic engagement” whereby marketisation is working as a “front for undemocratisation” (Clarke et al. 2005⁴⁸;

47 Williams, I. and Dickinson, H. (2015) ‘Going it alone or playing to the crowd? A critique of individual budgets and the personalisation of Health Care in the English National Health Service’, *Australian Journal of Public Administration*, 75 (2), 149–58.

48 Clarke, J., Smith, N. and Vidler, E. (2005) ‘Consumerism and the reform of public services: inequalities and instabilities’. In M. Powell, L.

Quiggan 2016⁴⁹). There is an imminent need to understand these critical tensions for the personalisation given the recent consequences of market failure in other public service sectors, such as in the childcare sector (Dodd 2013⁵⁰; Quiggan 2016⁵¹).

Flowing from these concerns are significant questions about equity and opportunity related to who wins and who loses in a market economy and under what conditions. How do we measure success, failure and differentiated risks in a market model, mainly when the transfer of risk from the public to the private is often concealed? How will self-management approaches and the associated risks of market and profit dynamics impact on established social investment and capital in the community? Can everyone be a winner in this new market landscape of consumer control and choice and where do inherent risks in the framework emerge (Dodd 2013⁵²; Meagher & Goodwin 2015⁵³)?

Bauld and K. Clarke(eds) Social Policy Review, Vol. 17, Bristol, UK, Policy Press, pp. 167–82.

49 Quiggan, J. (2016) ‘Face the facts: competition and profit don't work in health, education or prisons’, The Guardian, <https://www.theguardian.com/commentisfree/2016/sep/12/face-the-facts-competition-and-profit-dont-work-in-health-education-or-prisons>(accessed 9 November 2017).

50 Dodd, S. (2013) ‘Personalisation, individualism and the politics of disablement’, *Disability and Society*, 28(2), 260–73.

51 Quiggan, J. (2016) *Ibid*

52 Dodd, S. (2013) ‘Personalisation, individualism and the politics of disablement’, *Disability and Society*, 28(2), 260–73.

Internationally, efforts to understand the risks and benefits of individualised and self-managed funding approaches have been impeded by the diversity of programs, target groups, and levels of flexibility and choice, within and across countries (Laragy 2004⁵⁴). The lack of research about the long-term effects of marketisation in the disability sector has impeded efforts to understand and scrutinise impacts. The “multiple meanings” embedded in the personalisation narrative further complicate efforts to predict the risks and benefits of self-management for different groups (Bigby & Fyffe 2009⁵⁵; Needham 2011⁵⁶). It is imperative to consider the challenges of self-management for people with disabilities as service users as well as for support workers and service providers in an increasingly marketised and technology-based landscape. There is more research required on

53 Meagher, G. and Goodwin, S. (2015) ‘Introduction: capturing marketization in Australian social policy’. In G. Meagher and S. Goodwin (eds) *Markets, Rights and Power in Australian Social Policy*, Sydney, University Press, pp. 1–27.

54 Laragy, C. (2004) ‘Self-determination within Australian school transition programs for students with a disability’, *Disability and Society*, 19, 519–30.

55 Bigby, C. and Fyffe, C. (2009) ‘An overview of issues in the implementation of individualised funding’. In C. Bigby and C. Fyffe (eds) *Proceedings of the Third Annual Roundtable on Intellectual Disability Policy*, October 2008, Bundoora, La Trobe University, pp. 148.

56 Needham, C. (2011) *Personalising public services: Understanding the Personalisation Narrative*, Bristol, Policy Press.

the types of mechanisms that might mediate between different stakeholders' interests to ensure the implementation of the personalisation is rights-promoting for all rather than just for some. The types of regulation required to “tame” a disability services market at risk of being driven by profit rather than social justice motives are needed.

1.4.3 Autonomy and Independence

The literature suggests that both these terms can have a contested meaning, particularly regarding people with disabilities. Generally, autonomy and independence⁵⁷ are popularly associated with the ability to be self-sufficient and to self-care. In the case of people with disabilities, many need supports to achieve independent and autonomous lifestyles⁵⁸. Hence, as highlighted above, in the quest to achieving independence, social care professionals have tended to think that a definitive outcome of achieving an independent and independent lifestyle is the ability to do it alone (Leece &

57 Leece, J. and Peace, S., 2009. Developing new understandings of independence and autonomy in the personalised relationship. *British Journal of Social Work*, 40(6), pp.1847-1865.

58 Sims, D. and Cabrita Gulyurtlu, S.S., 2014. A scoping review of personalisation in the UK: approaches to social work and people with learning disabilities. *Health & social care in the community*, 22(1), pp.13-21.

Peace⁵⁹). However, some authors assert that independence is not about having to do everything alone, but about exercising choice and control (Clark and Spafford⁶⁰), and that dependence (relying on others for guidance, support and supplies) can have an autonomous element to it. Leece & Peace⁶¹ introduced the concept of autonomous dependence, which refers to when a person with disabilities willingly relies on help from a support worker yet maintains a level of control over the relationship, sometimes as their employer⁶². Williams & Holman⁶³ note that people with disabilities felt that employing a personal assistant gave them autonomy because they controlled their individualised service⁶⁴. These different perspectives on autonomy illustrate that

59 Leece, J. and Leece, D., 2010. Personalisation: Perceptions of the role of social work in a world of brokers and budgets. *The British Journal of Social Work*, 41(2), pp.204-223.

60 Clark, H. and Spafford, J., 2002. Adapting to the culture of user control?. *Social Work Education*, 21(2), pp.247-257.

61 Leece, J. and Leece, D., Ibid

62 Manthorpe, J., Martineau, S., Ridley, J., Cornes, M., Rosengard, A. and Hunter, S., 2015. Embarking on self-directed support in Scotland: a focused scoping review of the literature. *European Journal of Social Work*, 18(1), pp.36-50.

63 Williams, V. and Holman, A., 2006. Direct payments and autonomy: issues for people with learning difficulties. *Developments in direct payments*, pp.65-78.

64 Williams, V. and Porter, S., 2017. The Meaning of 'choice and control' for People with Intellectual Disabilities who are Planning their Social Care

a person does not have to act alone to be autonomous, but rather that there are various ways of achieving autonomy. Furthermore, Williams and Porter⁶⁵ believe that by recognising and supporting the process towards autonomy, rather than purely focussing on the outcome, this will further build a more inclusive and equal society.

The findings from the literature regarding the impact of Personalisation on social workers and their role in supporting people with disabilities revealed no specific peer-reviewed articles or papers exclusively focussing on the part of the social worker in respect of personalisation. The literature showed a range of documents which commented on personalisation and social work more generally, and many themes were identifiable. Cutting across these themes was the principle of social justice and a call by some writers for social workers to embrace personalisation (Duffy⁶⁶, Tyson *et al.* ⁶⁷). Three themes identified were: the impact of personalisation on social work and social workers; the potential

and Support. *Journal of Applied Research in Intellectual Disabilities*, 30(1), pp.97-108.

65 Williams, V. and Porter, S., *Ibid*

66 Duffy, S., 2010. The citizenship theory of social justice: exploring the meaning of personalisation for social workers. *Journal of Social Work Practice*, 24(3), pp.253-267.

67 Williams, B. and Tyson, A., 2010. Self-direction, place and community—re-discovering the emotional depths: A conversation with social workers in a London borough. *Journal of Social Work Practice*, 24(3), pp.319-333.

opportunities personalisation represents for changing social work practice; and the critiques and dilemmas impacting on social work practice.

1.4.4 Social Workers and Social Work Practice

Many papers from early in the timeframe illustrated social workers' initial perceptions of direct payments as implemented began following the 1996 Direct Payments Act⁶⁸. A clear element of caution was part of the early reaction of social workers to this development (Spandler & Vick⁶⁹). The literature suggests that social workers were hesitant about encouraging the use of direct payments and that they wished to be selective about which people with disabilities as service users should have the opportunity to benefit from them, believing there to be a 'right sort of person' who could most benefit (Ellis⁷⁰). Caution focused on concern about whether people can manage their own money, the degree of risk this exposed people to and potential for exploitation, and what

68 Glasby, J. and Littlechild, R., 2002. Social work and direct payments. Policy Press.

69 Spandler, H. and Vick, N., 2005. Enabling access to direct payments: An exploration of care co-ordinators decision-making practices. *Journal of Mental health*, 14(2), pp.145-155.

70 Ellis, K., 2007. Direct payments and social work practice: The significance of 'street-level bureaucracy' in determining eligibility. *British Journal of Social Work*, 37(3), pp.405-422.

cash payments should appropriately be spent on⁷¹. The literature indicates a paradoxical concern about the fact that the transfer of autonomy to people with disabilities as service users may represent a loss of autonomy for the social worker (Clark and Spafford⁷²)⁷³. The social workers' ambivalence towards Personalisation is noted on by Manthorpe *et al.*⁷⁴ However, early in the development of direct payments, the opportunities for increased service user control, flexibility and independence were also acknowledged and valued by social workers (Stainton⁷⁵) and were seen to be in line with the core of social work values about self-determination and empowerment.⁷⁶

71 Walsh, J., 2014. Theories for direct social work practice. Nelson Education.

72 Clark, H. and Spafford, J., 2002. Adapting to the culture of user control?. *Social Work Education*, 21(2), pp.247-257.

73 Sims, D. and Cabrita Gulyurtlu, S.S., 2014. A scoping review of personalisation in the UK: approaches to social work and people with learning disabilities. *Health & social care in the community*, 22(1), pp.13-21.

74 Manthorpe, J. and Stevens, M., 2009. Increasing care options in the countryside: Developing an understanding of the potential impact of personalization for social work with rural older people. *British Journal of Social Work*, 40(5), pp.1452-1469.

75 Stainton, T., 2002. Taking rights structurally: Disability, rights and social worker responses to direct payments. *British Journal of Social Work*, 32(6), pp.751-763.

76 Roets, G., Dean, H. and Bie, B.D., 2016. Disability rights and disability studies in social work: Uncovering different interpretations of rights and

In the papers reviewed a tension is identifiable between the opportunity to promote independence and the threat to the social work role itself. Early in the development of individual budgets, Leece suggested that social workers did not know enough about them and some incorrectly believed that people with learning and mental disabilities were not eligible for them (Leece⁷⁷). The first tendency by some local authorities was to exclude people with learning and mental disabilities from direct payments⁷⁸.

There is, however, evidence that social workers were aware that they undertook work with people who could be more autonomous. Poll *et al.*⁷⁹ identified that care managers felt they held many cases where they were not the best person to be involved. Consistent with this, Leece & Leece⁸⁰ found in their study that

needs of people with learning disabilities in social work practice.
In *European Social Work: a compendium*.

77 Leece, J., 2000. It's a matter of choice: Making direct payments work in Staffordshire. *Practice*, 12(4), pp.37-48.

78 Parsell, C., Eggins, E. and Marston, G., 2016. Human agency and social work research: A systematic search and synthesis of social work literature. *British Journal of Social Work*, 47(1), pp.238-255.

79 Poll, C., Duffy, S., Hatton, C., Sanderson, H. and Routledge, M., 2006. *A report on In Control's first phase 2003-2005*. Control; London.

80 Leece, J. and Leece, D., 2010. Personalisation: Perceptions of the role of social work in a world of brokers and budgets. *The British Journal of Social Work*, 41(2), pp.204-223.

over half the people they questioned did not see a need for social workers to be involved in Personalisation.

The literature also suggests that Personalisation represents an opportunity for the development of a new approach in social work precisely because it is compatible with traditional social work practice⁸¹. Leece & Leece⁸² associate this ‘traditional’ social work with a more therapeutic role, involving advocacy, group work and counselling, as carried out by many social workers in the 1970s and early 1980s. Glendinning *et al.*⁸³ note that in the individual budget pilots, some social workers felt invigorated. Parkinson⁸⁴ identifies the opportunity for relationship-based practice, and Williams & Tyson⁸⁵ suggest that the idea of self-directed support can revive a more emotionally engaged form of

81 McNeill, S. and Wilson, G., 2016. Use of Direct Payments in Providing Care and Support to Children with Disabilities: Opportunities and Concerns. *The British Journal of Social Work*, p.bcw159.

82 Leece, J. and Leece, D., *Ibid*

83 Glendinning, C., 2008. Increasing choice and control for older and disabled people: a critical review of new developments in England. *Social Policy & Administration*, 42(5), pp.451-469.

84 Smith, M., Doel, M., Cooper, A., Simmonds, J., Solomon, R., Kohli, R., Kroll, B., McMahan, L. and Parkinson, C., 2010. *Relationship-based social work: Getting to the heart of practice*. Jessica Kingsley Publishers.

85 Williams, B. and Tyson, A., 2010. Self-direction, place and community—re-discovering the emotional depths: A conversation with social workers in a London borough. *Journal of Social Work Practice*, 24(3), pp.319-333.

social work, taking it beyond the limitations of care management and assessment. Foster⁸⁶ identifies that the potential for higher creativity exists within social work provided that social workers are reinforced by improved support, supervision and reflective space. Sowerby⁸⁷ also asserts that guidance of those involved in personalisation is critical to its success, with new ways of thinking and working needed.

The third theme emerging from the social work literature paints the critiques and dilemmas which have developed in parallel with personalisation. Duffy⁸⁸ has sought to promote Personalisation through critical writing about the ‘professional gift model’ where care is a gift decided for the person with disabilities through the local authority. He advocates for a more person-centred approach but does acknowledge that given the political rhetorical use of personalisation to justify reform of public services, it can be

86 Stanley, N., Miller, P., Richardson Foster, H. and Thomson, G., 2010. A stop–start response: Social services' interventions with children and families notified following domestic violence incidents. *The British Journal of Social Work*, 41(2), pp.296-313.

87 Sowerby, D., 2010. What sort of helping relationships are needed to make personalisation happen and how can organisations be developed to support this?. *Journal of Social Work Practice*, 24(3), pp.269-282.

88 Duffy, S., 2004. In control. *Journal of Integrated Care*, 12(6), pp.7-13.

difficult for social workers to interpret accurately what this should mean to their practice.^{89 90}

Ferguson⁹¹ is critical that neoliberal ideas underpin Personalisation, endangering through marketisation the traditional services on which many vulnerable people rely. He suggests that personalisation favours the better educated, maybe a vehicle for cost-cutting and that it establishes a group of low paid personal assistants whose employment conditions are unprotected⁹². By implication, this is a threat to the social work role. Scourfield⁹³ suggests that personalisation creates a space, which suits 'entrepreneurial' people with disabilities as service users but that not all people with disabilities as service users can engage with

89 Duffy, S., 2010. The future of personalisation. *Journal of Care Services Management*, 4(3), pp.202-216.

90 Duffy, S., 2017. The value of citizenship. *Research and Practice in Intellectual and Developmental Disabilities*, pp.1-9.

91 Ferguson, I., 2007. Increasing user choice or privatizing risk? The antinomies of personalization. *British journal of social work*, 37(3), pp.387-403.

92 Lymbery, M., 2012. Social work and personalisation. *British Journal of Social Work*, 42(4), pp.783-792.

93 Scourfield, P., 2007. Are there reasons to be worried about the 'caretelization' of residential care?. *Critical Social Policy*, 27(2), pp.155-180.

this, exposing them to potential vulnerability⁹⁴. This situation is parodied by Houston,⁹⁵ who uses the term *homo economicus* to critique some of the budget management implications which lie behind Personalisation. A Family Carer can monitor expenditure, reducing their management and overhead costs on established services while enabling them to present themselves as pioneers of choice and control. The cost and complications of managing the support to individuals are not always, however, included in the direct payment made available⁹⁶.

Lymbery & Postle^{97 98} identify a fundamental dilemma for social workers in the application of personalisation, this being the challenge of achieving a role with vulnerable people which balances promoting autonomy and providing sufficient protection

94 Carey, M., 2009. Critical commentary: Happy shopper? The problem with service user and carer participation. *British Journal of Social Work*, 39(1), pp.179-188.

95 Lakeman, R., 2008. Family and carer participation in mental health care: perspectives of consumers and carers in hospital and home care settings. *Journal of Psychiatric and Mental Health Nursing*, 15(3), pp.203-211.

96 Beresford, P., 2008. Whose personalisation?. *Soundings*, (40), p.8.

97 Lymbery, M. and Postle, K., 2010. Social work in the context of adult social care in England and the resultant implications for social work education. *British Journal of Social Work*, 40(8), pp.2502-2522.

98 Lymbery, M., 2012. Social work and personalisation. *British Journal of Social Work*, 42(4), pp.783-792.

against abuse and exploitation. They express concern over the use of unqualified staff to replace the function of social work⁹⁹. In reflecting on the lack of research about how people who use self-directed support perceive and manage risk, Macintyre¹⁰⁰ suggests that social work skills are essential to promote risk enablement and to detect and prevent abuse¹⁰¹.

1.4.5 Summary

This scoping has revealed a lack of literature which directly reports on the outcomes of personalisation for people with disabilities and social workers and their engagement in personalisation with these people with disabilities as service users. There is, however, some anecdotal evidence that the roles of social workers in adult services are currently subject to scrutiny and may be affected by the economic downturn. The following extract suggests that services need to remain focused on their duty to support people in the process the most vulnerable individuals, for whom support is critical to be able to exercise choice and control:

99 Ferguson, I., 2012. Personalisation, social justice and social work: a reply to Simon Duffy. *Journal of social work practice*, 26(1), pp.55-73.

100 MacIntyre, G. and Paul, S., 2012. Teaching research in social work: Capacity and challenge. *British Journal of Social Work*, 43(4), pp.685-702.

101 Atwal, A., McIntyre, A., Spiliotopoulou, G., Money, A. and Paraskevopoulos, I., 2017. How are service users instructed to measure home furniture for provision of minor assistive devices?. *Disability and Rehabilitation: Assistive Technology*, 12(2), pp.153-159.

Personalisation is not a method or a singular approach. It is a social contract between individuals needing support and the state as the enabler of this support. Each individual will have their constellation of needs and preferences about meeting these needs.¹⁰²

The literature has revealed many important factors, which need to be well-thought-out if people with disabilities are to be reinforced in the process (and not just the tasks) of Personalisation. Themes in the literature focus on critical issues to do with choice, control, independence and autonomy. Although the results of the study reveal little empirical evidence about outcomes of personalisation, these important debates form an essential backdrop to its contemporary rapid implementation. They also confirm the need to extend knowledge about its impact.

Consequently, more evidence is needed to guide social care practice and promote independence, autonomy, choice and control for people with disabilities. Studies are required which compare and contrast the relative benefits of using personal budgets against the traditional funding model of services provided directly by

102 Sowerby, D., 2010. What sort of helping relationships are needed to make personalisation happen and how can organisations be developed to support this?. *Journal of Social Work Practice*, 24(3), pp.269-282. Pg 276

local authorities. This will enable a more critical judgement to be made about reported improvements to the quality of life resulting from personalisation as compared with other care arrangements.

1.5 Research Questions

The next step is to investigate the changes occurring in the implementation of the Care Act 2014 and the challenges for people with disabilities as service users; and how those persons may wish to challenge their assessment and who wish to develop their care plans. Leading to the two research questions for this thesis:

Firstly, whether choice and control have been achieved as envisaged under the Care Act, and secondly whether there are better alternatives to use of litigation and complaints procedure under the Care Act. The thesis reviews the legal reforms in terms of their effects on people with disabilities having choice and control for their care and support, as argued for many years before the 2014 Act. To this end, the review of the developing statute law includes the real-life consequences, as well as the legal implications of personalisation; looking at when there are disagreements on expectations or failings, have occurred.

The second aspect is with dispute resolution, and to legally challenge a Local Authority; the person with disabilities must

show that they have exhausted the complaint procedure like local resolutions and final stage being the ombudsman. The Act failed to make provisions for mediation or other alternative dispute resolution (ADR) despite discussions during the consultation period with the Law Commissioner in its early stages of developing and drafting the Act¹⁰³. Both the Law Commissioners Francies Patterson QC and Tim Spencer-Lane both argued that the present Complaints System, with recourse to Ombudsman and Litigation, was working well ¹⁰⁴ . They both suggested the introduction of a community care tribunal, which was rejected by the government. ¹⁰⁵ A small number of consultees expressed concern that the proposal would create unrealistic expectations amongst people with disabilities as service users to be able to change decisions. For example, concerning adaptations, Gateshead Council said “[disabled] people’s desired outcomes over and above what we would consider essential” and therefore “increase the level of expectation of choice and control would increase the numbers of complaints”¹⁰⁶.

103 Law Commission, 2011. Adult Social Care: A Consultation Paper. Stationery Office.

104 Law Commission 2012. Adult Social Care Consultation Analysis. Stationary Office

105 Law Commission 2012 Ibid

106 Law Commission 2012 ibid p35

Therefore, the hypothesis was that: if a provision had been made in the Care Act for mediation this would have the advantage of the following: Save on tax-payers money on unnecessary grants of legal aid; reducing the high costs to the Local Authority of both professional and legal staffs; avoid the need to issue judicial review proceedings at High Court involving high costs of legal fees and unnecessary distress to the service user and their families.

The research looks at whether mediation offers informal process to find common ground and with the outcome of a resolution which can be a win-win solution both for the service user and the Local Authority, as opposed to litigation.

1.6 Methodology

The most appropriate of the various socio-legal methods to the aims of the thesis is the experiential route of a theoretical approach that explores relationships of meaning, purpose and value internal to the research subjects lived-experiences. Particularly useful when researching the effect of the Act on people with disabilities and their right to ‘choice and control’ and dispute resolution.

The past decades have seen a return of interest in social science-oriented research within legal studies, the socio-legal approach¹⁰⁷. This research will use an interdisciplinary socio-legal approach for its methodology, which elaborates on the critical elements of history, sociology, politics and economics (Aspers¹⁰⁸). According to this method, the law is rooted within the structures and policy-making and enforcement processes of contemporary society¹⁰⁹. This methodology is especially relevant to the policy analysis part of the research.

Cotterrell¹¹⁰ suggests that socio-legal studies approaches can give insight into the nature of legal ideas and to clarify questions about legal doctrine – providing an analysis of the law's conceptual structures. Focusing primarily on the socio-legal model suggests that the object of enquiry is the 'law-society relationship'. Socio-legal researchers increasingly recognise the need to employ a wide variety of research methods in studying law and legal phenomena, and the need to be informed by an understanding of debates about

107 Baier, M. ed., 2016. Social and legal norms: Towards a socio-legal understanding of normativity. Routledge.

108 Aspers, P., 2010. The second road to phenomenological sociology. *Society*, 47(3), pp.214-219.

109 Aspers Ibid

110 Cotterrell, R., 2006. Comparative law and legal culture.

theory and practice in mainstream social science ¹¹¹ . This methodological reconstruction of the relationship between law and society is fundamental to the research. ¹¹²

The most appropriate of the various socio-legal methods to the aims of the project is the experiential route of a phenomenological methodology that explores relationships of meaning, purpose and value internal to the research subjects lived-experience. This approach allows real research into the socio-legal issues addressed above (Husserl ¹¹³ ; Giorgi ¹¹⁴ ; van Manen ¹¹⁵ ; Fischer ¹¹⁶ ; and Aspers ¹¹⁷). The reading of Reasons (1988) Human Inquiry in Action ¹¹⁸ adds a further dimension to the framework I am developing: the need for the investigation to be guided by

111 Roach Anleu, S. and Mack, K., 2014. Judicial performance and experiences of judicial work: Findings from socio-legal research.

112 Nonet, P., 2017. Law and society in transition: Toward responsive law. Routledge.

113 Husserl, E. and Heidegger, M., 1964. The phenomenology of internal time-consciousness.

114 Febbrajo, A., 2009. For a socio-legal theory of risk. *Sociologia del diritto*.

115 Van Manen, M., 2007. Phenomenology of practice. *Phenomenology & Practice*, 1(1).

116 Fischer, C.T., 2006. Phenomenology, Bruno Klopfer, and individualized/collaborative assessment. *Journal of personality assessment*, 87(3), pp.229-233.

117 Aspers Ibid

118 Reason, P. ed., 1988. *Human inquiry in action: Developments in new paradigm research*. Sage.

principles of cooperative inquiry and for the study to be mutually beneficial to all person with disabilities. This socio-legal method highlights the content and forms of people's subjective interpretations of the world. The research will focus on understanding how the law impacts on others, whether it be people with disabilities, commentators, professionals in local authorities or policymakers.

Moustakas¹¹⁹ used analysis to obtain comprehensive accounts of experiences. The aim is to determine what the experience means for the people who have had the experience of Personalisation, its limitations, the provision of care services and the any identified effect of legislation on its delivery. The focus is on an understanding of the meaning of the portrayal of the law and its implementation. Regarding Personalisation, thoroughly abstracted and presented the themes seen as essential to this experience and will be able to show the unique experience in a way that is understandable, recording the differences with other similar experiences in a themes analysis.

There were additional consultations with the legal experts and professionals using a semi-structured interview method. The reason this socio-legal study is interviewing experts is that they

119 Moustakas, C., 1994. Phenomenological research methods. Sage.

are the ones who have influenced the Law Commission in drafting the legislation¹²⁰ – and have their aims and objectives in moulding the law. Therefore, it is essential to compare – what they wanted about personalisation and dispute resolution. The effects have been reviewed and what challenges they thought there would be to the legislation in the final chapter and conclusion.

Therefore, the research has used the following methods:

- reviewing the details of the prior legislation and Care Act 2014;
- reviewing the developing case law to consider and compare the variations in case law alongside the hypothesis;
- providing an understanding of the research by using data taken from people with disabilities who receive a Personal Budget / Individual Budget
- researching the legal, political and social analysis of Personal Budget / Individual Budget from organisations such as the Directors of Social Services (ADASS), In Control, Department of Health, Law Commission and academic sources such as Mandelstam, Clements and Schwar;
- reviewing any ethical obligations that have been observed and will this impact upon the proposed Law Reform;

120 Wheeler, S. and Thomas, P.A., 2000. Socio-legal studies.

The analysis will move to the legal implications of dispute resolution in the Care Act. This will be achieved by:

- Critically analysing the socio-legal issues raised by the present legislation and personalisation, and how these are managed;
- Determining whether the law can protect disabled persons who will have personal budgets and have challenges for the Law;
- Identifying effects, gaps and limitations within the new legislation and addressing how these may be fulfilled and remedied;
- Showing how the new Act is planned to end legal contradictions and provide clear guidance to the authorities and vulnerable persons about their rights and responsibilities.

1.7 Structure of the Thesis

The overview starts with the background to the thesis and the challenges within social care within England, through economic austerity, the requirements of people with disabilities wanting more choice and control over their service and support provision; and changing the theoretical model of providing care and support.

This review looks at the philosophical concepts of social justice and whether this should be addressed through recognition or through financial distribution; and this is discussed through medical or social models of disability. There is a literature review concerning positive aspects of Personalisation while showing that there were nonconforming voices against the expansion of personal budgets and direct payments.

The past decades have seen a return of interest in social science-oriented research within legal studies¹²¹, the socio-legal approach. This research will use an interdisciplinary socio-legal approach for its methodology, which elaborates on the essential elements of history, sociology, politics and economics¹²². According to this approach, the law is embedded within the structures and policy-making and enforcement processes of contemporary society. This methodology is especially relevant to the policy analysis part of the research¹²³.

Therefore, the foundation for the Thesis is considering the history of the care system and its legislation; while examining why the

121 Schuck, P.H., 1989. Why don't law professors do more empirical research. *J. Legal Educ.*, 39, p.323.

122 Aspers, P., 2010. The second road to phenomenological sociology. *Society*, 47(3), pp.214-219.

123 McConville, M. ed., 2007. *Research methods for law*. Edinburgh University Press.

Act came into existence while considering the history and development of self- directed and personalisation. The thesis will critically analyse the relevant contents of the Act concerning ‘choice and control’, and the absence of any remedies to resolve community care disputes within the care system. The Thesis will be demonstrated how real choice and control could have been enacted; while showing how the Act in the absence of an alternative resolution process could have worked had there been a dispute procedure adopted in the Act.

The conclusions of the research are presented in a way that saw that improvement could be implemented to the process within government agencies such as local authorities, policymakers and court systems.

2 Approaches to Disability, Inclusion and Social Justice

2.1 Introduction

Among the topics in philosophy and disability, justice has received the lion's share of attention, because justice is regarded as the "first virtue of social institutions,"¹²⁴ which is central to the evaluation of social policies, law and public institutions. However, it is because political philosophers have seen disability, along with legal researchers and disability scholars as posing severe challenges to contractarian and contractual theories of justice: to arguments based on hypothetical agreement, mutual advantage, or reciprocity^{125 126}.

Disability also presents difficult issues as a social or group identity – as a central part of the way an individual understands, presents, or values herself. This aspect of disability has been made

124 Rawls, J., 2009. A theory of justice. Harvard university press. Pg 3

125 Goodley, D., Lawthom, R., Liddiard, K. and Cole, K.R., 2017. Critical Disability Studies. In The Palgrave Handbook of Critical Social Psychology (pp. 491-505). Palgrave Macmillan UK.

126 Harris, H., Mechenbier, M., Oswal, S.K., Stillman-Webb, N., Meloncon, L., Kerschbaum, S.L., Garland-Thomson, R. and Vidali, A., 2017. The Bedford Bibliography of Research in Online Writing Instruction.

noticeable by the civil liberties movement that established disability as an essential category in anti-discrimination law.

2.2 Starting Point: Rawls's Principles of Justice

Different philosophers propose different principles of distributive justice. Does that mean that we may choose any one of them with equal justification? A "yes" answer to this question would make disputes about fairness impossible to settle. To avoid this, we must find some nonarbitrary method of selecting the proposed principles of justice.

One method for resolving this issue might be to follow the traditions of various practices that have grown up over time. For example, the practise of assessing and grading people with disabilities for determining their care budget. In defence of such traditions, they have survived because they have proven more satisfactory to the parties affected, considered collectively, than other conceivable alternatives, such as individual budgets and the ability to pay. To argue this way would be to reinforce the argument from tradition ("we have done it that way for a long time") by a kind of Utilitarian argument ("let us optimise society's satisfaction").

Traditions can be oppressive and unjust. Activities that take place within unjust social systems can themselves be unjust, despite their traditional nature. Thus the practice of giving a person that is "her / his" can be unjust. What is needed is a way to determine when social systems, or the rules of justice that govern society as a whole, are fair: Rawls provides such an approach to the selection of rules of distributive justice. Rawls' approach is not Utilitarian, and it does not rely heavily on arguments from tradition¹²⁷.

We are to imagine ourselves in what Rawls calls the Original Position. Where we are all self-interested rational persons, and we stand behind "the Veil of Ignorance."¹²⁸ To say that we are self-interested rational persons is to say that we are motivated to select, in an informed and enlightened way, whatever seems advantageous for ourselves. Self-interested rational persons behind the Veil of Ignorance are given the task of choosing the principles that shall govern the actual world. Rawls believes that he has set up an inherently fair procedure here¹²⁹. Because of the fairness of the procedure, Rawls has described, he says, the

¹²⁷ Rahim, M.A., Garrett, J.E. and Buntzman, G.F., 1992. Ethics of managing interpersonal conflict in organizations. *Journal of Business Ethics*, 11(5-6), pp.423-432.

¹²⁸ Huang, K., Greene, J.D. and Bazerman, M., 2019. Veil-of-ignorance reasoning favors the greater good.

¹²⁹ Hare, R.M., 1973. Rawls' theory of justice. *Philosophical Quarterly*, 23(144).

principles that would be chosen employing this procedure would be fair principles.¹³⁰ In his principles of justice, Rawls argues that self-interested rational persons behind the veil of ignorance would choose two general principles of justice to structure society in the real world:

1) Principle of Equal Liberty: Each person has an equal right to the most extensive liberties compatible with similar liberties for all. (Egalitarian.)

2) Difference Principle: Social and economic inequalities should be arranged so that they are both:

(a) to the greatest benefit of the least advantaged persons, and

(b) attached to offices and positions open to all under conditions of equality of opportunity.¹³¹

Therefore, the observations on Rawls are:

¹³⁰ JOHN, W., 1971. *Rawls's Theory of Justice*.

¹³¹ Martin, R., 1985. *Rawls and rights* (p. 129). Lawrence: University Press of Kansas.

(1) is egalitarian, since it distributes extensive liberties equally to all persons.

(2b) is also quite egalitarian, since it distributes opportunities to be considered for offices and positions in an equal manner.

(2a) Is not egalitarian but makes a benefit for some (those with greater talents, training, etc.) proportionate to their contribution toward benefiting the least advantaged persons.

Without exactly duplicating, it is similar to libertarianism in its commitment to extensive liberties.

Rawls talks about Difference Principle¹³², where the economic, political, and social frameworks that each society has—its laws, institutions, policies, etc.—result in different distributions of benefits and burdens across members of the society. These frameworks are the result of human political processes and they constantly change both across societies and within societies over time. The structure of these frameworks is important because the distributions of benefits and burdens resulting from them fundamentally affect people's lives¹³³.

¹³² Schaller, W.E., 1998. Rawls, the difference principle, and economic inequality. *Pacific philosophical quarterly*, 79(4), pp.368-391.

¹³³ Dworkin, R., 2017. Rawls and the Law. In *Rawls and Law* (pp. 35-53). Routledge.

He notes that society may undertake projects that require giving some persons, for example, more power, income, status, than others, e.g., Business Development Managers more than assembly-line operatives, on condition on meeting the following conditions:

1. Each person has an equal claim to a fully adequate scheme of equal basic rights and liberties, which scheme is compatible with the same scheme for all; and in this scheme the equal political liberties, and only those liberties, are to be guaranteed their fair value.

2. Social and economic inequalities are to satisfy two conditions:

(a) They are to be attached to positions and offices open to all under conditions of fair equality of opportunity; and

(b), they are to be to the greatest benefit of the least advantaged members of society.¹³⁴

¹³⁴ Rawls, John, 1993, *Political Liberalism*, New York: Columbia University Press Pages 5-6. The principles are numbered as they were in Rawls' original *A Theory of Justice* 1971.)

Where the rules may conflict in practice, Rawls says that Principle (1) has lexical priority over Principle (2), and Principle (2a) has lexical priority over (2b). As a consequence of the priority rules, Rawls' principles do not permit sacrifices to basic liberties in order to generate greater equality of opportunity or a higher level of material goods, even for the worst off¹³⁵. While it is possible to think of Principle (1) as governing the distribution of liberties, it is not commonly considered a principle of distributive justice given that it is not governing the distribution of economic goods *per se*. Equality of opportunity is discussed in the next section. In this section, the primary focus will be on (2b), known as the Difference Principle.

The main purpose of distributive justice theory is not to inform decisions about ideal societies but about our societies. To help correct this misunderstanding it is important to acknowledge that there has never been, and never will be, a purely libertarian society or Rawlsian society¹³⁶, or any society whose distribution conforms to one of the proposed principles. Rather than guiding choices between ideal societies, distributive principles are most

¹³⁵ White, A., 2018. The Difference Principle: Rawls's Two Oversight.

¹³⁶ Vallier, K., 2015. A moral and economic critique of the new property-owning democrats: on behalf of a Rawlsian welfare state. *Philosophical Studies*, 172(2), pp.283-304.

usefully thought of as providing moral guidance for the choices that each society faces right now. So, for instance, advocates of Rawls' Difference Principle are most constructively understood as arguing for changes to our basic institutional structures which would improve the lifetime prospects of the least advantaged in society¹³⁷. We may reasonably assume that the "least advantaged" have the greatest needs and that those who receive special powers (hinted at under "social inequalities") also have special responsibilities or burdens. However, the merit principle that the use of special skills should be rewarded is also included in the Difference Principle. What (2a) does not permit is a change in social and economic institutions that makes life better for those who are already well off but does nothing for those who are already disadvantaged, or makes their life worse.

Rawls is not opposed in principle to a system of strict equality *per se*; his concern is about the *absolute* position of the least advantaged group rather than their *relative* position¹³⁸. If a system of strict equality maximizes the absolute position of the least

¹³⁷ Brock, G., 2005. The difference principle, equality of opportunity, and cosmopolitan justice. *Journal of Moral Philosophy*, 2(3), pp.333-351.

¹³⁸ Eyal, N., 2005. 'Perhaps the most important primary good': self-respect and Rawls's principles of justice. *Politics, Philosophy & Economics*, 4(2), pp.195-219.

advantaged in society, then the Difference Principle advocates strict equality. If it is possible to raise the absolute position of the least advantaged further by having some inequalities of income and wealth, then the Difference Principle prescribes inequality up to that point where the absolute position of the least advantaged can no longer be raised. Rawls' theory of justice was set forth in his book *A Theory of Justice*. Since then it has been much discussed, and attempts have been made to improve and clarify it, not least by Rawls himself¹³⁹. One of those attempts at improvement is that of Martha C. Nussbaum (*Women and Human Development*)¹⁴⁰, who has reinterpreted Rawls' argument from the perspective of Substantial Freedom, an idea she gets from Amartya Sen¹⁴¹.

For Nussbaum the liberties mentioned in the Principle of Equal Liberty¹⁴², if they are to be meaningful at all, are capabilities or substantial freedoms, real opportunities based on natural and developed potentialities as well as the presence of governmentally supported institutions, to engage in political deliberation and planning over one's own life.

¹³⁹ Rawls, J., 2009. *A theory of justice*. Harvard university press.

¹⁴⁰ Nussbaum, M.C., 1997. Capabilities and human rights. *Fordham L. Rev.*, 66, p.273.

¹⁴¹ Sen, A., 2004. *Rationality and freedom*. Harvard University Press.

¹⁴² Buchanan, J.M., 1976. The justice of natural liberty. *The Journal of Legal Studies*, 5(1), pp.1-16.

Likewise, for Nussbaum¹⁴³, the concern of the Difference Principle to raise up those who are least advantaged must be clarified in light of substantial freedoms. What is needed, in her view, is a commitment by citizens and governments to a threshold of real opportunities below which no human being should fall if she is able to rise above it. These are some of the challenges within the Care Act 2014.

2.3 Disability: recognition or redistribution?

Theories that assess justice in terms of the distribution of resources or opportunities have been criticised for failing to take adequate account of such identities¹⁴⁴. However, the embrace of social status as a component of justice can be equally problematic¹⁴⁵. Disability is of interest for justice and law because of the way in which it contrasts two basic and powerful senses of *injustice*¹⁴⁶: Firstly, the treatment of some people as moral, social, or political inferiors based on irrelevant characteristics; and

¹⁴³ Alexander, J.M., 2016. Capabilities and social justice: The political philosophy of Amartya Sen and Martha Nussbaum. Routledge.

¹⁴⁴ Siebers, T., 2008. Disability theory. University of Michigan Press.

¹⁴⁵ Beaudry, J.S., 2016. The anxious heart of injustice: negative affective responses to disabilities.

¹⁴⁶ Francis, L., 2015. Disability and philosophy: applying ethics in circumstances of injustice. *Journal of medical ethics*, pp.medethics-2015.

secondly, the creation, perpetuation, or simple failure to correct disparities between individuals in income, wealth, health, and other aspects of well-being based on morally irrelevant factors.

These two broad categories of injustice – roughly, disrespect and distributive inequity – correspond closely to Nancy Fraser's crucial distinction between recognition and redistribution¹⁴⁷ as alternative responses to the problem of injustice. Recognition seeks to secure equal respect for individuals to whom it has been denied; redistribution aims to correct unfair disparities in advantages of various kinds. The relationship and comparative importance of these two forms of injustice have been the subject of considerable discussion between Anderson¹⁴⁸; Fraser¹⁴⁹; and Honneth¹⁵⁰.

Within the disability rights movement, there is an opinion that the two types of injustice mentioned above – disrespect and

147 Fraser, N., 1995. What's critical about critical theory. Also Fraser, N., 1995. From redistribution to recognition? Dilemmas of justice in a 'post-socialist' age. *New left review*, (212), p.68.

148 Anderson, P.S., 1999. Justice and inequality don't mix. *ABAJ*, 85, p.6.

149 Fraser, N., 2001, May. Social justice in the knowledge society: redistribution, recognition, and participation. In *Gut zu Wissen* conference paper, Heinrich Böll Stiftung (Vol. 5, pp. 1-13).

150 Honneth, A., 1992. Integrity and disrespect: Principles of a conception of morality based on the theory of recognition. *Political theory*, 20(2), pp.187-201.

distributive inequity – are related¹⁵¹. Historians and Social Policy experts have noted that people with disabilities are treated as moral and social inferiors^{152 153}. Routinely, people with disabilities have traditionally been denied jobs for which they are highly qualified because they have been considered incompetent, or because employers have not been comfortable with their presence in the workplace. The economic inequalities are primarily the result of exclusion and stigmatisation; of what Fraser calls “misrecognition”¹⁵⁴. At the same time, the distributive injustice faced by people with disabilities heightens their exclusion and stigmatisation. As Gideon Calder ¹⁵⁵ asserts, “in particular, internally diverse ways, people with disabilities have been on the end of a kind of pincer movement between Fraser's two impediments to parity; maldistribution and misrecognition.”¹⁵⁶

151 Wendy Taormina-Weiss (Disabled World) 2011-12-05 (Revised/Updated 2017-06-28); [.https://www.disabled-world.com/editorials/justice.php](https://www.disabled-world.com/editorials/justice.php)

152 Barnes, C., 2014. . A brief history of discrimination and disabled people.

153 Barnes, C., 1996. Theories of disability and the origins of the oppression of disabled people in western society. *Disability and society: Emerging issues and insights*, pp.43-60.

154 Fraser, N., 2007. Identity, exclusion, and critique: a response to four critics. *European Journal of Political Theory*, 6(3), pp.305-338.

155 Calder, G., 2011. Disability and misrecognition. *The politics of misrecognition*, pp.105-124.

156 Ibid pg 63

In some cases, Barnes argues that just encouragement for people with disabilities requires significant additional resources and expenses from governmental funding¹⁵⁷. In any society whose physical structures and social practices are intended for average or conventional members, people with disabilities will be disadvantaged just because of their minority status¹⁵⁸. A similar point has been made by feminist scholars¹⁵⁹, who have pointed out the “structural discrimination” of workplaces and public settings designed exclusively for men. The expenses of additional bathrooms and toilets do not compensate women for their deficiencies; they accommodate differences ignored in a society that saw a woman's place as in the home (Wendell¹⁶⁰ ; Wasserman¹⁶¹). Disability scholars and activists have also argued that the costs of including people with disabilities in all aspects of

157 Barnes, C. and Mercer, G., 2005. Disability, work, and welfare: challenging the social exclusion of disabled people. *Work, employment and society*, 19(3), pp.527-545.

158 Millward, G., 2017. Disability and the Welfare State in Britain: Changes in Perception and Policy. By Jameel Hampton. *Twentieth Century British History*, 28(2), pp.313-315.

159 Morris, J., 2014. *Feminism, gender and disability* and Baker, J., Lynch, K., Cantillon, S. and Walsh, J., 2016. *Equality: From theory to action*. Springer.

160 Wendell, S., 1996. *The rejected body: Feminist philosophical reflections on disability*. Psychology Press.

161 Silvers, A., Wasserman, D.T. and Mahowald, M.B., 1998. *Disability, difference, discrimination: Perspectives on justice in bioethics and public policy* (Vol. 94). Rowman & Littlefield. 178–179

social, political, and economic life have been greatly exaggerated and are rarely a significant factor in rectifying injustice.¹⁶² The issues of distribution and the importance of recognition in achieving justice are complex.

2.4 Reframing justice: Issues of political representation

In Nancy Fraser's work *Adding insult to injury: Nancy Fraser debates her critics*¹⁶³, she uses it to explore issues of social

162 The common sense assumptions about the costliness of accommodation are not fully supported by existing empirical research (Acemoglu and Angrist 1998; Blanck 1992; Blanck and Steele 1998; Schartz et al. 2006). Many people with disabilities can live, work, study, and play alongside the non-disabled with no specific physical or institutional changes requiring expensive outlays of dollars or time. Sometimes all that is necessary is eliminating an arbitrary non-job-related requirement. For example, a city civil service requirement for a social worker was that she climb 42 stairs in two minutes – thereby excluding people who walked more slowly with crutches or braces. Upon investigation, the New York City Civil Service department acknowledged that it could not justify the requirement. Furthermore, empirical research indicates that not only are accommodations low cost but are actually beneficial and effective (Schartz et al. 2006; Schreuer et al. 2009; Solovieva et al. 2009). Furthermore, as Frank Bowe pointed out in 1980, a society that keeps people with disabilities out of school, work, and neighbourhoods is paying billions in benefits to keep people dependent. Bowe sought to demonstrate that it would be less expensive to create an inclusive society than to keep intact the special benefits and programs for people with disabilities.

163 Fraser, N., 2008. *Adding insult to injury: Nancy Fraser debates her critics*. Verso.

justice. The review of her work focuses on the applicability and usefulness of Fraser's three-dimensional model for understanding matters of social justice for people with disabilities. *Adding insult to injury: Nancy Fraser debates her critics* (Olson, 2008¹⁶⁴) provides an excellent account of such developments and challenges.

While the first two dimensions (economic and cultural) of Fraser's model are featured and discussed in *Adding Insult to Injury*, the later sections of the book track the arguments that prompted her to add the third dimension (political). The book provides a rich and detailed account of debates and counter-debates associated with Fraser's theorising that have appeared in other publications since 1995¹⁶⁵. For example, it features early concerns with her work – articulated in separate chapters by Iris Young¹⁶⁶ and Judith Butler¹⁶⁷ about the model's dichotomising/polarising of economic and cultural justice as analytically distinct. For these theorists, this distinction does not reflect the complex political realities and

¹⁶⁴ Olson, K. (2008). *Adding Insult to Injury: Nancy Fraser debates her critics*. London: Verso.

¹⁶⁵ Fraser, N., 1995. From redistribution to recognition? Dilemmas of justice in a 'post-socialist' age. *New left review*, (212), p.68.

¹⁶⁶ Unruly Categories: A Critique of Nancy Fraser's Dual Systems Theory Iris Marion Young p89 In K. Olson (Ed), *Adding Insult to Injury: Nancy Fraser debates her critics* (pp. 273-294). London: Verso.

¹⁶⁷ Merely Cultural - Judith Butler p42 In K. Olson (Ed), *Adding Insult to Injury: Nancy Fraser debates her critics* (pp. 273-294). London: Verso.

intersections of justice claims. Other concerns about Fraser's earlier work are associated with how she theorises the integration and pursuit of justice on these two dimensions. Here Fraser's rejection of an affirmative approach to group recognition, as in tension with the principles of distributive justice, is challenged in a chapter by Elizabeth Anderson¹⁶⁸ who highlights how affirmative action can support distributive principles. A further chapter by Ingrid Robeyns¹⁶⁹ offers Amartya Sen's capability framework as more effective than Fraser's in theorising how matters of distributive and recognitive justice can be tracked simultaneously. In the later sections of the book the failure of Fraser's two-dimensional model to account for matters of political justice is highlighted in chapters by Leonard Feldman¹⁷⁰ and Kevin Olson¹⁷¹. These commentators argue that political injustices are 'analytically distinct from, and cannot be reduced to, inequities

168 In K. Olson (Ed), *Adding Insult to Injury: Nancy Fraser debates her critics* (pp. 273-294). London: Verso.

169 *Is Nancy Fraser's Critique of Theories of Distributive Justice Justified?* Ingrid Robeyns p176 in K. Olson (Ed), *Adding Insult to Injury: Nancy Fraser debates her critics* (pp. 273-294). London: Verso.

170 *Status Injustice: The Role of the State* Leonard Feldman – 221 in K. Olson (Ed), *Adding Insult to Injury: Nancy Fraser debates her critics* (pp. 273-294). London: Verso.

171 *Participatory Parity and Democratic Justice* Kevin Olson p246 In K. Olson (Ed), *Adding Insult to Injury: Nancy Fraser debates her critics* (pp. 273-294). London: Verso.

of economy or culture’ and thus should be assigned a privileged place in Fraser’s theorising (Olson, 2008, p. 6). Further shortcomings to Fraser’s work are noted in chapters by Nikolas Kompridis¹⁷² and Rainer Forst¹⁷³ who question the philosophical underpinnings of her critical theorising around recognition, justice, public claims-making and participatory parity.

Fraser provides detailed responses to, and reconciliations of, the major criticisms of her work in *Adding Insult to Injury* – indeed, as she concedes, they have developed and extended her theorising¹⁷⁴. Perhaps the most enduring criticism of her work (highlighted by Young and Butler) relates to the model’s polarising of economic, cultural and political justice issues as analytically distinct – this criticism prevails despite Fraser’s insistence of the ‘interimbrication’ and overlap of these issues¹⁷⁵. The assumption of this thesis considers how this criticism can be

172 Struggling over the Meaning of Recognition - Nikolas Kompridis p295 In K. Olson (Ed), *Adding Insult to Injury: Nancy Fraser debates her critics* (pp. 273-294). London: Verso.

173 First Things First: Redistribution, Recognition and Justification Rainer Forst 310 in K. Olson (Ed), *Adding Insult to Injury: Nancy Fraser debates her critics* (pp. 273-294). London: Verso.

174 Prioritizing Justice as Participatory Parity: A Reply to Kompridis and Forst - Nancy Fraser in K. Olson (Ed), *Adding Insult to Injury: Nancy Fraser debates her critics* (pp. 273-294). London: Verso.

175 Heterosexism, Misrecognition, and Capitalism: A Response to Judith Butler - Nancy Fraser in K. Olson (Ed), *Adding Insult to Injury: Nancy Fraser debates her critics* (pp. 273-294). London: Verso.

addressed concerning research and theorising within disability and social justice.

The thesis focuses on the usefulness of Fraser's three-dimensional model for understanding and approaching matters of justice and disability. As such it builds on the already expansive body of research and writing across a collection disciplines that draws on her work (see, for example, Atweh, 2009¹⁷⁶; Gilbert et al., 2011¹⁷⁷; Huttunen, 2007¹⁷⁸; Keddie, 2012¹⁷⁹; Mills, 2012¹⁸⁰; Power & Frandji, 2010¹⁸¹; Tikly & Barrett, 2011¹⁸²). In Fraser's earlier

176 Atweh, B. (2009). What is this thing called social justice and what does it have to do with US in the context of globalisation. In P. Ernest, B. Greer & B. Sriraman (Eds.), *Critical issues in mathematics education* (pp. 111-124). USA: Information Age Publishing.

177 Gilbert, R., Keddie, A., Lingard, B., Mills, M., Renshaw, P. (2011). *Equity and Education Research, Policy and Practice: A review*. Carlton, Victoria

178 Huttunen, R., 2007. Critical adult education and the political-philosophical debate between Nancy Fraser and Axel Honneth. *Educational Theory*, 57(4), pp.423-433.

179 Keddie, A., 2012. *Educating for diversity and social justice*. Routledge.

180 Mills, C., 2012. When 'picking the right people' is not enough: A Bourdieuan analysis of social justice and dispositional change in pre-service teachers. *International Journal of Educational Research*, 53, pp.269-277.

181 Power, S. and Frandji, D., 2010. Education markets, the new politics of recognition and the increasing fatalism towards inequality. *Journal of Education Policy*, 25(3), pp.385-396.

work, there is limited theorising around matters of political or representative justice. This absence has been a key criticism. As mentioned earlier, Feldman and Olson in *Adding Insult to Injury*, argue that political injustices are analytically distinct from economic and cultural injustices. In his chapter '*Participatory parity and democratic justice*'¹⁸³, Olson draws attention to the distinctly political character that is central to Fraser's notion of participatory parity. He argues that matters of political representation (i.e. being heard and accorded a voice) are crucial in any conception of justice – as he states, 'participation is distinctively *political* in character'¹⁸⁴ and furthermore, that such participation or non-participation frames and informs how distributive and recognitive justice are understood and approached. Following this, for Olson, matters of political representation are not only analytically distinct from economic redistribution and cultural recognition but should be assigned a privileged place in Fraser's theory. While the development of Fraser's ideas does not obstruct the possibility of considering

182 Tikly, L. and Barrett, A.M., 2011. Social justice, capabilities and the quality of education in low income countries. *International Journal of Educational Development*, 31(1), pp.3-14.

183 Olson, K. 2008. Participatory parity and democratic justice. In K. Olson (Ed), *Adding Insult to Injury: Nancy Fraser debates her critics* (pp. 246-272). London: Verso.

184 Olson, K. 2008. Participatory parity and democratic justice. In K. Olson (Ed), *Adding Insult to Injury: Nancy Fraser debates her critics* London: Verso. P252

matters of political justice, her later work engages with these matters. Consistent with Olson's argument, her chapter *Reframing justice in a globalising world*¹⁸⁵ explicates a three-dimensional theory of justice that specifies the political. Fraser defines political injustices as arising when some individuals or groups are not accorded equal voice in decision making – i.e. when the constitution of political space is such that all social actors are not equitably represented.

Fraser detects the significance of a focus on political justice within the global context. Fraser argues that the demise of the modern territorial nation-state has changed the way we think about and consider justice issues – processes such as the rise of neoliberalism and global governance, migration and politics have destabilised and prompted a questioning of previous paradigms and structures for understanding justice. The challenge for the Care Act is analysing it within a national framework rather than the global one, as suggested by Fraser.

185 See Fraser, N., 2007. *Reframing justice in a globalizing world*. *Global inequality: Patterns and explanations*, pp.252-272. And Fraser, N., 2008. *Abnormal justice*. *Critical inquiry*, 34(3), pp.393-422.

In this ‘post-Westphalian’ environment¹⁸⁶, she contends, there is greater uncertainty and disagreement about, for example, who might be entitled to consideration in matters of justice and how such injustices can be remedied. This uncertainty, in her view, brings to the fore problematics and tensions associated with representative justice. This is a key consideration for people with disabilities in the UK and their representation in developing legislation and social justice around the Care Act.

According to Fraser there are at least two types of political in/justice: firstly, *ordinary* mis/representation¹⁸⁷ – which, she contends, has tended to be understood within nation-state boundaries and relates to parity of political representation for minority groups within these boundaries and, secondly, *mis/framing*¹⁸⁸ – where the focus is on the global and on the ways in which nation-state boundaries include and exclude questions of justice. In relation to the latter type, Fraser argues that political space or frames can be powerful instruments of injustice as they ‘furnish the stage on which struggles for justice are played out’¹⁸⁹;

186 Fraser, N., 2009. Scales of justice: Reimagining political space in a globalizing world (Vol. 31). Columbia University Press.

187 Fraser, N., 2008. Abnormal justice. *Critical inquiry*, 34(3), pp.393-422.

188 Owen, D., 2012. Scales of Justice: Reimagining Political Space in a Globalizing World by Nancy Fraser. *Constellations*, 19(1), pp.135-139.

189 Fraser, N., 1995. From redistribution to recognition? Dilemmas of justice in a 'post-socialist' age. *New left review*, (212), p.68.

they ‘establish the criteria of social belonging’ and thus determine who and what counts in matters of distributive, recognitive and representative justice¹⁹⁰.

In *Reframing justice*, most of Fraser’s theorising relates to the macro-politics of the global – especially how the ‘gerrymandering’ of political space impacts on ‘who counts as a subject of justice’¹⁹¹. However, her analysis of political justice issues in this chapter has clear resonance with some of the key tensions of representation identified within the sphere of disability and social care at a more micro-political level.

While not sharing the same macro-political focus (concerning global exclusions), disability theory, policy and practice have long been cognisant of similar *mis/framing* issues associated with such representation. Certainly, initiatives to increase the representation of people with disabilities from differing backgrounds in UK local authorities – tend to omit or distort issues of economic, cultural and political justice for people with disabilities. Concerning matters of economic justice, (as noted earlier), for example, the

190 Olson, K. 2008. Adding Insult to Injury: A introduction. In K. Olson (Ed.), *Adding Insult to Injury: Nancy Fraser debates her critics* (pp. 1-8). London: Verso. p. 278

191 Fraser, N., 2007. Reframing justice in a globalizing world. *Global inequality: Patterns and explanations*, pp.252-272.

deficit thinking and low expectations associated with people with disabilities that are common within mainstream frames have curtailed people with disabilities's capacities to take advantage of the material benefits of social care.

These frames clearly 'furnish the stage' on which struggles for justice are played out. Moving beyond their exclusions, for Fraser, requires re-constituting political space so that all are accorded a voice. While again associated with the demarcation of global space, her 'all- affected principle' has been instructive here. This principle 'holds that all those affected by a given social structure or institution have moral standing as subjects of justice concerning it' ¹⁹² . Moves to increase the representation of people with disabilities in western social care contexts reflect this principle. While predominantly focused on quantifying disability groups representation, increasing representation in this sense creates environments where genuine engagement with, and inclusion of, marginalised voices are possible.

The re-constitution of political space to be more inclusive of people with disabilities and groups is, of course, crucial to

¹⁹² Reframing Justice in a Globalizing World - Nancy Fraser p 273 In K. Olson (Ed.), *Adding Insult to Injury: Nancy Fraser debates her critics* (pp. 1-8). London: Verso.

supporting representative justice. It is well recognised that attending to, and thinking from the space of, marginalised groups can enable just and democratic societies because beginning from the lives and interests of these groups identifies and makes visible the workings of power and inequity (Mohanty, 2003¹⁹³; Hooks, 1994¹⁹⁴). Greater representation of people with disabilities within social care supports this thinking and challenging of exclusionary (mainstream) social care frames.

However, it is also evident, as reflected in the previous section concerning matters of cultural / cognitive justice, that efforts to increase minority representation of people with disabilities within local authorities are vulnerable to, and often shaped by, a politics of reification. One of the key problematics that continues to undermine political justice is the assumption that one needs to be a member of a particular group (whether based on disability, racial, cultural, gender or class difference) to authentically represent the interests of the group (McConaghy, 2005¹⁹⁵; Keddie, 2012¹⁹⁶). The

193 Mohanty, C.T., 2003. *Feminism without borders: Decolonizing theory, practicing solidarity*. Zubaan. And Mohanty, C.T., 2003. "Under Western eyes" revisited: feminist solidarity through anticapitalist struggles. *Signs: Journal of Women in culture and Society*, 28(2), pp.499-535.

194 Hooks, B., 1994. *Outlaw culture: Resisting representations*. Routledge.

195 Minichiello, V., Somerville, M., McConaghy, C., McParlane, J. and Scott, A., 2005. The challenges of ageism. *Contemporary issues in gerontology*, pp.1-33.

‘cultural bio-determinism’ within this politics – where one’s membership to a certain identity group is a literal determinant of their knowledge and actions concerning the group – is seen to be highly problematic (see Spivak, 1990¹⁹⁷). It also places undue expectation and responsibility on members of marginalised groups to authentically represent, and act on behalf of, the interests of their group¹⁹⁸ It is evident then, that the ‘links between racialised identity, knowledge and legitimacy can no longer be sustained’.¹⁹⁹

Consistent with the theorising presented, working through such complexities, as Fraser contends, is supported by focusing on *how* such representation is approached. Concerning political justice, may mean ‘unburdening’ disability groups of their constructed distinctiveness, for example, the Deaf Community. These initiatives appreciate that group identity is important in struggles for justice and that cultural distinctiveness is a means by which

196 Keddie, A. (2012). *Educating for diversity and social justice*. New York: Routledge. Ladson-Billings, G. (1995). Toward a theory of culturally relevant pedagogy. *American Educational Research Journal*, 32(3), 465-491.

197 Spivak, G.C., 1990. *The post-colonial critic: Interviews, strategies, dialogues*. Psychology Press.

198 Moreton-Robinson, A., 2000. Troubling business: difference and whiteness within feminism. *Australian Feminist Studies*, 15(33), pp.343-352.

199 McConaghy, C., 2000. *Rethinking indigenous education: Culturalism, colonialism, and the politics of knowing*. Post Pressed.

minority groups can assert their presence to achieve material and symbolic transformations (Hooks, 1994)²⁰⁰.

For Fraser, the important issue here is *how* such distinctiveness is represented and mobilised – it can be prepared as a strategy of the particular that is not about exclusions or the simplifying and hypostatizing of culture but about overcoming status subordination²⁰¹. McConaghy (2000²⁰²) contends along these lines that there will be times when such distinctiveness is useful for political strategies, and there will be times when it is not. Referring to people with disabilities - when do the ‘disabled’ terms cease to become useful and instead work to limit, exclude and contain the possibilities that people with disabilities have for attaining institutional, disciplinary and political capacity?

In response to this question, for Fraser, the notion of disability would be useful when the focus is on overcoming the subordination. Concerning political justice, while this view might

200 Hooks, B., 1994. *Outlaw culture: Resisting representations*. Routledge.

201 Spivak, G.C., 1990. *The post-colonial critic: Interviews, strategies, dialogues*. Psychology Press.

202 McConaghy, C. (2000). *Rethinking indigenous education: Culturalism, colonialism, and the politics of knowing*. Flaxton: Post Pressed.

support quotas to increase representation, it would reject the bio-deterministic premise that delimits who can speak for disabled groups. Rather than beginning with an identity politic, the focus would alternatively be on genuinely including and engaging with disabled voices in ways that problematise all modes of domination and oppression that compromise democratic relations.

In summary, the introduction to *Adding Insult to Injury*, Olson²⁰³ attributes the wide resonance of her work across many disciplines and areas of study to her capacity to shift justice debates away from ‘sterile’ arguments that construct ‘cultural politics’ as antithetical to the politics of ‘social democracy’ towards more productive and useful questions of how to recognise and pursue justice in multidimensional ways. For Olson, a second reason that Fraser’s work has wide resonance is in its capacity to ‘make the presently chaotic scene surveyable and intelligible’ – it affords ‘a synoptic view of the political landscape [connecting] the dots among apparently discrete injustices [and] enabling us to consider how we might relate otherwise disparate, fragmentary struggles to the larger picture’²⁰⁴. Perhaps the key strength but also the weakness of Fraser’s work. The danger in making ‘chaos’

203 Redistribution or Recognition? A False Antithesis – Kevin Olsen in K. Olson (Ed.), *Adding Insult to Injury: Nancy Fraser debates her critics* (pp. 1-8). London: Verso.

204 Ibid

‘intelligible’ is that it necessarily delimits and contains. Such delimitation in the case of Fraser’s three distinctive dimensions is problematic in underplaying the significance of their intersection and overlap. Matters of distribution, for example, are not purely about economics – they are informed and shaped by matters of cultural recognition and political representation. Fraser’s work does attend to these intersections particularly in her later work around misframing and the propensity of political demarcation to intersect with and distort matters of justice on all three dimensions. Indeed, as she argues, this demarcation determines who and what counts in matters of distribution, recognition and representation. However, the overwhelming emphasis, especially in her earlier work, on the analytic distinctiveness of economic, cultural and political justice remains vulnerable to the criticisms originally articulated by Butler and Young²⁰⁵ – as falsely separating and polarising these areas of justice. As such, drawing on Fraser’s model to make sense of the messy terrain of social care policy, research and practice requires a cautious approach that is mindful of, and transparent about, the arbitrariness of this boundary-making and the often lack of distinctiveness between and amid matters of economic, cultural and political justice.

205 In K. Olson (Ed), *Adding Insult to Injury: Nancy Fraser debates her critics* (pp. 273-294). London: Verso.

Presenting matters of injustice within these categories should not be about fixing them or diluting their complexity and inter-relatedness. Fraser's model should not be offered as an ideal of justice that is static and uncomplicated but rather as a productive lens for thinking about and addressing some of the key ways in which different dimensions of injustice are currently hindering the social care participation, engagement and outcomes of marginalised students. It is clear, as Fraser ²⁰⁶ argues, that contemporary global processes have profoundly changed the way we think about and consider justice claims. Such shifting frames for thinking about equity alongside this rising diversity mean that there will never be a sense of closure in our attempts to understand and address issues of equity for people with disabilities.

Amid this climate of uncertainty, what is certain is that we must continue to engage in an ongoing monitoring and critical examination of our presumptions for understanding and approaching matters of social justice. The key challenge is developing more productive responses to the new justice questions for people with disabilities – that engage with the broader historical and political contexts that produce disadvantage in the

²⁰⁶ Fraser, N., 2014. Justice interruptus: Critical reflections on the "postsocialist" condition. Routledge.

first place²⁰⁷. Fraser's theorising is useful in supporting this monitoring and engagement²⁰⁸. While not unproblematic, her work moves the terrain forward in providing a comprehensive and multi-dimensional approach to navigating through some of the 'chaos' of justice issues for people with disabilities towards greater economic, cultural and political parity for all.

2.5 The Medical and Social Models

The next stage is to review the *medical and social model* of disability and review alongside the issue of identity and recognition or redistribution in social justice. The Care Act 2014 has its philosophical focus rooted firmly in 'social model of disability', through independence and wellbeing²⁰⁹.

²⁰⁷ Mitchell, F., 2015. Facilitators and barriers to informed choice in self-directed support for young people with disability in transition. *Health & social care in the community*, 23(2), pp.190-199.

²⁰⁸ Fraser, N., 2014. *Justice interruptus: Critical reflections on the "postsocialist" condition*. Routledge.

²⁰⁹ Shardlow, S., Aldgate, J., Gibson, A., Brearley, J., Daniel, B., Statham, D., Sheppard, M., Macdonald, G., Marsh, P., Walker, S. and Doel, M., 2015. *Handbook for practice learning in social work and social care: knowledge and theory*. Jessica Kingsley Publishers.

The medical model treats disability as an individual physical or mental characteristic with significant personal and social consequences²¹⁰. It sees the limitations faced by people with disabilities as resulting primarily or solely from their impairments²¹¹. By contrast, the various *social models* see disability as a relationship between individuals and their social environments: physical and mental characteristics are limiting only or primarily in virtue of social practices that lead to the exclusion of people with those traits²¹². This exclusion is demonstrated not only in segregation but in-built environments and social practices that restrict the participation of people regarded as having disabilities, whether intellectual, physical or sensory²¹³.

The medical model is less often explicitly defended²¹⁴. However, there is a growing awareness of the environmental contribution to

210 Oliver, M., 2017. Defining impairment and disability. *Disability and Equality Law*, p.3.

211 Barnes, C., 2014. An ethical agenda in disability research: Rhetoric or reality?

212 Barnes, C. and Mercer, G. eds., 2004. *Implementing the social model of disability: Theory and research*. Leeds: Disability Press.

213 O Shea, E.C., Pavia, S., Dyer, M., Craddock, G. and Murphy, N., 2016. Measuring the design of empathetic buildings: a review of universal design evaluation methods. *Disability and Rehabilitation: Assistive Technology*, 11(1), pp.13-21.

214 Thomas, C., 2004. How is disability understood? An examination of sociological approaches. *Disability & society*, 19(6), pp.569-583.

disability and a partial embrace of the social model by the likes of Cureton and Brownlee²¹⁵, while it raises some of the most urgent claims of justice (Barclay²¹⁶). However, the model would tend to see the justice required in terms of medical correction or material compensation. Some critics, such as Samaha accuse social model theorists of if any disadvantage caused by the social environment is *ipso facto* unjust²¹⁷. The difficulty of inferring injustice from socially created disadvantage is evident in contexts where greater social provision secures incremental advantage.²¹⁸ Equally, the fact that social arrangements do not cause or contribute to a difficulty does not insulate it from claims of justice – the failure to alleviate that obstacle may be unjust on reasonable accounts of justice, says Wasserman.²¹⁹ Finally, reducing the problems

215 Brownlee, K. and Cureton, A.S. eds., 2009. Disability and disadvantage. Oxford University Press.

216 Barclay, L., 2011. Justice and Disability: What Kind of Theorizing Is Needed?. *Journal of Social Philosophy*, 42(3), pp.273-287.

217 Samaha, A.M., 2007. What good is the social model of disability?. *The University of Chicago Law Review*, 74(4), pp.1251-1308.

218 Moreover, proportionality is not an absolute requirement of justice – in some contexts (though probably not parking), the opportunity costs of achieving proportionality might be too great, taking resources that were more urgently required elsewhere to redress or reduce injustice

219 The appearance of a closer connection between causation and justice may reflect the use of the same moral baseline for determining both, i.e., the view that a disadvantage is caused by a social arrangement if and only if it would not have existed under a morally-privileged baseline – e.g., a state of nature or a collectivist utopia. If causation is assessed by the latter

attributable to prejudice or stigma will enjoy priority on any theory of justice that treats disadvantage resulting from discrimination or stigma as a more substantial injustice than an innocently-created disadvantage.²²⁰

The social model with its *human variation version*²²¹ holds that many of the challenges faced by people with disabilities do not result from deliberate exclusion but a mismatch between their characteristics and the physical and social environment²²². This version of the social model requires the removal of barriers and practices serving to exclude people with disabilities. The demand for greater inclusiveness is less categorical than the desire to eliminate discrimination. Although any environment can be made more inclusive, none can be fully inclusive for everyone believes

baseline, then any disadvantage caused by an existing social arrangement will be an injustice. But the use of such a baseline for determining causation or justice needs to be justified.

220 For a distinction between several ways in which social institutions can causally contribute to the distribution of advantage, and an argument that these distinctions are morally relevant to the assessment of justice claims, see Pogge, T.W., 1994. An egalitarian law of peoples. *Philosophy & Public Affairs*, 23(3), pp.195-224 and Pogge, T.W., 2003. The incoherence between Rawls's theories of justice. *Fordham L. Rev.*, 72, p.1739.

221 Degener T. A New Human Rights Model of Disability. In *The United Nations Convention on the Rights of Persons with Disabilities 2017* (pp. 41-59). Springer International Publishing.

222 Scotch, R.K. and Schriener, K., 1997. Disability as human variation: Implications for policy. *The ANNALS of the American academy of political and social science*, 549(1), pp.148-159.

Barclay²²³. Shakespeare claims that full inclusion, like universal design, is an ideal – one that cannot be adequately achieved, and that must be compromised in the partial satisfaction of other legitimate claims²²⁴.

Owren believes that it would be impossible or unreasonable to achieve full inclusion through wholesale changes in the physical or social environment; modest changes could significantly increase inclusion at little cost²²⁵. The human variation model would not attribute all the problems of environmental fit to deliberate or negligent exclusion.²²⁶

223 Barclay, L., 2010. Disability, respect and justice. *Journal of Applied Philosophy*, 27(2), pp.154-171.

224 Shakespeare, T., 2006. The social model of disability. *The disability studies reader*, 2, pp.197-204.

225 Owren, T. and Stenhammer, T., 2013. Neurodiversity: accepting autistic difference: Thomas Owren and Trude Stenhammer explain why a more accepting attitude towards ‘autistic’ needs and behaviour may contribute to better services. *Learning disability practice*, 16(4), pp.32-37.

226 It is not clear that the minority-group model would, either. Seeing people with disabilities as a “discrete and insular minority subject to a history of persecution and exclusion” - does not mean seeing every disadvantage to that group as resulting from that history. Some proponents of a minority group model regard anything less than full inclusion as discriminatory, and dismiss undue burden exceptions as political concessions (Drimmer 1993). But most proponents of that model appear to reject this view; most recognize that the costs of physical and social environmental reconstruction set limits on how much of it is required (e.g., Amundson 1992, 116). They differ, however, in whether they see these limits as a matter of distributive justice. To the extent they do, their policy

Some theorists (Haegal and Hodge) ²²⁷ contend that these conditions pose more of a challenge for the social model than even the most severe physical disabilities, in part because the measures required for greater inclusion are not as concrete or tangible, and may demand higher imagination to envision and implement.²²⁸ Although significant practical work has been done in educational and workplace integration, philosophers have been overwhelmed by the challenge of social reconstruction for intellectual disabilities. Philosophers, therefore, need to pay more attention to practical and policy work that applies social models of disability to people with mental, intellectual, and complex physical impairments (Biklen²²⁹; Block²³⁰; Connor et al.²³¹; Hehir²³²).

prescriptions may not differ from those offered by proponents of the human variation model.

227 Haegele, J.A. and Hodge, S., 2016. Disability discourse: Overview and critiques of the medical and social models. *Quest*, 68(2), pp.193-206.

228 Profound intellectual and psychiatric impairments may also pose serious challenges for the medical model, in that many of those impairments may be difficult to understand as biomedical dysfunction or disease or to treat with biomedical interventions.

229 Biklen, D., Morton, M.W., Gold, D., Berrigan, C. and Swaminathan, S., 1992. Facilitated communication: Implications for individuals with autism. *Topics in language disorders*, 12(4), pp.1-28.

230 Block, P., Balcazar, F. and Keys, C., 2001. From pathology to power: Rethinking race, poverty, and disability. *Journal of Disability Policy Studies*, 12(1), pp.18-27.;

231 Ensrud, K.E., Ewing, S.K., Taylor, B.C., Fink, H.A., Cawthon, P.M., Stone, K.L., Hillier, T.A., Cauley, J.A., Hochberg, M.C., Rodondi, N. and Tracy, J.K., 2008. Comparison of 2 frailty indexes for prediction of falls,

There is a resurgence of philosophical interest in justice, which is often dated to the publication of John Rawls' *A Theory of Justice*²³³ in 1971. It represented the social model of disability, well before the academic reconceptualisation of disability²³⁴ as a social phenomenon. For the 25 years after *A Theory of Justice*, many justice theorists tacitly accepted the medical model, e.g. Dworkin²³⁵; Daniels²³⁶. They treated disability as an individual physical or mental limitation causing severe disadvantages of various kinds. Disability thus posed a problem for justice theories based on mutual advantage, hypothetical agreement, or material or social equality. People with disabilities did not appear to offer mutual benefits; they complicated the task of reaching a

disability, fractures, and death in older women. *Archives of internal medicine*, 168(4), pp.382-389.

232 Memel, D.S., Kirwan, J.R., Langley, C., Hewlett, S. and Hehir, M., 2002. Prediction of successful application for disability benefits for people with arthritis using the Health Assessment Questionnaire. *Rheumatology*, 41(1), pp.100-102.

233 Rawls, J., 2009. *A theory of justice*. Harvard university press.

234 Central to the reconceptualization of disability is the idea that disability does not involve an automatic or intrinsic cost to an individual's overall well-being. See Lim, C.M., 2017, October. Reviewing resistances to reconceptualizing disability. In *Proceedings of the Aristotelian Society* (Vol. 117, No. 3, pp. 321-331). Oxford University Press.

235 Dworkin, R., 1981. What is equality? Part 2: Equality of resources. *Philosophy & Public Affairs*, pp.283-345.

236 Daniels, N., 1985. *Just health care*. Cambridge University Press.

theoretical agreement on the basic structure of society, and they made the goal of equality seem impossibly demanding²³⁷.

By the late 1990s, some mainstream political philosophers were becoming acquainted with social models of disability, and some disability theorists were gaining a hearing among political philosophers²³⁸. Some philosophers (Crow) sought to modify distributive theories of justice to take account of the social and environmental character of disability²³⁹; others (Marks) cited the failure of those arguments to take appropriate account of disability as one reason to reject exclusively distributive approaches.²⁴⁰

Other philosophers and disability scholars would deny that the inequalities associated with impairments can be regarded as “natural” such as Amundson²⁴¹ and Wasserman²⁴². In questioning

237 Ibid; Dworkin Ibid

238 Shakespeare, T. and Watson, N., 2001. The social model of disability: an outdated ideology?. In *Exploring theories and expanding methodologies: Where we are and where we need to go* (pp. 9-28). Emerald Group Publishing Limited.

239 Crow, L., 1992. *Renewing the social model of disability*. University of Leeds.

240 Marks, D., 1997. Models of disability. *Disability and rehabilitation*, 19(3), pp.85-91.

241 Disadvantage, which is man-made, then we are left with the contribution of impairment alone, which is “natural.” But states of nature are artificial constructs, and the conclusions yielded by their examination largely depend on the features built into them. Proponents of a medical model of disability might invoke a Hobbesian state of nature, wherein

the very notion of “natural inequalities,” they join a broader philosophical debate about whether it is possible to draw a coherent distinction between natural and artificial or social inequalities (see Lippert-Rasmussen²⁴³; Nagel²⁴⁴; Pogge²⁴⁵)²⁴⁶.

people who are missing limbs or senses would be at a fatal disadvantage in the war of all against all. It should be apparent that such a state of nature is not merely a fiction, but an implausible one: any human environment contains pervasive artifice, technology, some social order, and an implicit or explicit system of entitlements. There is no obvious reason for relying on a hypothetical state of affairs lacking these features as a baseline for assessing the causal role of impairments, or the advantages conferred on people with impairments in moving to a political state. In contrast, some disability activists appear to invoke an environment of limitless resources and technologically-assisted access. Although the reliance on such an environment as a baseline may seem utopian, it can more reasonably be seen as a corrective for the tendency to take the present environment as fixed or past environments as nasty and brutish (Gliedman and Roth 1980, 13–15; Wasserman 2001). Some philosophers have attempted to make the distinction between artificial and natural disadvantages without recourse to a state of nature (see Lippert-Rasmussen 2004 and Nagel 1997). But in the absence of an accepted basis for making the distinction, what counts as “natural” for humanity remains a contentious normative judgment.

241 Wasserman, D., 2001. Philosophical issues in the definition and social response to disability. *Handbook of disability studies*. Amundson, R., 1992. Disability, handicap, and the environment. *Journal of Social Philosophy*, 23(1), pp.105-119.

242 Wasserman, D., 2001. Philosophical issues in the definition and social response to disability. *Handbook of disability studies*.

243 Lippert-Rasmussen, K., 2013. Offensive Preferences, Snobbish Tastes, and Egalitarian Justice. *Journal of Social Philosophy*, 44(4), pp.439-458.

244 Kemp, H.V., Chen, J.S., Erickson, G.N. and Friesen, N.L., 2003. ADA accommodation of therapists with disabilities in clinical training. *Women & Therapy*, 26(1-2), pp.155-168.

Even if such a distinction can be plausibly drawn, it may turn out that many or most inequalities in abilities are artificial: as with of obsolete skills, those inequities may be attributable primarily to the physical and social environment.²⁴⁷

245 Pogge, T., 2004. Relational conceptions of justice: Responsibilities for health outcomes. *Public health, ethics and equity*, pp.135-161.

246 It may be tempting to respond to such claims by invoking a state of nature as a baseline for assessing which disadvantages are natural. The thought is that if we “subtract away” society's contribution to disadvantage, which is man-made, then we are left with the contribution of impairment alone, which is “natural.” But states of nature are artificial constructs, and the conclusions yielded by their examination largely depend on the features built into them. Proponents of a medical model of disability might invoke a Hobbesian state of nature, wherein people who are missing limbs or senses would be at a fatal disadvantage in the war of all against all. It should be apparent that such a state of nature is not merely a fiction, but an implausible one: any human environment contains pervasive artifice, technology, some social order, and an implicit or explicit system of entitlements. There is no obvious reason for relying on a hypothetical state of affairs lacking these features as a baseline for assessing the causal role of impairments, or the advantages conferred on people with impairments in moving to a political state. In contrast, some disability activists appear to invoke an environment of limitless resources and technologically-assisted access. Although the reliance on such an environment as a baseline may seem utopian, it can more reasonably be seen as a corrective for the tendency to take the present environment as fixed or past environments as nasty and brutish (Gliedman and Roth 1980, 13–15; Wasserman 2001). Some philosophers have attempted to make the distinction between artificial and natural disadvantages without recourse to a state of nature (see Lippert-Rasmussen 2004 and Nagel 1997). But in the absence of an accepted basis for making the distinction, what counts as “natural” for humanity remains a contentious normative judgment.

247 Wasserman, D., 2001. Philosophical issues in the definition and social response to disability. *Handbook of disability studies*.

Other distributive theories of justice take a less procedural approach; they are more directly concerned with the kinds of outcomes a just society should pursue. These theories differ in the outcome metrics they adopt; in what has been called the “currency” of distributive justice (Cohen²⁴⁸). Some assume a resource metric (Dworkin²⁴⁹); still others, a parameter based on opportunities for welfare (Arneson²⁵⁰) or access to advantage (Cohen²⁵¹). Finally, capability theories, such as Nussbaum²⁵² and Sen,²⁵³ assess outcomes not only by the goods or resources that people have but also by what people can do with what they have. Such outcome-oriented theories may be demanding, depending on whether they require equality or merely priority for the worst-off, and on whether they support equality of a sort that may not need the significant redistribution of goods or resources.

248 Cohen, G.A., 1989. On the currency of egalitarian justice. *Ethics*, 99(4), pp.906-944.

249 Dworkin, R., 1981. What is equality? Part 2: Equality of resources. *Philosophy & Public Affairs*, pp.283-345.

250 Arneson, R.J., 2006. Justice After Rawls. Dryzek, J., Honig, B. & Phillips, A.(eds.), pp.45-64.

251 Cohen, G.A., 1989. On the currency of egalitarian justice. *Ethics*, 99(4), pp.906-944.

252 Kräuchi, H., Nussbaum, P. and Virz-Justice, A., 1990. Consumption of Svveets and Caffeine in the Night Shift: Relation to Fatigue.

253 Sen, A., 2000. Social justice and the distribution of income. *Handbook of income distribution*, 1, pp.59-85.

2.6 Outcome-Oriented Approach

The most prominent outcome-oriented approach has been called “luck egalitarianism” (see, for example, Arneson²⁵⁴; Dworkin²⁵⁵). According to the dominant characterisation of that position, its central claim is that all injustices are analysable as unfair inequalities in the distribution of “brute luck” – advantage or disadvantage that is not attributable to an individual's fault, choice, or assumption of risk. “Option luck,” in contrast, refers to an advantage or disadvantage an individual acquires through the foreseeable consequences of his or her actions. The stronger versions of luck egalitarianism such as Dworkin²⁵⁶ deny that the inequality resulting from option luck generates any claims of justice. On those versions, only some disabilities create justice claims – those that resulted from lousy luck – whereas others, which may involve the same or more significant disadvantage, do not, merely because they arose from a free choice (e.g., reckless pastimes or an unhealthy lifestyle).

254 Arneson, R.J., 2000. Luck egalitarianism and prioritarianism. *Ethics*, 110(2), pp.339-349.

255 Dworkin, R., 2003. Equality, luck and hierarchy. *Philosophy & Public Affairs*, 31(2), pp.190-198.

256 Ibid

Some philosophers have taken these implications as a *reductio ad absurdum*²⁵⁷ of luck egalitarianism (Anderson²⁵⁸), and they would no doubt be rejected by many writers on health care, who have questioned the moral and policy relevance of individual responsibility (Cavallero²⁵⁹; Feiring²⁶⁰; Galvin²⁶¹; Wikler²⁶²). The more significant concern for disability scholars maybe with the fusing of disadvantages resulting from unchosen impairments with difficulties. It resulted from unchosen social conditions under the one heading of “bad brute luck.” The bad luck for people with disabilities is not primarily in their physical or mental variations but in the unfortunate fit between those inequalities and the social environment. The brute bad luck of a person with a disability is to

257 In formal logic, the *reductio ad absurdum* is a legitimate argument, but it is often applied fallaciously. The fallacy follows the idea that if the premises of someone's argument are taken as true, then it necessarily will lead to absurd conclusions.

258 Barry, N., 2006. Defending luck egalitarianism. *Journal of applied philosophy*, 23(1), pp.89-107.

259 Cavallero, E., 2011. Health, luck and moral fallacies of the second best. *The Journal of ethics*, 15(4), pp.387-403.

260 Feiring, E., 2008. Lifestyle, responsibility and justice. *Journal of Medical Ethics*, 34(1), pp.33-36.

261 Galvin, R., 2002. Disturbing notions of chronic illness and individual responsibility: Towards a genealogy of morals. *Health*., 6(2), pp.107-137.

262 Wikler, D., 1987. Personal responsibility for illness. *Health Care Ethics: An Introduction*, pp.326-358.

find herself in a disabling climate (Fine and Asch)²⁶³. For example, much of the bad luck in lacking the ability to walk is in living in a built environment designed for people who do, rather than people who move around in wheelchairs. As we will see in discussing the capabilities approach, though, this view on the locus of misfortune can be accommodated by some forms of luck egalitarianism.

The implications of outcome-oriented theories for disability and the extent to which they address the need for recognition and respect depend on two features of those arguments. The first is the metric, or “currency” of justice they adopt – welfare, resources, primary goods, or capabilities (Cohen²⁶⁴). The second is the distributive standard they impose – strict equality, priority for the worse off, or merely some minimum for everyone

263 It is interesting to point out that the debate about causation, responsibility and justice that occurs between proponents of the medical and social models is in a sense orthogonal to the debate in which luck egalitarians are engaged. Whereas the former debate centers on the relationship of individual traits and social arrangements, luck egalitarians contrast fortune and choice, and generally don't include society as an actor whose causal responsibility is at issue. Historically, this difference in emphasis may be due to the fact that luck egalitarianism arose as a response to Nozickian right-of-center arguments against Rawlsian egalitarianism (see, Dworkin 1981a) which emphasized individual choice and property rights

264 Cohen, G.A., 1989. On the currency of egalitarian justice. *Ethics*, 99(4), pp.906-944.

(sufficientarianism²⁶⁵). Consideration is given to two features in order, although they are sometimes intertwined.

Several alternatives for assessing outcomes for purposes of political and social equality seem more responsive to the disabling role of the social environment. The most familiar and influential of these alternatives is the capabilities approach, developed in different ways by Martha Nussbaum²⁶⁶ and Amartya Sen.²⁶⁷ Their accounts are concerned not only with the resources an individual has but also with what she can do with them; with her “capability” of engaging in many valuable “functionings²⁶⁸,” such as forming intimate relationships and having rich sensory and aesthetic experiences.

Less ambitiously than Nussbaum, Jonathan Wolff²⁶⁹ classifies equality-enhancing measures for people with disabilities by the extent to which they address recognition as well as redistribution.

265 Shields, L., 2012. The prospects for sufficientarianism. *Utilitas*, 24(1), pp.101-117.

266 Nussbaum, M.C., 2009. *Frontiers of justice: Disability, nationality, species membership*. Harvard University Press.

267 Sen, G., 1997. Globalization justice and equity: a gender perspective. *Development*, 40(2), pp.21-6.

268 Sen, A., 1993. Capability and Well-Being⁷³. *The quality of life*, 30.

269 Wolff, J., 2009. Disadvantage, risk and the social determinants of health. *Public Health Ethics*, 2(3), pp.214-223.

Thus, the individual limitations of people with disabilities can be resolved with either cash compensation or “personal enhancement,” medical, surgical, or rehabilitative measures to correct those limitations²⁷⁰. “Targeted resource enhancement”²⁷¹ offers an intermediate option, which tries to improve the fit of the individual and the environment with a range of restricted resources such as personal assistance and assistive technology. Finally, “status enhancement”²⁷² alters the built environment and social practices to reduce the impact of individual differences in abilities on social equality. Wolff generally favours status enhancement as the most respectful intervention, because it shapes the environment to the needs of all members of society²⁷³. It is also the most stable intervention because it protects social equality against sudden changes in individuals' levels of functioning — this a useful intervention for disabled persons but one which may limit any notion of choice and control.

270 Wolff, J., 2009. Disability, status enhancement, personal enhancement and resource allocation. *Economics & Philosophy*, 25(1), pp.49-68.

271 Goodley, D., 2014. *Dis/ability studies: Theorising disablism and ableism*. Routledge.

272 Vehmas, S. and Watson, N., 2014. Moral wrongs, disadvantages, and disability: a critique of critical disability studies. *Disability & Society*, 29(4), pp.638-650.

273 Wolff, J., 2009. Disability, status enhancement, personal enhancement and resource allocation. *Economics & Philosophy*, 25(1), pp.49-68.

2.7 Sufficientarian Approaches

Although Wolff does not adopt the device of hypothetical decision making to justify a preference for status enhancement, that choice is underwritten by a suitably modified Original Position. One takes the end-state of justice (i.e. social care provision) not as equality or priority but sufficiency: it requires that every member of society reach some minimum, in the appropriate “currency” – welfare, resources, opportunities for welfare or resources, or capabilities. This approach, labelled by Arneson “sufficientarian”²⁷⁴, is suggested but not endorsed by Nussbaum, and it serves to make capabilities a less demanding metric for distributive justice²⁷⁵. The requirement that a just society ensures that every citizen reaches a minimum level of each ability may be far less onerous than the provision of equal abilities. One way of setting the minimum appeals to the requirements for participation in a democratic society (Gutmann ²⁷⁶; Anderson²⁷⁷).

274 Arneson, R.J., 2000. Luck egalitarianism and prioritarianism. *Ethics*, 110(2), pp.339-349.

275 Nussbaum notes that certain capabilities must be distributed equally if anyone is to have a sufficient level of them, e.g., voting rights.

276 Gutmann, A., 1995. Civic education and social diversity. *Ethics*, 105(3), pp.557-579.

277 Anderson, E.S., 1999. What is the Point of Equality?. *Ethics*, 109(2), pp.287-337.

Although sufficientarian approaches claim to make the demands of justice less oppressive, they have been criticised as demanding too much and too little. They require too much if the minimum for every capability must be met in the face of nonconforming impairments or environments. They require too little if attaining the minimum could still leave the individual with a miserable life (Arneson²⁷⁸ ; Wasserman²⁷⁹ ; Wolff and de-Shalit²⁸⁰). Those approaches are criticised for lacking a mechanism for prioritising capabilities (Wolff and de-Shalit²⁸¹) and for assessing whether the minimum has been reached for anyone's abilities (Riddle²⁸²). The extent to which justice is achievable on such approaches for people with severe disabilities will depend on where the minimum is set, how its satisfaction is assessed, and how the capabilities are defined. This a vital viewpoint when considering the care and support requirements under the Care Act 2014 – and trying to consider the minimum requirements. Is this what the local authorities are required to provide to meet capabilities or is it to meet the disabled person's expectations and satisfaction criteria?

278 Ibid

279 Wasserman, D., 2001. Philosophical issues in the definition and social response to disability. Handbook of disability studies.

280 Wolff, J. and De-Shalit, A., 2007. Disadvantage. Oxford University Press on Demand.

281 Ibid

282 Riddle, C.A., 2010. Indexing, Capabilities, and Disability. Journal of Social Philosophy, 41(4), pp.527-537.

A second approach would replace equality on a specific metric of advantage with social justice or equality of respect (Anderson²⁸³; Miller²⁸⁴; Norman^{285 286}). This approach would involve a more radical departure from luck egalitarianism than a sufficiency account since it does not lower the standard for a just distribution so much as propose a non-distributive standard for justice. That measure would see justice in terms of recognition rather than, or as well as redistribution²⁸⁷. Although this approach may demand strict equality of a sort, it is a sort that does not appear to set determinate distributive requirements²⁸⁸. A society of social equals, abounding in mutual respect, can arguably tolerate significant disparities in welfare, resources, opportunities, or capabilities. Therefore, the local authorities are required to provide

283 Anderson, P.S., 1999. Justice and inequality don't mix. *ABAJ*, 85, p.6.

284 Miller, D., 1999. Justice and global inequality. *Inequality, globalization, and world politics*, pp.187-210.

285 Daniels, N., 2001. Justice, health, and healthcare. *American Journal of Bioethics*, 1(2), pp.2-16.

286 Wenzel, M., Okimoto, T.G., Feather, N.T. and Platow, M.J., 2008. Retributive and restorative justice. *Law and human behavior*, 32(5), pp.375-389.

287 Danermark, B. and Gellerstedt, L.C., 2004. Social justice: redistribution and recognition—a non-reductionist perspective on disability. *Disability & Society*, 19(4), pp.339-353.

288 Weinstock, D., 2015. Integrating intermediate goods to theories of distributive justice: The importance of platforms. *Res Publica*, 21(2), pp.171-183.

to meet capabilities under the Care Act – what we are considering is the person with disabilities as a citizen and assessing what that role is up to the ‘choice’ of the disabled person. This view has been put forward by Duffy and the Centre for Welfare Reform²⁸⁹.

2.8 Social Identity

The social model of disability, which informed the movement for disability rights, emphasised what people with various impairments have in common – their stigmatisation and exclusion²⁹⁰ – and thereby promoted the emergence of disability as a powerful social identity²⁹¹. One of the principal criticisms of distributive justice is that it fails to take account of such prominent social personalities; that it treated individuals in isolation from their race, sex, sexual orientation, and (dis)abilities – ascriptions and affiliations that play a vital role in how they regard themselves and respond to the world. This is important in the developing theories of ‘normalisation’ by Wolfensberger²⁹² people with intellectual disabilities – how could people with disabilities be

289 Duffy, S., 2017. The value of citizenship. *Research and Practice in Intellectual and Developmental Disabilities*, 4(1), pp.26-34.

290 Padmavati, R., 2014. Stigmatization and exclusion. *Essentials of global mental health*, pp.85-92.

291 Jenkins, R., 2014. *Social identity*. Routledge.

292 Wolfensberger, W.P., Nirje, B., Olshansky, S., Perske, R. and Roos, P., 1972. *The principle of normalization in human services*.

‘normal’. This initial view has been discredited but was valued in moving forward the notions of ‘choice and control’ and social identity for people with disabilities²⁹³.

Critics like Fraser²⁹⁴ argue that the importance of social identity cannot be adequately captured in any metric of individual advantage. An effective social response to stigmatised identities requires both recognition and transformation – changes in cultural framing and social perception that are poorly served by redistribution. An emphasis on redistribution is often self-defeating, making worse stigma and reinforcing the impression of the stigmatised group as deficient (Fraser²⁹⁵; Olson²⁹⁶). The discussion shows ways of transforming social identity have significant dangers as well.

293 Mathews, I., 2017. Not like us? Wolfensberger’s ‘major historic roles’ reconsidered. *Disability & Society*, 32(9), pp.1351-1365.

294 Fraser, N., 2014. *Justice interruptus: Critical reflections on the "postsocialist" condition*. Routledge.

295 Fraser, N., 1995. Recognition or redistribution? A critical reading of Iris Young's *Justice and the Politics of Difference*. *Journal of Political Philosophy*, 3(2), pp.166-180.

296 Olson, J.M. and Hafer, C.L., 2001. Tolerance of personal deprivation. *The psychology of legitimacy: Emerging perspectives on ideology, justice, and intergroup relations*, pp.157-175.

The sense of individual identity most directly relevant to respect is that of practical identity. Following Korsgaard²⁹⁷, we understand an actual character to be a description under which a person values herself, where valuing oneself involves treating oneself as a source of reasons. For example, a person with disabilities who identifies as a mother in this sense values herself under the description “mother” and for that reason treats the fact that she is a mother as a source of (normative practical²⁹⁸) rights. Respect for another's identity consists of not obstructing an individual's ability to enact her character in her choices or to work to change it if she so desires²⁹⁹.

Respecting a person's choices (and control) about identity falls under the broader moral requirement of respect for personal autonomy³⁰⁰, one of the foundational principles that undergird our moral relations with others. It is also a political tenet of liberal and pluralist societies, whose laws and policies do not require

297 Korsgaard, C., 2008. Taking the Law into our own Hands: Kant on the Right to Revolution.

298 Normative ethics is the study of ethical action. It is the branch of philosophical ethics that investigates the set of questions that arise when considering how one ought to act, morally speaking.

299 Vehmas, S. and Watson, N., 2016. Exploring normativity in disability studies. *Disability & society*, 31(1), pp.1-16.

300 Wehmeyer, M.L. and Garner, N.W., 2003. The impact of personal characteristics of people with intellectual and developmental disability on self-determination and autonomous functioning. *Journal of Applied Research in Intellectual Disabilities*, 16(4), pp.255-265.

individuals to organize their lives around any particular identity, but rather give them the latitude to make of their identities what they will (Appiah³⁰¹; Appiah and Gutmann³⁰²). This idea is as a part of liberalism's broader commitment to neutrality about conceptions of the good, where Rawls³⁰³ derives his account of goods from the conception of the citizen as free and equal, reasonable and rational.

These issues become especially charged if we move from individual to group identities, bringing us closer to the question of disability identities. Appiah points out, though individual identity is different from group identity, it nevertheless has a collective or social dimension (Appiah³⁰⁴). Moreover, since this social identity is often part of one's individual identity, such treatment is likely to be injurious to the self-respect of the one with this identity, and in that sense constitutes an instance of misrecognition³⁰⁵. Ironically, the fact of being unfairly stereotyped can itself shape the identities

301 Appiah, K.A., 2006. The politics of identity. *Daedalus*, 135(4), pp.15-22.

302 Appiah, K.A. and Gutmann, A., 1996. *Color Consciousness. The Political Morality of Race*. Princeton: Princeton UP.

303 Rawls, J., 1993. The law of peoples. *Critical Inquiry*, 20(1), pp.36-68.

304 Anthony, A.K., 2005. *The Ethics of Identity*.

305 Garland-Thomson, R., 2011. Misfits: A feminist materialist disability concept. *Hypatia*, 26(3), pp.591-609.

of those who are treated in this way, as Appiah notes, even if initially they did not identify strongly with the group in question. However, whether or not stereotyping has this effect, being subject to it is offensive, and it can have other consequences as well, including the denial of basic rights of equal citizenship. Fundamentally, this is when person-centred planning with a person with disabilities are developed; services are provided within a day centre rather accessing community services with support. The issue is one of choice and control for the disabled person³⁰⁶.

There are two other risks for an identity politics of disability. One involves the danger of assuming that the members of a particular marginalised group all share the same culture. There are some examples of a shared disability culture: Deaf culture is perhaps the best known. But many people who are deaf, particularly those who do not sign, do not identify as Deaf or take part in Deaf culture (Tucker³⁰⁷) So even for those who participate, Deaf culture does not appear to be the kind of “encompassing” or “comprehensive”

306 Val Williams Choice and control: social care must not disable people with intellectual disabilities 2016 British Politics and Policy LSE London at: <http://blogs.lse.ac.uk/politicsandpolicy/choice-and-control-social-care-must-not-disable-people-with-intellectual-disabilities/>

307 Tucker, B.P., 1997. The ADA and Deaf culture: contrasting precepts, conflicting results. *The Annals of the American Academy of Political and Social Science*, 549(1), pp.24-36.

culture claimed by Kymlicka, Margalit, and Raz³⁰⁸ to provide a “context of choice” for its members³⁰⁹.

The second, related risk involves privileging one identity over others. Their ‘identity’ is especially important for people with multiple or “intersectional” identities. People who are black and disabled, or female and disabled, or disabled and LGBTQIA may sometimes feel a conflict between those identities. At the same time, disabled women are often particularly vulnerable to the injustices that motivate the feminist movement: they are frequently victims of sexual exploitation³¹⁰. Crawford and Ostrove³¹¹ say that they encounter many obstacles to leaving dissatisfying relationships because of physical, psychological and financial dependency³¹².

It is instructive to compare how the medical and social models would address these challenges. The medical model suggests a

308 Wasserman, D., Asch, A., Blustein, J. and Putnam, D., 2013. Disability and Justice.

309 Spinner-Halev, J. and Theiss-Morse, E., 2003. National identity and self-esteem. *Perspectives on politics*, 1(3), pp.515-532.

310 Bryson, V., 2016. *Feminist political theory*. Palgrave Macmillan.

311 Crawford, D. and Ostrove, J.M., 2003. Representations of disability and the interpersonal relationships of women with disabilities. *Women & Therapy*, 26(3-4), pp.179-194.

312 Olkin, R. and Pledger, C., 2003. Can disability studies and psychology join hands?. *American Psychologist*, 58(4), p.296.

disability identity that is both fragmented and negative³¹³. Because the medical model defines disability in terms of particular physical or mental impairments, the primary commonalities it recognises among people with disabilities are strictly functional³¹⁴. It views the blind person and the deaf person as having very different problems. Although it could recognise the fact that such biomedically distinct conditions had similar social consequences – stigmatisation and exclusion – it would treat those similar consequences merely as secondary effects of the two conditions³¹⁵. Even within a single impairment, a medical model encourages distinctions based on aetiology³¹⁶ - the study of causation. For example, it would distinguish blindness due to Leber's congenital amaurosis³¹⁷ from blindness due to retinopathy of prematurity, focusing on genetic testing for the former and treatment for the latter, and placing less emphasis on the shared challenges of living with blindness. Using this method, a care plan would be developed

313 Goodley, D., 2016. Disability studies: An interdisciplinary introduction. Sage.

314 Smith, S.R., 2008. Social justice and disability: Competing interpretations of the medical and social models. Routledge.

315 Smith, S.R., 2008 Ibid

316 The cause, set of causes, or manner of causation of a disease or condition.

317 Leber congenital amaurosis (LCA) is an inherited retinal degenerative disease characterized by severe loss of vision at birth. A variety of other eye-related abnormalities including roving eye movements, deep-set eyes, and sensitivity to bright light also occur with this disease.

around making the person independent by reviewing the adaptations required, while linking with support groups rather than working on getting the person into the community.

Although this narrow focus may be appropriate for clinical intervention, it obscures the recognition of disability as a social and political problem, except insofar as it raises perennial questions about how to distribute scarce health-care resources (Barnett et al.³¹⁸). However, if the political conversation about disability is limited to debates about resource allocation, it leaves power in the hands of the able-bodied majority, i.e. the local authority³¹⁹. To make matters worse, it puts people with disabilities in the position of competing with one another for resources³²⁰. Altogether, the medical model emphasises the ways in which people with disabilities are dependent and divided, rather

318 Barnett, J.E. and Hillard, D., 2001. Psychologist distress and impairment: The availability, nature, and use of colleague assistance programs for psychologists. *Professional Psychology: Research and Practice*, 32(2), p.205.

319 Pearson, C. and Ridley, J., 2017. Is Personalization the Right Plan at the Wrong Time? Re-thinking Cash-for-Care in an Age of Austerity. *Social Policy & Administration*, 51(7), pp.1042-1059.

320 Fleming, P., Furlong, M., McGilloway, S., Keogh, F., Herson, M. and Stainton, T., 2016. Protocol: Personal Budgeting Interventions to Improve Health and Social Care Outcomes for People with a Disability: A Systematic Review. Retrieved from The Campbell Library website: <http://campbellcollaboration.org/lib/project/350>.

than empowered and united. The ideas of ‘choice and control’ fits more comfortably in the notion of being ‘empowered and united’.

Therefore, the various social models suggest a more politically viable disability identity. The increased inclusion of people with a vast array of different impairments in the UK and the legal rights of persons with disabilities has helped to forge a shared disability identity³²¹. Though the minority group viewpoint has proven extremely useful in passing anti-discrimination laws³²², it may do so at the expense of emphasising the *differences* between people with disabilities and people without them, rather than highlighting the many ways in which identity need not be secured to the presence or absence of impairment. The human variation model tempers this emphasis, and resists essentialism about disability identity, by treating the group itself as socially constructed³²³. It sees the category of “the disabled” as resting on an artificial dichotomy imposed on a continuum of variation³²⁴. The

321 Riddell, S. and Watson, N., 2014. Disability, culture and identity. Routledge.

322 Degener, T., 2017. A new human rights model of disability. In The United Nations convention on the rights of persons with disabilities (pp. 41-59). Springer, Cham.

323 Gilson, S.F. and DePoy, E., 2015. Disability, identity, and cultural diversity. Review of Disability Studies: An International Journal, 1(1).

324 Anastasiou, D. and Kauffman, J.M., 2013, August. The social model of disability: Dichotomy between impairment and disability. In The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine (Vol. 38, No. 4, pp. 441-459). Oxford University Press.

conceptualisation of disability as just one source of difference, and as a difference in kind more than a degree, can undercut a sense of disability as the basis for a unique and exclusive identity. Therefore, consideration must be given to the concept that ‘everyone is unique’ in the assessment and planning stages of providing support.

When guided the human-variation model, the redesign of the physical and social environment, the less dominant disability identity and identity politics may become for people with disabilities. A society in which disabilities lack the social and practical significance they currently have maybe one in which the equality of people with disabilities can be fully recognised without having to treat disability as a prominent feature of their identities. Disability theorists who adopt different social model approaches might profitably consider how different views about the group and individual identity apply to people with disabilities.

The issues of disability and justice; and disability and identity both require further philosophical study. Perhaps it would be useful to start by asking not about the resources necessary for functioning in a community, but instead about the activities that are essential or valuable for social participation and individual flourishing. Alternatively, even ask the person with disabilities what they feel they need to be able to fully participate in the community – the simple notion of choice and control.

Such an inquiry admittedly poses a challenge for neutrality among competing conceptions of the good, neutrality that has been a tenet for many liberal political philosophers since Rawls. That challenge can be addressed by critically examining what counts as *reasonable* conceptions of the good. This examination could both narrow the range of conceptions and broaden their characterisation of valuable activities. Such an examination may be implicit in some of the capabilities approaches now being developed. However, there are also critics of Rawlsian liberalism who find the commitment to neutrality unduly constraining or impossible (Sher³²⁵; Galston³²⁶; Fishkin³²⁷)³²⁸. That determination may be eroded as well by the increasing sway of “objective list” accounts of well-being, which appear to violate neutrality in specifying what counts as a good life.

325 Sher, G., 1997. *Beyond neutrality: Perfectionism and politics*. Cambridge University Press.

326 Galston, W.A., 1998. Expressive liberty, moral pluralism, political pluralism: three sources of liberal theory. *Wm. & Mary L. Rev.*, 40, p.869.

327 Fishkin, J.S., 1983. The boundaries of justice. *Journal of Conflict Resolution*, 27(2), pp.355-375.

328 Martin, N., 2017. Conceptions of the good, rivalry, and liberal neutrality. *Critical Review of International Social and Political Philosophy*, 20(2), pp.143-162.

2.9 Final thoughts

If we are willing to narrow the range of reasonable and necessary conceptions of the good or forego neutrality among them, we may be able to identify the broad categories of activity that are central to social participation and individual flourishing.

We can then turn to the issues of how a just society can create or modify environments and practices in ways that permit all, or almost all, its members to engage in these activities. Rather than seeing the ramp, the flexible work schedule, the audiobook, or the visual display of words spoken at a meeting as “accommodations” to individual deficits, they can be seen as the conventional components of Gliedman and Roth's³²⁹ inclusive society.

Nancy Fraser's theory of social justice seeks to regenerate critical theory in a form fit for present predicaments by developing a unique and powerful synthesis between (post)Marxism, feminism and poststructuralism. It interrogates key concepts in social and political thought and facilitates in-depth analyses of contemporary political-economic structures, social welfare programmes, mechanisms of political participation and social movement

329 Gliedman, J. and Roth, W., 1980. The unexpected minority-Handicapped children in America. *International Journal of Rehabilitation Research*, 3(4), pp.601-604.

activism. Drawing on Fraser's model to make sense of the messy terrain of social care policy, research and practice requires a cautious approach that is mindful of, and transparent about, the arbitrariness of this boundary-making and the often lack distinctiveness between and amid matters of economic, cultural and political justice.

Fraser's model should not be offered as an ideal of justice that is static and uncomplicated but rather as a productive lens for thinking about and addressing some of the key ways in which different dimensions of injustice are currently hindering the social care participation, engagement and outcomes of marginalised students. It is clear, as Fraser³³⁰ argues, that contemporary global processes have profoundly changed the way we think about and consider justice claims. Amid this climate of uncertainty, what is certain is that we must continue to engage in an ongoing monitoring and critical examination of our presumptions for understanding and approaching matters of social justice. This will be the key challenge in developing more productive responses to the new justice questions for people with disabilities – that engage with the broader historical and political contexts that produce

³³⁰ Fraser, N., 2014. Justice interruptus: Critical reflections on the "postsocialist" condition. Routledge.

disadvantage in the first place³³¹. Fraser's theorising is useful in supporting this monitoring and engagement ³³². While not unproblematic, her work moves the terrain forward in providing a comprehensive and multi-dimensional approach to navigating through some of the 'chaos' of justice issues for people with disabilities towards greater economic, cultural and political parity for all.

The next chapter reviews the development of the legislation and social policy of disability in the UK that led to Direct Payment and Personal Budgets³³³ and the construction of personalisation and its 'choice and control' for the person with disabilities within the Care Act 2014³³⁴.

³³¹ Mitchell, F., 2015. Facilitators and barriers to informed choice in self-directed support for young people with disability in transition. *Health & social care in the community*, 23(2), pp.190-199.

³³² Fraser, N., 2014. *Justice interruptus: Critical reflections on the "postsocialist" condition*. Routledge.

³³³ Duffy, S., Waters, J. and Glasby, J., 2010. Personalisation and adult social care: future options for the reform of public services. *Policy & Politics*, 38(4), pp.493-508.

³³⁴ Duffy, S., 2017. The value of citizenship. *Research and Practice in Intellectual and Developmental Disabilities*, pp.1-9.

3 HISTORICAL BACKGROUND

3.1 Introduction to Chapter

It is impossible to understand the debates about the future of social care without having some awareness of the history of welfare and the critical policy developments that have shaped policy and practice³³⁵. The purpose of this chapter is to provide a summary of the thought and context regarding post-war social policy to demonstrate some of the current and emerging debates both ‘choice and control’ for social care for people with disabilities and about its relationship with other public services.

The UK social welfare system has undergone a major transformation since 1980³³⁶. Economic globalisation and technological developments have fundamentally altered the nation’s political economy, the nature of work, and the economic prospects of millions of people. The political system has become increasingly polarised on ideological grounds, and the electoral process has changed because of the influence of money on

335 Lewis, J. and West, A., 2014. Re-shaping social care services for older people in England: policy development and the problem of achieving ‘good care’. *Journal of social policy*, 43(1), pp.1-18.

336 Anttonen, A., Baldock, J. and Sipilä, J. eds., 2003. *The young, the old, and the state: social care systems in five industrial nations*. Edward Elgar Publishing.;

politics³³⁷. Demographic and cultural shifts—particularly the ageing of the population, the growing proportion of European, racial and ethnic minorities in the UK population (especially in urban areas), the expansion of women’s and LGBT rights, and the increase in the number of children born outside marriage—have created new social complications.³³⁸ As distrust of government has become more widespread, market-oriented ideas and values have permeated the culture of non-profit and public-sector organisations. Dent (2017) argues that new unprecedented issues also emerged during this period, such as the HIV/AIDS epidemic, crack cocaine, pervasive and chronic homelessness, terrorism, and the effects of climate change³³⁹.

Therefore, the focus and purpose of local government social care services have altered, and the models of care required to deliver this have transformed. The focus of social welfare policy has shifted from the expansion of legal entitlements to concerns over

337 Lewis, J. and West, A., 2014. Re-shaping social care services for older people in England: policy development and the problem of achieving ‘good care’. *Journal of social policy*, 43(1), pp.1-18.

338 Greenwood, N., Habibi, R., Smith, R. and Manthorpe, J., 2015. Barriers to access and minority ethnic carers' satisfaction with social care services in the community: a systematic review of qualitative and quantitative literature. *Health & social care in the community*, 23(1), pp.64-78.

339 Dent, S., 2017. Introduction. In *Collaboration, Communities and Competition* (pp. 93-106). Sense Publishers, Rotterdam.

fiscal responsibility, and from the protection of vulnerable populations to an emphasis on work over welfare. The consequences of the early-21st-century Great Recession and its austerity exacerbated long-standing political and social conflicts and created new sources of tension in society, particularly over the future of UK domestic policy and a generational shift to pluralist approaches to society³⁴⁰.

This situation has led to a new narrative, in which people with disabilities have come to realise and develop an awareness of their right to control their own lives, around their need for support to sustain and allow them to choose where to live and how they wish to contribute to society³⁴¹. Many people with disabilities have considered this a long unfinished journey³⁴², that started in the inter-war period.

340 Urscheler, L.H., 2016. *Concepts of Law: Comparative, Jurisprudential, and Social Science Perspectives*. Routledge.

341 In *R (JF) v Merton LBC* 15 the High Court held that there was a statutory duty to have regard to the matters listed in section 1(2) in addition to those in section 1(3) for which an explicit duty 'have regard' exists. This included (e) individual participating (with support if needs be) as fully as possible in decisions about them; (f) balance between the individual's well-being and that of any friends or relatives involved in their care.

342 Rummery, K., 2016. *Equalities: the impact of welfare reform and austerity by gender, disability and age. The Coalition Government and Social Policy: Restructuring the Welfare State*, p.309.

3.2 Social Care: Before Personalisation and the Care Act?

The first community-based alternatives were suggested and tentatively implemented in the 1920s and 1930s³⁴³ by charities, some church organisations and free-thinkers, although institutionalised asylum numbers continued to increase up to the 1950s.³⁴⁴ Killaspy (2006) argued through the study of Medline documents that community care was consistently associated with greater patient satisfaction and quality of life across specialities³⁴⁵. It was not a cheaper alternative to hospital care. However, she said that it leads to disadvantages included the exodus of experienced inpatient staff to community settings and the development of alternative institutions in the non-statutory sector³⁴⁶. The movement for deinstitutionalisation came to the fore in various Western countries in the 1950s and 1960s³⁴⁷ through the

343 Lewis, J & Glennester, H (1996) *Implementing the New Community Care*, Buckingham, Open University Press.

344 Gosling, G.C., 2017. *Payment and philanthropy in British healthcare, 1918–48*. Manchester University Press.

³⁴⁵ Helen Killaspy; From the asylum to community care: learning from experience, *British Medical Bulletin*, Volume 79-80, Issue 1, 1 June 2006, Pages 245–258, <https://doi.org/10.1093/bmb/ldl017>

³⁴⁶ Killaspy Ibid

³⁴⁷ Clear, M., 2015. Book Review: *The Disability Rights Movement: From Deinstitutionalization to Self-Determination*. *Review of Disability Studies: An International Journal*, 1(4).

developing Disability Rights Movement and its call for self-determination³⁴⁸. The prevailing public arguments, time of onset, and pace of reforms varied by country.³⁴⁹ Alaszewski³⁵⁰, Unsworth³⁵¹ and others³⁵², while Pfeiffer and Ried³⁵³ argued that such institutions maintained or created dependency, passivity, exclusion, and disability, causing people to be institutionalised. There was an argument that community services would be cheaper. While Thuillier (1999) suggested that new psychiatric medications made it more feasible to release people into the community.³⁵⁴ There were some voices against this approach.³⁵⁵ There were differing views on deinstitutionalisation from different

348 Stroman, D.F., 2003. The disability rights movement: From deinstitutionalization to self-determination. *Univ Pr of Amer*.

349 Rochefort DA (Spring 1984). "Origins of the "Third psychiatric revolution": the Community Mental Health Centers Act of 1963". *J Health Polit Policy Law* 9 (1): 1–30.doi:10.1215/03616878-9-1-1. PMID 6736594.

350 Alaszewski, A., Harrison, L. and Manthorpe, J., 1998. Risk, health and welfare. Policies, strategies and practice. Open University Press.

351 Unsworth, Clive. "Law and Lunacy in Psychiatry's 'Golden Age'", *Oxford Journal of Legal Studies*. Vol. 13, No. 4. (Winter, 1993), pp. 482.

352 See Pfeiffer, D., 2015. An essay on the beginnings of disability culture and its study. *Review of Disability Studies: An International Journal*, 1(1).

353 Reid, S., 2017. Policies of Disability: From Ugly Ordinances to the Disability Rights Movement. *Disability and US Politics: Participation, Policy, and Controversy* [2 volumes], p.37.

354 Thuillier, Jean (1999). Ten Years that Changed the Face of Mental Illness. Trans. Gordon Hickish. Martin Dunitz: pp. 110,114, 121–123, 130. ISBN 1-85317-886-1

355 Gøtzsche Peter C, Young Allan H, Crace John. ‘Does long term use of psychiatric drugs cause more harm than good?’ *BMJ* 2015; 350 :h2435

groups such as mental health professionals, public officials, families, advocacy groups, public citizens, and unions.³⁵⁶

3.2.1 Post-War Developments

After the second world war, the so-called humanitarian response to the problem of the growing problem of disability did not emerge until the post-1945 period.³⁵⁷ After the second world war, the National Health Service (NHS) using the ³⁵⁸ Beveridge Report recommendation to create "comprehensive health and rehabilitation services for prevention and cure of disease";³⁵⁹ with Welfare Services in hospitals, which later became known as Social Services.

The National Assistance Act 1948 formally abolished the Poor Law system that had existed since the reign of Elizabeth I,³⁶⁰ and established a social safety net for those who did not pay National

356 Scherl DJ, Macht LB (September 1979). "Deinstitutionalization in the absence of consensus". *Hosp Community Psychiatry* 30 (9): 599–604. doi:10.1176/ps.30.9.599.PMID 223959

357 Drake, R.F., 1999. *Understanding disability policies* (p. 49). London: Macmillan.

358 "Let Us Face the Future: A Declaration of Labour Policy for the Consideration of the Nation". Labour Party. 1945. Retrieved 3 March 2013.

359 Beveridge, William (November 1942). "Social Insurance and Allied Services" (PDF). HM Stationery Office. Retrieved 3 March 2013.

360 Spicker, P., 2004. *An introduction to social policy*. Aberdeen, Scotland: The Robert Gordon University.

insurance contributions (such as the homeless, the physically disabled, and unmarried mothers) and were therefore left uncovered by the National Insurance Act 1946 and the National Insurance (Industrial Injuries) Act 1946. It also provided help to elderly Britons who required supplementary benefits to make a subsistence living³⁶¹ and obliged local authorities to provide suitable accommodation for those who through infirmity, age, or any other reason, who were in need of care and attention not otherwise available.³⁶² The legislation also empowered local authorities to grant financial aid to organisations of volunteers concerned with the provision of recreational facilities or meals.³⁶³

People with disabilities³⁶⁴, in this period became entitled to welfare benefits and sheltered employment schemes were set-up to develop training and employment prospects. Since the 1950s various governments had been attracted to the policy of

361 Taylor, S.E. and Brown, J.D., 1988. Illusion and well-being: a social psychological perspective on mental health. *Psychological bulletin*, 103(2), p.193.

362 Byrne, T. and Padfield, C.F., 2014. *Social Services: Made Simple* Books. Elsevier.

363 Clements, L.J., Thompson, P., Goodall, C., Gould, J., Mitchell, E., Palmer, C. and Pickup, A., 2004. *Community care and the law*. London: Legal Action Group.

³⁶⁴ The definition of disabilities, was described as various physical and mental impairments that can hamper or reduce a person's ability to carry out his day to day activities.

community care³⁶⁵. Shakespeare (2005) for several reasons including cost savings and increased awareness of the needs of people with disabilities³⁶⁶.

3.2.2 The 1970s: The first steps forward

In 1970, the Chronically Sick and Disabled Persons Act (CSDPA)³⁶⁷ was introduced. Section 2 of CSDPA gave Local Authorities a duty to assist people with disabilities (as defined by Section 29 of the National Assistance Act 1948³⁶⁸) with Practical assistance in the home; Provision (or assistance to obtain) radio, TV, library or other recreational services; Provision of lectures, games, outings, recreational or educational activities outside the home; Provision of services or assistance in obtaining travel to and from the home to participate in any of the activities mentioned; Assistance in arranging adaptations or provision of additional

365 Bulmer, M., 2015. *The Social Basis of Community Care* (Routledge Revivals). Routledge.

³⁶⁶ Shakespeare, T., 2005. Disability studies today and tomorrow. *Sociology of health & illness*, 27(1), pp.138-148.

367 Sick, C. and Act, D.P., 1970. HMSO. See <http://www.legislation.gov.uk/ukpga/1970/44/contents>; http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Selecteddiscontinuedseries/DH_4017592

368 Disabled people under the Act meant (i) chronically sick or disabled persons; or (ii) persons suffering from mental disorder, Not very wide ranging

facilities to promote "safety, comfort or convenience"; Provision of meals in the home or elsewhere; Assistance in obtaining a phone and any special equipment necessary to use it. The CSDPA Act sought to give people with disabilities an equal opportunity of a place in society, free from disadvantage. The Act has been described as 'a Magna Carta for the disabled' - at the time it was revolutionary in transforming official policy. As seen above that it set down specific provisions to improve access and support for people with disabilities. The Act stipulated that local authorities had to keep records of people with disabilities³⁶⁹ living in the community and had to provide certain services to enable people to live in their homes. This legislation would remain the centrepiece of regulation until the Care Act came into force in 2015.

3.2.3 The 1980s: The contemplation and new thinking for the future?

Institutionalised Care care was a congregate living environment designed to meet the functional, medical, personal, social, and housing needs of individuals who have physical, mental, and/or developmental disabilities. Both Conservative and Labour governmental policy that specifically applied to individuals

369 Verdonschot, M.M., De Witte, L.P., Reichrath, E., Buntinx, W.H.E. and Curfs, L.M., 2009. Community participation of people with an intellectual disability: a review of empirical findings. *Journal of Intellectual Disability Research*, 53(4), pp.303-318.

believed to be experiencing a mental illness or developmental disabilities that impaired their reasoning ability to such an extent that the agents of the law, state, or courts determined that decisions will be made for the individual, under a legal framework.

Institutional care, as a policy,³⁷⁰ had become the target of widespread criticism during the 1960s and 1970s,³⁷¹ but it was not until 1983 that the Government of Margaret Thatcher adopted a new policy of care after the Audit Commission published a report called 'Making a Reality of Community Care'³⁷² which outlined the advantages of domiciled care. Care in the Community (also called "Community Care") was the British policy of deinstitutionalisation, treating and caring for physically and intellectually people with disabilities in their homes rather than in an institution³⁷³.

370 Walmsley, J., 2001. Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society*, 16(2), pp.187-205.

371 Report of the Committee of Inquiry, Socialist Health Association, Retrieved February 28, 2010

372 Making a Reality of Community Care, Audit Commission for Local Authorities in England and Wales, ISBN 978-0-11-701323-0

373 Morris, J., 1997. Care of empowerment? A disability rights perspective. *Social Policy & Administration*, 31(1), pp.54-60.

Although this policy has been attributed to the Margaret Thatcher government in the 1980s, community care was not a new idea, and it had existed since the early 1950s.³⁷⁴ Its general aim was a more cost-effective way of helping people with mental health problems and physical disabilities, by removing them from impersonal, often Victorian, institutions, and caring for them in their own homes³⁷⁵.

Despite support for the policy, the number of in-patients in large hospitals and residential establishments continued to increase³⁷⁶. Boxhall et al. (2009) argued that public opinion was gradually turned against long-stay institutions by allegations from the media³⁷⁷. However, through a literature review, there was little academic evidence to prove or disprove this comment. Some might such as Leif argue that such allegations were politically driven and that the deliberate underfunding, mismanagement and thus undermining of some institutions by the government was

374 Campbell, P., 1996. The history of the user movement in the United Kingdom. In *Mental health matters: A reader* (pp. 218-225). Macmillan Education UK.

375 Berghs, M., 2017. Cash not care: the planned demolition of the UK welfare state. *SELF*, 45(3-4), pp.336-341.

376 Barnes, C., 2014. . A brief history of discrimination and disabled people.

377 Boxall, K., Dowson, S. and Beresford, P., 2009. Selling individual budgets, choice and control: local and global influences on UK social care policy for people with learning difficulties. *Policy & politics*, 37(4), pp.499-515.

manipulated as an excuse by the government to shut them down³⁷⁸. It is argued that although there might have been incidents of where care should have been improved, the care in many such institutions may have been satisfactory or good.

The central aim of community care policy has always been to maintain individuals in their own homes wherever possible, rather than provide care in a long-stay institution or residential establishment.³⁷⁹ Taken for granted that this policy was the best option from a humanitarian and moral perspective. It was also thought to be cheaper. Three key objectives of Community Care policy³⁸⁰ were:

- The overriding objective was to cap public expenditure on independent sector residential and nursing home care. This was achieved in that local authorities became responsible for operating a needs-based yet cash-limited system.
- There was a clear agenda about developing a mixed economy of care, i.e. a variety of providers. The mixed economy

378 Leff, J. ed., 1997. *Care in the community: illusion or reality*. Wiley.

379 Spicker, P., 2014. *Social policy: Themes and approaches* (Revised second edition). Policy Press.

380 Ramon, S., 2016. *Beyond community care: Normalisation and integration work*. Springer.

provision in residential and nursing home care has been maintained despite the social security budget being capped. Moreover, there are now many independent organisations providing domiciliary care services.

- To redefine the boundaries between health and social care. Much of the continuing care of elderly and people with disabilities was provided by the NHS. Now, much of that has been re-defined as social care and is the responsibility of local authorities.

Stewart (2016) argues that since Thatcher started the implementation of Community Care, the UK has been observing a move of health and care services towards neoliberal models whereby duties and rights of care have been slowly eroded. The effects on disability services, people with disabilities, veterans and long-term sick have been devastating³⁸¹. Others such as Bulmer that it is was the start of people with disabilities taking control, and the long-term effects are positive.³⁸²

Sir Roy Griffiths thought that the causation of many of the problems facing the State and community care was by the lack of

381 Stewart, M., 2016. Cash not care: The planned demolition of the UK welfare state. London: New Generation Publishing.

382 Bulmer, M., 2015. The social basis of community care (routledge revivals). Routledge.

strong, effective leadership and management³⁸³. Griffiths asked by the Thatcher Government to examine the whole system of community care. However, Dopson believed that this report was influenced by the ideology of managerialism rather than values and disability rights³⁸⁴. In 1988 he produced a report or a Green Paper called 'Community Care: Agenda for Action'³⁸⁵, also known as The Griffiths Report³⁸⁶. In 1988 Griffiths said of community care that it was *everybody's distant cousin but nobody's baby*.³⁸⁷ He was saying that community care was not working because no one wanted to accept the responsibility for community care. Community Care: Agenda for Action made the key

383 Harrison, S. and Wistow, G., 2000. Policy Entrepreneurship in Action: the Contribution to Health and Social Care Policy-making of Sir Roy Griffiths, 1982–92. In *Bureaucrats and Leadership* (pp. 171-199). Palgrave Macmillan UK.

384 Dopson, S., 2009. Changing forms of managerialism in the NHS. *The new sociology of the health service*. Abingdon: Routledge, pp.37-55.

385 Community care: agenda for action: a report to the Secretary of State for Social Services by Sir Roy Griffiths. HM Stationery Office, 1988.

386 Griffith, R. (1988). Community Care: Agendas for Action: A Report to the Secretary of State for Social Services. HM Stationery Office.

387 <http://www.sochealth.co.uk/national-health-service/griffiths-report-october-1983/>

recommendations for action with Local Authorities should have a key role in community care³⁸⁸.

Additionally, it was to promote the use of the Independent sector and making maximum use of the voluntary and private sector of welfare. The Griffiths Report on Community Care seemed to back local government³⁸⁹. In 1989 the government published its response to the Griffiths Report in the White Paper *Caring for People: Community Care in the Next Decade and Beyond*³⁹⁰, the principle was that the State should be an 'enabler' rather than a provider of care.

3.2.4 The Foundations: National Health Service and Community Care Act 1990

This new legislation which was enacted in the National Health Service and Community Care Act 1990³⁹¹ creating for the first-time a purchaser and provider split in local authorities, coming

388 Priestley, M., 1999. Disability politics and community care. Macmillan.

389 Ibid

390 Alison Dunn (ed): The Voluntary Sector, the State and the Law Bloomsbury Publishing, 1Feb.,2000

391 Audit Commission for Local Authorities and the National Health Service in England, 1992. The community revolution: personal social services and community care (No. 8). The Stationery Office/Tso.

into force in April 1993³⁹². This Act would lay the foundation of Direct Payments and Personalisation, and later the Care Act 2014.

Many authors have been highly critical of the reforms. Hadley and Clough claim the reforms 'had created care in chaos'.³⁹³ They claimed the reforms have been “inefficient, unresponsive, offering no choice or equity”³⁹⁴. Other authors, however, are not quite so pessimistic.³⁹⁵ Means and Smith claimed that the reforms: introduced a system that is no better than the previous more bureaucratic systems of resource allocation and that the voluntary sector (such as MENCAP and Scope) was the main beneficiary of this attempt to develop a "mixed economy of care."³⁹⁶

In January 1998, the Labour Health Secretary, Frank Dobson, said the care in the community care programme launched by the

392 Cornes, M., Mathie, H., Whiteford, M., Manthorpe, J. and Clark, M., 2016. The Care Act 2014, personalisation and the new eligibility regulations: implications for homeless people. *Research, Policy and Planning*, 31(3), pp.211-223.

393 Hadley, R., & Clough, R. (1998). *Care in chaos*. A&C Black.

394 Clements, L.J., Thompson, P., Goodall, C., Gould, J., Mitchell, E., Palmer, C. and Pickup, A., 2004. *Community care and the law*. London: Legal Action Group.

395 Means, R. (2012). A brave new world of personalized care? Historical perspectives on social care and older people in England. *Social Policy & Administration*, 46(3), 302-320.

396 Means, R; Smith, R (1998). *Community Care: Policy and Practice* (2 ed.). London: Macmillan Press.

Conservatives had failed.³⁹⁷ That the NHS and Community Care Act 1990 was passed so that patients could be individually assessed, and assigned a specific care worker to develop their needs³⁹⁸.

However, two years previous, under the Major Conservative Government the start of the Personalisation process in legislation had begun in earnest with the implementation of the Direct Payment Act 1996.

3.3 The Pre-Care Act 2014 Legal Framework

The new theories were developed, challenges to the new ways of working were generated; but the legislation was virtually still the same, other than the Direct Payment Act 1995.

The framework that people with disabilities were required to access services were still based on the chronically sick and Disabled Persons Act 1970 and the national assistance act 1948. It was appraised that there were over 30 Acts of Parliament dealing³⁹⁹, to varying degrees, with UK adult social care. These were Acts being used a piecemeal manner to decipher was services

397 "Care in the community to be scrapped, BBC, 1998". Retrieved September 26, 2005.

398 Ibid

399 Clements, L. J., & Thompson, P. (2004). Community care and the law. London: Legal Action Group.

could be provided and how – it also created an additional issue as the legal challenges and Case Law started to contradict other parts of Acts⁴⁰⁰. Law Commission Review gave this as one of two main reasons for the Consultation⁴⁰¹; the other was to update legislation to make Personalisation written in the law⁴⁰².

Although ‘Personalisation’ was not defined in any existing Acts, the legislation had been used in a piecemeal manner to recognise self-management and ‘choice and control’ in law. Therefore, the Association of Directors of Adult Social Care (ADASS) obtained a legal opinion and guidelines whether the central tenets of personalisation (Choice and Control, and financial self-management) could be implemented within the pre-Care Act legal framework⁴⁰³. On the group of eight people, there was one legal person Belinda Schwehr from ‘Care and Health Law’⁴⁰⁴; the rest were local authority managers putting forward their perceptions of

400 Means, R., Richards, S. and Smith, R., 2008. Community care: policy and practice. Palgrave Macmillan.

401 The Law Commission: ADULT SOCIAL CARE - Consultation Paper No 192 (HMSO) 2011

402 ASS, A., 2009. Personalisation and the law: Implementing Putting People First in the current legal framework'. Association of Directors of Adult Social Services, available online at www.adass.org.uk.

403 ADASS Personalisation and the law: Implementing Putting People: First in the current legal framework (2009)

404 <http://www.schwehroncare.co.uk/care-and-health-law/>

how the legal system could implement personalisation or not⁴⁰⁵. This writing became the ‘go-to’ document for Complaints Managers and Senior Managers within local authorities. It led to each local authority making its own localised rules on the understanding what the text said. Therefore, neighbouring authorities in Manchester had a differing understanding of how and on what a person with disabilities could use their Personal Budget⁴⁰⁶. As an example, in neighbouring Local Authorities you could buy a gym membership for themselves and a carer, in the other Authority the person with disabilities were expected to pay for this themselves.

Although Direct Payments (to individuals) had existed since 1996, Person-centred care and support planning were not new.⁴⁰⁷ The Assessment Directions already required it (in force since 2004), which required the client to be kept at the centre of the process, and consulted before the assessment was completed, between the

405 Schwehr, B., 2010. Safeguarding and personalisation. *The Journal of Adult Protection*, 12(2), pp.43-51.

406 Glasby, J., 2012. The controversies of choice and control: why some people might be hostile to English social care reforms. *British Journal of Social Work*, 44(2), pp.252-266.

407 HM Government, *The Case for Change: Why England Needs a New Care and Support System* (2008) p 24.

authority and these parties⁴⁰⁸. It should be noted that giving clients Direct Payments with which to buy long-term residential care – was unlawful under the current Direct Payments regulations and would continue so to be after November 2009⁴⁰⁹. Using s2 of the Local Government Act 2000 to achieve something that is already prohibited by another Act or Regulations is also ineffective and illegal, under s3 LGA 2000⁴¹⁰.

There was confusion over whether Personal Budgets were different from Direct Payments. A ‘personal budget’ is simply the name given to a sum of money, which the person’s needs ought reasonably to be able to be met with it.⁴¹¹ Generally, in cases where the client was interested in a Direct Payment, that budget would be the net sum after the user’s contribution has been deducted. In conventionally arranged packages managed by local authority commissioners, the Personal Budget would also be the

408 The Community Care Assessment Directions 2004 at http://webarchive.nationalarchives.gov.uk/+http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsLegislation/DH_4088476

409 Councils, L. and Stewart, E., 2012. Keeping the dream alive: Delivering real personalisation.

410 Barnes, D., Boland, B., Linhart, K. and Wilson, K., 2017. Personalisation and social care assessment—the Care Act 2014. *BJPsych Bull*, 41(3), pp.176-180.

411 Carney, T., 2013. Participation and service access rights for people with intellectual disability: A role for law?. *Journal of Intellectual and Developmental Disability*, 38(1), pp.59-69.

net amount, but the authority will pay the full cost of the package, and the user's contribution recouped as happened unless the provider agrees to collect it as the authority's collection agent.

Local authorities by allocating a notional sum of money, local people with disabilities as service users and taxpayers would see fairness being achieved⁴¹². Simply, it was giving the person the largest possible measure of control and choice as to the spending of that money. Using the local authority's staff to work more closely with the clients and families⁴¹³, was only seen as another way of offering more control than is currently the then general practice⁴¹⁴.

There was no new 'vehicle' in the legal framework called a 'Personal' Budget' which was different from the funding invested in a Direct Payment or spent on local authority arranged services. Nevertheless, there were many ways of organising Direct Payments and contracts, which would possibly deliver greater satisfaction and enable reconfiguration of services across the

412 Slasberg, C. and Beresford, P., 2015. Building on the original strengths of direct payments to create a better future for social care. *Disability & Society*, 30(3), pp.479-483.

413 It should be noted that the LA was still providing internal contracting for preferred services from providers

414 Beresford et al: *Ibid*

country⁴¹⁵. The development of mixed packages of partly Direct Payments, and partly services commissioned by one's responsible authority, enabled everyone, even those in residential care, to have the benefits of a personalised budget. Personalisation was relying on Providers to make changes – many were not⁴¹⁶.

By autumn 2007, the English government's Putting People First⁴¹⁷ document set out a new vision for the delivery of health and social care based around a cross-government commitment to greater 'personalisation'.⁴¹⁸ Signed by a series of national health and social care bodies as well as six different government departments, this vision for the future pledged to achieve a 'system-wide transformation' in which people using services have 'maximum choice, control and power over the support services

415 Webber, M., Treacy, S., Carr, S., Clark, M. and Parker, G., 2014. The effectiveness of personal budgets for people with mental health problems: a systematic review. *Journal of Mental Health*, 23(3), pp.146-155.

416 Rodrigues, R. and Glendinning, C., 2015. Choice, competition and care—developments in English social care and the impacts on providers and older users of home care services. *Social Policy & Administration*, 49(5), pp.649-664.

⁴¹⁷ First, P.P., 2007. A shared vision and commitment to the transformation of Adult Social Care. *Department of Health*.

⁴¹⁸ First, P.P., 2007. A shared vision and commitment to the transformation of Adult Social Care. *Department of Health*.

they receive' (HM Government, 2007, pp. 2–3 ⁴¹⁹). Similar principles have since been adopted by the subsequent Cameron/Clegg Coalition government, which has reiterated its commitment to this agenda as part of its Vision for Adult Social Care:

Our vision starts with securing the best outcomes for people. People, not service providers or systems, should hold the choice and control about their care. Personal budgets and direct payments are a powerful way to give people control. Care is a uniquely personal service. It supports people at their most vulnerable, and often covers the most intimate and private aspects of their lives. With choice and control, people's dignity and freedom are protected, and their quality of life is enhanced. Our vision is to make sure everyone can get the personalised support they deserve (Department of Health, 2010, p. 15).

Amongst the various policy commitments, two key approaches form the basis for this document: direct payments (which successive Labour governments had pledged to extend) and personal budgets (which were to be rolled out to everyone eligible for publicly funded adult social care).

⁴¹⁹ First, P.P., 2007. A shared vision and commitment to the transformation of Adult Social Care. *Department of Health*. P2-3

In addition to the initial focus on adult social care, further, attempts were also underway to extend this way of working to other forms of health care and children's services (see, e.g. Darzi, 2008⁴²⁰; Crosby, 2010⁴²¹; Needham, 2010⁴²², 2011⁴²³; Department of Health, 2009⁴²⁴). The Cameron-Clegg Coalition described the initial progress around the implementation of personal budgets as 'disgraceful' (Smith, 2010⁴²⁵), and reaffirmed its commitment that all adult social care will be delivered via this approach. They were explicit that it expected direct payments to be the norm in most cases. The Cameron-Clegg Coalition has also pledged that personalisation would be at the heart of the outcomes framework being implemented in adult social care and to embed personalisation in new social care legislation being planned for

⁴²⁰ Darzi, A., 2014. High quality care for all: NHS Next Stage Review final report. London: Department of Health, 2008.

⁴²¹ Crosby N. Personalisation: Children, Young People and Families 2010 Wythall, In Control

⁴²² Needham, C., 2010. Debate: Personalized public services—a new state/citizen contract?.

⁴²³ Needham, C., 2011. Personalising public services: Understanding the personalisation narrative. Policy Press.

⁴²⁴ Department of Health Personal Health Budgets: First Steps 2009 London Department of Health

⁴²⁵ Smith R. Paul Burstow: Personal budget take-up is a disgrace, Community Care 2010 22 September, available online at www.communitycare.co.uk/Articles/2010/09/22/115395/paul-burstow-personal-budget-take-up-is-a-disgrace.htm

2012 (Department of Health, 2010⁴²⁶, 2011⁴²⁷). The development of more individualised forms of funding is common in many developed countries. Seeking to respond to growing numbers of people with disabilities, medical and technological advances and rising public expectations, many systems are experimenting with and/or rolling out similar concepts⁴²⁸ (Lord and Hutchinson, 2003⁴²⁹; Lundsgaard, 2005⁴³⁰; O'Brien and Duffy, 2009⁴³¹; SCIE, 2007⁴³²).

While England and Wales may have been unusual in terms of the speed and scale of its reforms, the debate and polarised views were developed and fervently upheld by both sides. The debate

426 Department of Health A Vision for Adult Social Care: Capable Communities and Active Citizens 2010 London Department of Health

427 Department of Health Think Local, Act Personal 2011 London Department of Health

428 whether this be 'consumer-directed support' and 'cash and counselling' in the USA, German social insurance reforms or Dutch personal budgets.

429 Lord, J. and Hutchison, P., 2003. Individualised support and funding: building blocks for capacity building and inclusion. *Disability & Society*, 18(1), pp.71-86.

430 Lundsgaard J. Consumer Direction and Choice in Long-Term Care for Older Persons ...: How Can It Help Improve Outcomes, Employment and Financial Sustainability? 2005 Paris OECD

431 O'Brien J., Duffy S., Glasby J., Dickinson H. Self-directed support as a framework for partnership working *International Perspectives on Health and Social Care* 2009 Oxford Wiley-Blackwell

432 SCIE Choice, Control and Individual Budgets: Emerging Themes 2007 London SCIE

drove the development and underpinning values and principles for the Care Act 2014. It is to this debate that we transfer to, so as to understand the pre-Care Act research and dialogue that propelled the Act – and later its important Statutory Guidance in 2016 ⁴³³.

3.4 The controversies of ‘choice and control’: polarised views

The Cameron-Clegg Government’s pledges and the relatively new concepts at stake have generated a strong response, from policymakers from the social care trade press and academic commentators alike. In many ways, this is hardly surprising given the highly charged nature of debates which surround broader notions of choice, control, consumerism, privatisation and welfare reform (see, e.g. Le Grand, 2007 ⁴³⁴ 2011⁴³⁵; Pollock, 2004⁴³⁶; Lister, 1996). Thus, Oliver and Sapey ⁴³⁷ have described the

433 Whittington, C., 2016. The Promised Liberation of Adult Social Work under England’s 2014 Care Act: Genuine Prospect or False prospectus?. *British Journal of Social Work*, 46(7), pp.1942-1961.

434 Le Grand, J., 2007. The politics of choice and competition in public services. *The Political Quarterly*, 78(2), pp.207-213.

435 Grand, J.L., 2011. Quasi-Market versus State Provision of Public Services: Some Ethical Considerations. *Public Reason*, 3(2).

436 Pollock A. NHS plc: The Privatisation of Our Health Care 2004 London Verso

437 Oliver, M., Sapey, B. and Thomas, P., 2012. *Social work with disabled people*. Palgrave Macmillan.

advent of direct payments as holding out ‘the potential for the most fundamental reorganisation of welfare for half a century’, while Browning⁴³⁸ has described the broader development of self-directed support in a similar way as ‘potentially the biggest change to the provision of social care in England in 60 years’⁴³⁹ In contrast, Ferguson's ⁴⁴⁰ (2007) critique of the broader personalisation agenda argues that:

In its uncritical acceptance of the marketization of social work and social care; in its neglect of poverty and inequality; in its flawed conception of the people who use social work services; in its potentially stigmatizing view of welfare dependency; and in its potential for promoting, rather than challenging, the deprofessionalization of social work, the philosophy of personalization is not one that social workers should accept uncritically.⁴⁴¹

438 Browning D Evaluation of the Self-Directed Support Network: A Review of Progress up to 31st March 2007 2007 London Care Services Improvement Partnership

439 Browning Ibid p3

440 Ferguson, I., 2007. Increasing user choice or privatizing risk? The antinomies of personalization. *British journal of social work*, 37(3), pp.387-403.

441 Ferguson, I., 2007. Increasing user choice or privatizing risk? The antinomies of personalization. *British journal of social work*, 37(3), pp.401-403.

Although it is early days, views from the field seem equally divided - The Guardian newspaper surveyed 500 social workers. This survey suggested that 70% feel that the Putting People First agenda will benefit both users and carers, with 59 per cent agreeing that this would have a positive impact on their roles⁴⁴². However, this contrasts strongly with regular articles in the trade press (see, e.g. Samuel, 2008⁴⁴³ ; Lombard, 2008⁴⁴⁴), which frequently convey a negative impression of the policy. An online survey of 600 social workers for *Community Care* magazine also suggested that only 11 per cent view plans to extend personalisation to all users as appropriate⁴⁴⁵, with 96 per cent of local authority staff feeling that it would make people with disabilities as service users more vulnerable⁴⁴⁶.

It is a simplification, but by 2011/12, the battle lines seem to have been drawn between many people with disabilities with direct payment/personal budget and their allies on the one hand, and

442 Jackson L. The choice is yours 2009 Social Care supplement to The Guardian Society, 28 January, p. 2

443 Samuel M. Rape warning over plan to extend Direct Payments Community Care 2008 13 November, p. 5

444 Lombard D. Self-directed care schemes in Scotland break employment law Community Care 2008 17 June

445 Mickel A. What's the outlook for adult social care? Community Care 2008 (pg. 28 - 30) 23 October

446 Community Care 2008 (pg. 28 - 30) 23 October Ibid

some social care professional bodies and broader public service trade unions on the other. As an example of those passionate about the potentially liberating impact of direct payments and personal budgets, Simon Stevens (an independent disability trainer and consultant, and a regular columnist in *Community Care* magazine) argued that: This is an interesting opening standpoint in what is clearly going to be a long and bloody battle between the rights of people with disabilities as service users and indeed their staff with the demands.^{447 448} Shortly afterwards, a study by Unison showed care assistants hired by people with disabilities using personal budgets worked under conditions which broke employment law.⁴⁴⁹

The reaction they generated is important because it suggests that finding common ground in a way that brings people needing support together with those who provide it can be difficult and that the issues can quickly become polarised - an important viewpoint when we try and consider dispute resolution within the later Care Act 2014.

447 Stevens S. My problem with trade unions *Community Care* 2008 2 June, available online at www.communitycare.co.uk

448 Leece, J. and Peace, S., 2009. Developing new understandings of independence and autonomy in the personalised relationship. *British Journal of Social Work*, 40(6), pp.1847-1865.

449 Lombard D. Self-directed care schemes in Scotland break employment law *Community Care* 2008 17 June

3.4.1 For or Against Personalisation: The role of ‘evidence.’

One of the interesting issues emerging from this agenda is the extent to which both supporters and critics appeal to ‘the evidence’. Depending on their point of view, advocates for these changes have claimed that ‘the evidence’ shows significant positives (choice and control; social justice; citizenship; value for money, etc). While critics have claimed that there is not enough ‘evidence’ to date and what exists is often of poor quality, and arguing that personalisation is too complex, discriminatory towards people with disabilities, lowers standards of care, etc.

In the rapidly evolving policy context, the issues involved are always likely to be far in advance of the evidence base, which has inevitably had to struggle to keep up with such a rapid pace of change. Meaning that, with a few notable exceptions, much of the debate to date has had to take place *in advance* of clear and consistent evidence and/or has had to build on a *different kind of evidence*.

The next stage is to summarise key concerns that have been raised in the literature to date and explore some of the underlying factors that might be contributing to the almost opposing views that seem to be emerging. Also, a summary of more complex material

presented elsewhere (Glasby and Littlechild⁴⁵⁰) are considered. There is a mix of evidence from policy, practice, research and personal experience and is intended to further existing debates about the future of adult social care⁴⁵¹.

3.4.2 What are Direct Payments and Personal Budgets?

The 1996 Community Care (Direct Payments) Act⁴⁵², which came into force on 1 April 1997, has often been a defining moment in the struggle by the people with disabilities's movement for greater civil rights⁴⁵³. After longstanding pressure from a range of user groups, the act empowered local authority social services to make cash payments to people with disabilities as service users aged between eighteen and sixty-five in place of direct service

450 Glasby J., Littlechild R. Direct Payments and Personal Budgets: Putting Personalisation into Practice 2009 Bristol The Policy Press

451 Other key accounts are available via Needham, C., 2011. Personalising public services: Understanding the personalisation narrative. Policy Press. Is study of the narratives of personalisation, the national IBSEN study - Glendinning, C., Moran, N., Rabiee, P., Challis, D., Jacobs, S., Wilberforce, M., Knapp, M., Fernandez, J.L., Netten, A., Jones, K. and Manthorpe, J., 2008. The IBSEN project: national evaluation of the Individual Budgets Pilot Projects. University of York: Social Policy Research Unit., pragmatic monitoring by In Control (Poll et al., 2006; Hatton et al., 2008; Tyson et al., 2010) and websites such as www.in-control.org.uk and www.centreforwelfarereform.org. are considered.

452 www.legislation.gov.uk/ukpga/1996/30/pdfs/ukpga_19960030_en.pdf

453 Priestley, M., Jolly, D., Pearson, C., Ridell, S., Barnes, C. and Mercer, G., 2006. Direct payments and disabled people in the UK: supply, demand and devolution. *British Journal of Social Work*, 37(7), pp.1189-1204.

provision (see Leece and Bornat ⁴⁵⁴ 2006; SCIE, 2007 ⁴⁵⁵, 2008 ⁴⁵⁶; Glasby and Littlechild ⁴⁵⁷, for an overview). Although progress was initially slow, the number of direct payments has continued to increase and became compulsory for all local authorities to offer to those who met the criteria and wanted to receive a payment.

From 2003, the concept of a direct payment was augmented by the notion of a personal budget. Although technically entirely separate from direct payments, personal budgets nevertheless have much in common with this agenda and seem to offer an even more powerful tool for reforming the system. Invented and piloted by a national social innovation network called ‘In Control’⁴⁵⁸, personal

454 Leece J., Bornat J. *Developments in Direct Payments 2006* Bristol The Policy Press

455 SCIE *Choice, Control and Individual Budgets: Emerging Themes 2007* London SCIE

456 SCIE *Personalisation: A Rough Guide 2008* London SCIE

457 Glasby J., Littlechild R. *Direct Payments and Personal Budgets: Putting Personalisation into Practice 2009* Bristol The Policy Press

⁴⁵⁸ In Control are “a national charity working for an inclusive society where everyone has the support they need to live a good life and make a valued contribution.” Currently funded by government bodies such as the Department of Health, Department for Education and NHS England as well as through councils, clinical commissioning groups, provider organisations and sector-related bodies such as Think Local Act Personal, ADASS and ADCS.

budgets were part of a new approach to delivering adult social care called ‘self-directed support’⁴⁵⁹. Personal budgets began as a series of small-scale, bottom-up pilots in six local authorities, designed to find new ways of freeing up existing resources to meet needs in new ways, while still working within the existing legal and policy framework (see Poll *et al.* ⁴⁶⁰ ; Glasby and Littlechild,⁴⁶¹).

Under this approach, the local authority gave the person with disabilities an immediate indication of how much money was available to spend on meeting their needs and then allows them to choose how this money is consumed and how much direct control they have over the money itself. The options ranged from having a social worker manage the personal budget on your behalf right the way through to taking the full amount as a direct payment (with several other options in between). In this way, self-directed support seems likely to offer more of a spectrum of options that differs significantly from the more ‘all or nothing’ nature of direct payments. By September 2010, it was estimated that some

459 Slasberg, C., Beresford, P. and Schofield, P., 2012. How self directed support is failing to deliver personal budgets and personalisation. *Research, Policy and Planning*, 29(3), pp.161-177.

460 Poll, C., Duffy, S., Hatton, C., Sanderson, H. and Routledge, M., 2006. *A report on in Control’s first phase, 2003-2005*. Control; London.

461 Glasby J. , Littlechild R. *Direct Payments and Personal Budgets: Putting Personalisation into Practice 2009* Bristol The Policy Press

244,000 people with ongoing support needs had a personal budget (ADASS, 2010⁴⁶²)—a long way from the first sixty people testing this way of working in 2003 (Poll *et al.*,⁴⁶³).

From the beginning, In Control adopted a very different approach to implementing change than is sometimes the case with national policy developments, even borrowing language and concepts from the manufacture of computer software.⁴⁶⁴ As a membership organisation, In Control describes itself as a social innovation network or, in more everyday terms, as a ‘think tank that does’⁴⁶⁵ (personal communication, In Control⁴⁶⁶). After high-profile early

⁴⁶² ADASS - Councils on track to meet 30 per cent target for personal budgets, 2010 press release, available online at www.adass.org.uk/index.php?option=com_content&view=article&id=665:adass-councils-on-track-to-meet-30-per-cent-target-for-personal-budgets&catid=127:press-releases-2010&Itemid=419

⁴⁶³ Poll, C., Duffy, S., Hatton, C., Sanderson, H. and Routledge, M., 2006. A report on in Control’s first phase, 2003-2005. Control; London.

⁴⁶⁴ In Control sees its contribution as creating a new ‘operating system’ for adult social care which is ‘open-source’ in nature (i.e. In Control makes new versions of its tools and models available to all members to implement as they are developed, constantly seeking feedback and developing new, improved versions—much the same as IT companies issue new versions of their software).

⁴⁶⁵ <http://www.in-control.org.uk/events/past-events/watch-out-it's-the-law-april-2011.aspx>

⁴⁶⁶ <http://www.in-control.org.uk/events/past-events/east-midlands-think-local,-act-personal-workshop-1-july.aspx>

results⁴⁶⁷ this way of working was taken up with enthusiasm by the English government (Department of Health ⁴⁶⁸ ; Prime Minister's Strategy Unit,⁴⁶⁹). Interestingly, the model piloted by the Department of Health and subsequently evaluated by the national IBSEN⁴⁷⁰ study was very different from the initial, more bottom-up work of In Control. While Glasby and Littlechild⁴⁷¹ describe this process in some detail, a key difference was that the Department of Health sought to pilot an approach based on an integrated funding pot⁴⁷². For the government, this was a crucial extension of the work of In Control to simplify the multiple potential sources of support available to people with disabilities by

467 Glendinning C., Arksey H., Jones K., Moran N., Netten A., Rabiee P. The Individual Budgets Pilot Projects: Impact and Outcomes for Carers 2009 York Social Policy Research Unit

468 Department of Health A Vision for Adult Social Care: Capable Communities and Active Citizens 2010 London Department of Health

469 Prime Minister's Strategy Unit Improving the Life Chances of Disabled People 2005 London Prime Minister's Strategy Unit

470 Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. and Wilberforce, M., 2008. Evaluation of the individual budgets pilot programme. Final Report. York: Social Policy Research Unit, University of York.

471 Glasby J. , Littlechild R. Direct Payments and Personal Budgets: Putting Personalisation into Practice 2009 Bristol The Policy Press

472 The integrated funding pot with the personal budget comprising not just adult social care funding, but also money from a range of other housing, employment and social security sources. See Littlechild, R., 2009. Direct payments and personal budgets: putting personalisation into practice. Policy Press.

moving towards a single integrated funding stream, and governed by a single assessment. In developing this approach, it hoped to facilitate access to support, enhance the choice and control available to people with disabilities, and reduce unnecessary spending on multiple/repeated assessments⁴⁷³. With the benefit of hindsight, this was too much too soon, and perhaps greater progress could have been made by focusing only on the much larger adult social care budget. Webber believed that rather than running the risk of diluting the In Control model by taking on too many different funding streams at once (many of which were relatively small yet very complex)⁴⁷⁴. Seeking to integrate so many different budgets at once also ran the risk of increasing opposition to this way of working from organisations with a vested interest in maintaining their single agency approach⁴⁷⁵, and the subsequent failure to achieve the level of integration initially envisaged may also call into question the government's commitment.

473 Needham, C., 2014. Personalization: From day centres to community hubs?. *Critical Social Policy*, 34(1), pp.90-108.

474 Webber, M., Treacy, S., Carr, S., Clark, M. and Parker, G., 2014. The effectiveness of personal budgets for people with mental health problems: a systematic review. *Journal of Mental Health*, 23(3), pp.146-155.

475 Mladenov, T., Owens, J. and Cribb, A., 2015. Personalisation in disability services and healthcare: A critical comparative analysis. *Critical Social Policy*, 35(3), pp.307-326.

Partly because of this, Central Government has changed its language to use the term ‘individual budget’ to refer to the integrated funding pot approach, reserving the term ‘personal budget’ for the way of working developed initially by In Control in adult social care⁴⁷⁶. Similarly, the government tended not to use the concept of ‘self-directed support’ developed by In Control, but to refer instead to a broader ‘personalisation’ agenda⁴⁷⁷ (of which direct payments/personal budgets are a part, but which also includes a broader consideration of the role of universal services, the development of greater social capital and the promotion of a more preventative approach—see SCIE for a summary⁴⁷⁸). These were all eventually encompassed in the Care Act 2014.

Overall, In Control characterised its approach as shifting from a ‘professional gift’ model⁴⁷⁹ (in which the state uses the money it receives from taxes to slot people into pre-paid services through the work of professional assessors and gate-keepers) to a

⁴⁷⁶ Glasby, J., 2012. The controversies of choice and control: why some people might be hostile to English social care reforms. *British Journal of Social Work*, 44(2), pp.252-266.

⁴⁷⁷ Burchardt, T., Obolenskaya, P. and Vizard, P., 2015. The Coalition’s record on adult social care: Policy, spending and outcomes 2010–2015. *Social policy in a cold climate working paper*, 17.

⁴⁷⁸ SCIE Personalisation: A Rough Guide 2008 London SCIE

⁴⁷⁹ Ellis, K., 2015. Personalisation and adult social work: recasting professional discretion at the street level?. *Understanding Street-level Bureaucracy*, p.187.

‘citizenship model’⁴⁸⁰ (in which the person with disabilities is at the centre of the process, is part of the community and organises the support they need and want)⁴⁸¹. While personal budgets are important, therefore, it is this shift in the relationship between the state and the individual that lies at the heart of self-directed support. Helpfully captured by Rummery (2006), who argues that:

The problem is that community care policy has never been framed within a discourse of citizenship New Labour has left largely unchallenged a system of providing care and support for people with disabilities that was designed by the Conservative government to curb the spiralling cost of residential care provision and marketise the delivery of welfare. The fundamental aims and discourse of community care policy need to be challenged. We need to stop talking about ‘the cost of care’ and start talking about supporting citizenship and challenging social exclusion (Rummery, 2006, pp. 646–7).

3.4.3 Common concerns and reaction to Personalisation

Despite widespread enthusiasm (particularly from people with disabilities's organisations) about the potential of direct payments,

480 Duffy, S. and Perez, W., 2015. Citizenship for all. *Learning Disability Practice* (2014+), 18(1), p.15.

481 Duffy, S., 2016. Citizenship and the welfare state.

there was a reaction against this way of working⁴⁸². For some commentators, there is a strong sense that the numbers of direct payments have not grown as rapidly as some had hoped and that their impact on the social care system has been less profound than might have been the case⁴⁸³. According to the former Commission for Social Care Inspection (2004, p. 5), for example, ‘the number of people receiving direct payments remains disappointingly low’⁴⁸⁴. However, more recent accounts have perhaps started to be more healthily sceptical—still identifying the many positives of direct payments but also spending time on some of the potential barriers (Ferguson⁴⁸⁵; Scourfield, 2005⁴⁸⁶, 2014⁴⁸⁷; Spandler⁴⁸⁸).

⁴⁸² Roulstone, A. and Morgan, H., 2009. Neo-liberal individualism or self-directed support: are we all speaking the same language on modernising adult social care?. *Social Policy and Society*, 8(3), pp.333-345.

⁴⁸³ Young, D., 2017. Direct Payments and Personal Budgets: Putting Personalisation into Practice, By Jon Glasby and Rosemary Littlechild Bristol: Policy Press, 2016. *Social Policy & Administration*, 51(7), pp.1506-1508.

⁴⁸⁴ Commission for Social Care Inspection Direct payments: what are the barriers? 2004 London, CSCI

⁴⁸⁵ Ferguson, I., 2007. Increasing user choice or privatizing risk? The antinomies of personalization. *British journal of social work*, 37(3), pp.387-403.

⁴⁸⁶ Scourfield, P., 2005. Social care and the modern citizen: client, consumer, service user, manager and entrepreneur. *British journal of social work*, 37(1), pp.107-122.

⁴⁸⁷ Scourfield, P., 2014. Reflections on the utilisation of 'universalist' discourse in contemporary English policy on adult social care. *Critical and Radical Social Work*, 2(3), pp.371-380.

In the case of personal budgets, the emerging evidence is small but growing. At a national level, the main overviews were provided by internal In Control evaluation and monitoring (Poll *et al.*⁴⁸⁹; Hatton *et al.*⁴⁹⁰; Tyson *et al.*⁴⁹¹) as well as the national evaluation of Department of Health individual budget pilots (Glendinning *et al.*⁴⁹²). While these sources provide an essentially positive overview of the potential of personal budgets, they need to be interpreted with caution. As a result, there is evidence to suggest that personal budgets can use existing resources to achieve better outcomes, greater choice and control, and more community-focused approaches to meeting needs—albeit that there are a range of practical issues to overcome, a series of caveats to such a broad overview and a lack of consensus about some of the longer-term implications.

⁴⁸⁸ Spandler, H., 2004. Friend or foe? Towards a critical assessment of direct payments. *Critical Social Policy*, 24(2), pp.187-209.

⁴⁸⁹ Poll, C., Duffy, S., Hatton, C., Sanderson, H. and Routledge, M., 2006. A report on in Control's first phase, 2003-2005. *Control; London*.

⁴⁹⁰ Hatton C., Waters J., Duffy S., Senker J, Crosby N., Poll C., Tyson A., O'Brien J., Towell D. *A Report on In Control's Second Phase: Evaluation and Learning 2005–2007* 2008 London In Control Publications

⁴⁹¹ Tyson A., Brewis R., Crosby N., Hatton C., Stansfield J., Tomlinson C., Waters J., Wood A., *A Report on In Control's Third Phase: Evaluation and Learning, 2008–2009* 2010 London In Control Publications

⁴⁹² Glendinning C., Arksey H., Jones K., Moran N., Netten A., Rabiee P., *The Individual Budgets Pilot Projects: Impact and Outcomes for Carers* 2009 York Social Policy Research Unit

Over time, the literature has started to reveal a series of underlying concerns about some of the potential implications of direct payments and personal budgets, Glasby and Littlechild believe that they are the product of a government seeking to restrict public spending and expand a flawed notion of consumerism in community care services.⁴⁹³

The summary of other main concerns included: are direct payments and personal budgets adequately financed and do recipients receive enough money to purchase sufficient care? Could direct payments and personal budgets introduce a two-tier system, leaving people who opt for direct services in a disadvantageous position and/or enabling those with the loudest voice/the greatest family support to get better outcomes? Might direct payments and personal budgets lead to the greater exploitation of care workers and women? Could direct payments and personal budgets leave people with disabilities as service users vulnerable to abuse or at risk of significant harm? All these concerns need to be addressed in the Care Act – and if not the complaints and legal challenges would be immense.

⁴⁹³ Glasby J., Littlechild R. Direct Payments and Personal Budgets: Putting Personalisation into Practice 2009 Bristol The Policy Press

3.5 Personalisation: The limitations of the conversation

Although direct payments, personal budgets and self-directed support seem to have attracted strong support and fervent criticism in equal measure. The different approaches to ‘evidence-based practice’, different views about the role of the state as a direct provider of welfare and different attitudes about the best way of improving social care. There are three main issues.

3.5.1 Misunderstanding of the key concepts

At a national level, some of the key terms and issues have rarely been described well, and there remains widespread confusion in front line practice. Anecdotally, some front-line practitioners and their managers do not seem to know the difference between direct payments and personal budgets; do not realise that the individual can decide how to receive a personal budget; are unaware of the spectrum of support options available⁴⁹⁴. While they may have legitimate concerns about aspects of self-directed support. Therefore, some of the more factual issues can be dealt with relatively easily.

494 Foot, C., Gilbert, H., Dunn, P., Jabbal, J., Seale, B., Goodrich, J., Buck, D. and Taylor, J., 2014. People in control of their own health and care. King’s Fund.

On the other hand, one danger may be that current policy rhetoric is so strong that it is difficult for people with legitimate concerns and questions to raise these in an open and safe environment. Speaking to front line practitioners, some feel as if expressing such doubts can sometimes be seen as ‘heresy’ (personal communications), and they are reluctant to say what they are thinking⁴⁹⁵. While this may not have been the intention of policymakers, it could be a significant barrier to change if people feel concerned about a policy or implementation of the Care Act but do not feel comfortable exploring this further and disagree in silence⁴⁹⁶.

3.5.2 Not comparing like with like

The national IBSEN study⁴⁹⁷ ensured that it was comparing individual budgets against conventional services. Given the scale, breadth and rigour of IBSEN, a more complex and nuanced

495 Hamilton, S., Tew, J., Szymczynska, P., Clewett, N., Manthorpe, J., Larsen, J. and Pinfold, V., 2015. Power, choice and control: How do personal budgets affect the experiences of people with mental health problems and their relationships with social workers and other practitioners?. *The British Journal of Social Work*, 46(3), pp.719-736.

496 Folger, J., Poole, M.S. and Stutman, R.K., 2017. *Working through conflict: Strategies for relationships, groups, and organizations*. Routledge.

497 Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. and Wilberforce, M., 2008. *Evaluation of the individual budgets pilot programme. Final Report*. York: Social Policy Research Unit, University of York.

picture were always likely to emerge than was the case in earlier and more pragmatic evaluations by In Control. Considering the complexities involved, moreover, any national evaluation of self-directed support was always likely to find a mix of positives, negatives, enablers and barriers⁴⁹⁸. As a result, there was always likely to be a risk of mixed messages when the final IBSEN evaluation was published⁴⁹⁹, and supporters and critics alike are likely to find much in the final report to debate and to reflect on in more detail.

More generally, Page called for ‘well-paid, well-trained public-sector caseworkers providing reliable, high-quality services’ rather than ‘fragmented private provision’⁵⁰⁰. Ferguson is concerned to address poverty and inequality, to avoid the risk of cost-cutting and to prevent future approaches from primarily benefitting the

498 Some of the pilots being evaluated were set up very quickly, with a potential lack of clarity over the exact nature of the intervention to be tested, and subsequently struggled to overcome a range of practical problems (including very tight timescales, strong political interest and the difficulty of establishing cross-government pilots.

499 Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. and Wilberforce, M., 2008. Evaluation of the individual budgets pilot programme. Final Report. York: Social Policy Research Unit, University of York.

500 Page R. Individual budget bother 2008 letter to The Guardian, 12 November, available online at www.guardian.co.uk

middle classes⁵⁰¹ This must be balanced against a counterclaim that some social care services currently have a poor track record with poverty and inequality, that cost-cutting already happens and that current services are often felt to benefit groups at the expense of others⁵⁰². Indeed, supporters of self-directed support would probably turn these arguments round the other way, suggesting that the new agenda could improve support for disadvantaged groups by giving equal resource to equal need, by focusing support on those who need it most and by tailoring support more fully to personal circumstances⁵⁰³. Equally, they might claim that self-directed support makes cost-cutting more visible and hence easier to challenge⁵⁰⁴. Whichever interpretation is correct, the fact remains that some critics of self-directed support do not seem to be comparing like with like when they comment on the implications of new ways of working.

501 Ferguson, Iain. "Increasing user choice or privatizing risk? The antinomies of personalization." *British journal of social work* 37, no. 3 (2007): 387-403.

502 Lewis, J. and West, A., 2014. Re-shaping social care services for older people in England: policy development and the problem of achieving 'good care'. *Journal of Social Policy*, 43(1), pp.1-18.

503 Henderson, F., Reilly, C., Moyes, D. and Whittam, G., 2017. From charity to social enterprise: the marketization of social care. *International Journal of Entrepreneurial Behavior & Research*.

504 Pearson, C. and Ridley, J., 2017. Is Personalization the Right Plan at the Wrong Time? Re-thinking Cash-for-Care in an Age of Austerity. *Social Policy & Administration*, 51(7), pp.1042-1059.

3.5.3 Attitudes to current services and the role of the state

Linked to this, some commentators seem to be contrasting a new and emerging system (with inevitable teething problems) with an idealised version of how current services work. While this general tendency could be for a range of reasons, it is hard to avoid the conclusion that some commentators may be predisposed to adopt a standpoint on self-directed support based not on the emerging evidence, but their personal and political beliefs about the role of the state and their understanding of the strengths and limitations of the current system. This viewpoint is important when we consider the effectiveness of the Care Act and the disputes that arise from it.

3.6 Conclusion: Personalisation and the ‘evidence’?

Considering the rapid expansion of direct payments, personal budgets and self-directed support (i.e. personalisation), consideration has been given to current debates in context by setting out key concepts and exploring why different commentators might have drawn on the same evidence to produce such different conclusions. With such rapid and fundamental changes, it was always likely that emerging views would quickly become polarised. Ultimately, whether adoption of an optimistic or a more cautious view of the future, it depends in part on the attitude to current services and the role of the state.

While IBSEN and early In Control monitoring are very different in terms of their focus, scale and approach, these studies point towards an underlying issue with regards to the nature of the evidence. Although, it has previously been argued that the current emphasis on ‘evidence-based practice’ has become too dominated by formal research in general and by medical and quantitative research in particular. (Glasby and Beresford⁵⁰⁵; Miller *et al.*, 2016⁵⁰⁶). Instead, Needham and Glasby⁵⁰⁷ have called for a new and more inclusive notion of ‘knowledge-based practice’, combining different types of research, the practice wisdom of front line staff and the lived experience of people who use services⁵⁰⁸. Therefore, a potentially exciting shift away from traditional ‘evidence-based practice’ towards a form of ‘practice-based evidence’.

There is in no way to deny that there are complexities to consider when implementing self-directed support — on the contrary,

⁵⁰⁵ Glasby, J. and Beresford, P., 2006. Commentary and Issues: Who knows best? Evidence-based practice and the service user contribution. *Critical Social Policy*, 26(1), pp.268-284.

⁵⁰⁶ Miller, R., Glasby, J. and White, S., 2016. Muddling through or evidence based? Realities of integration. *Journal of Integrated Care*, 24(2).

⁵⁰⁷ Needham, C. and Glasby, J., 2015. Personalisation—love it or hate it?. *Journal of Integrated Care*, 23(5), pp.268-276.

⁵⁰⁸ Pearson, C., Watson, N. and Manji, K., 2017. Changing the culture of social care in Scotland: Has a shift to personalization brought about transformative change?. *Social Policy & Administration*.

learning from In Control who drew on the lived experience of people receiving direct services who are starting to test out new, more flexible ways of working. While this can often be dismissed as ‘anecdotal evidence’, viewing it as a form of ‘human testimony’ arguably changes the nature of the debate and starts to review the success of the Care Act 2014.

For all the heated debate they have generated, perhaps the positive and negative interpretations of direct payments, personal budgets and self-directed support are not really to do with ‘the evidence’ at all, but with different approaches to understanding the world and changing it. This consideration is required when understanding how the Care Act was drafted and used from 2015.

4 THE CARE ACT 2014: PROS AND CONS

4.1 Introduction to the chapter

The Care Act 2014⁵⁰⁹ represents the latest evolution in current attitudes to care. It was asserted by Norman Lamb MP, Care and Support Minister in the UK coalition government, as ‘the most significant reform of care and support in more than 60 years’.⁵¹⁰ Think Local Act Personal (TLAP), a partnership of more than 50 organisations, which is ‘committed to transforming health and social care through personalisation and community-based support’⁵¹¹. TLAP saw the Care Act 2014 as representing a significant change in legislation, and of importance to people with disabilities as service users and carers in England and Wales. They argue that ‘for the first time it [the Act] puts people with disabilities in control of their care and support. It also makes clear what kind of care they should expect.’⁵¹²

The fact that the Act slipped quietly into law reflects the broad consensus underpinning it, despite criticism of the care funding

509 Act, C., 2014. Care Act 20 and at <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

510 Lamb N. Care Bill becomes Care Act 2014. Department of Health, 2014.

511 www.thinklocalactpersonal.org.uk/About-us/

512 www.thinklocalactpersonal.org.uk/Browse/careact2014/

reforms included in the Act after the Dilnot Report⁵¹³. Although Labour leaders believe the reforms fall well short of a solution to the care crisis, they opted not to force the issue⁵¹⁴. The consensus of support, both in and beyond Westminster, was sustained by ministers' willingness to accept changes to the legislation during almost two years of scrutiny. The Law Commission in February 2010, published a consultation paper setting out several provisional proposals to reform the law governing adult social care in England and Wales. It then undertook a broad public consultation on these interim proposals, which closed on 1 July 2010. It produced the Adult Social Care Consultation Paper and the Adult Care Analysis of Responses; with a government response in July 2012. In May 2013 the Care Bill was introduced into the House of Lords by Earl Howe on 9 May 2013, receiving Royal Assent on 14 May 2014. The Act came into force in April 2015.

The Bill, while working through Parliament, was scrutinised by MPs and Peers who made one hundred and seven

513 See Barrett, C., 2015. The cost of care: charging reform within the Care Act 2014. *Nursing And Residential Care*, 17(5), pp.285-287; Jarman, H. and Greer, S.L., 2015. The Big Bang: Health and Social Care Reform under the Coalition. In *The Conservative-Liberal Coalition* (pp. 50-67). Palgrave Macmillan, London.

514 Hockley, T., 2017. The manifestos on the NHS: sticking plasters for health and social care. *British Politics and Policy* at LSE.

recommendations for amendment,⁵¹⁵ by no means all, were adopted. Recommendation-76 saw the idea of a Community Care Tribunal being established and a review of the complaints and redress system⁵¹⁶. Further changes were agreed as the Bill worked its way through parliament, starting its progress unusually in the House of Lords in recognition of the knowledge and relevant experience of so many members. Paul Burstow, the left-wing Liberal Democrat MP and former care services minister who chaired the joint committee, says: “[The Care Act] contains some revolutionary ideas that, given their head over the next few years, will be very important.⁵¹⁷” Other people⁵¹⁸ were more critical and argued that the Care Act and its rush to assimilate the ideas of personalisation (and self-directed support) legitimated the practice in which the state monitors and coordinates but does not intervene. While many disability organisations seemed to welcome the ideas

515 <https://www.theguardian.com/social-care-network/2014/jun/05/care-act-most-important-amendments>

516

http://www.lawcom.gov.uk/app/uploads/2015/03/lc326_adult_social_care.pdf

517 <https://www.city.ac.uk/news/2016/feb/paul-burstow-to-chair-new-review-of-the-care-act>

518 Duffy, S., Waters, J. and Glasby, J., 2010. Personalisation and adult social care: future options for the reform of public services. *Policy & Politics*, 38(4), pp.493-508 and Slasberg, C., Beresford, P. and Schofield, P., 2012. Can personal budgets really deliver better outcome for all at no cost? Reviewing the evidence, costs and quality. *Disability & Society*, 27(7), pp.1029-1034.

in the new Act⁵¹⁹, this contrasted to many provider organisations who were opposed to the required organisational changes⁵²⁰ and extra costs of implementation such individualised billing rather than block billing⁵²¹.

The next part of the Chapter will look at the reasons why the Care Act was instigated and developed. It will move to the key provisions of the Act and assess their pros and cons.

4.2 Why was the Care Act 2014 passed?

There were several reasons why the Act was developed and then later review how successful the Act was in meeting the objectives.

4.2.1 Single Act of Adult Community Care Legislation

The Act's main aim was to bring together many of the existing provisions in the current law were across a complicated patchwork of statutes, regulations, and statutory guidance. Social Care Law can be said to have begun with the National Assistance Act in

519 Duffy, S., 2011. A fair society and the limits of personalisation. The Centre for Welfare Reform, Sheffield.

520 Krachler, N. and Greer, I., 2015. When does marketisation lead to privatisation? Profit-making in English health services after the 2012 Health and Social Care Act. *Social Science & Medicine*, 124, pp.215-223.

521 Cornes, M., Mathie, H., Whiteford, M., Manthorpe, J. and Clark, M., 2015. The care act, personalisation and the new eligibility regulations: a discussion paper about the future of care and support services for homeless people in England.

1948 which contained provisions for the basis of Disability Support and the modern welfare state⁵²². The Care Act was the largest single piece of community care legislation since the great Beveridge reforms of 1948, sweeping away and re-codifying more than 50 years' worth of law and policy. The list of 'repeals' is extensive including the National Assistance Act 1948, as well as the Acts and regulations that govern such things as direct payments, charging for social care and so on⁵²³. The intention was that the reform would create a single Act that regulated all adult social law – but due to the rushed implementation this was no longer the case – so some of the previous Acts will remain in force in England – for example, the NHS & Community Care Act 1990, section 467 and the Carers (Recognition & Services) Act 1995, section 1.

4.2.2 Provide a Legal Basis for Personalisation

However, as the social welfare system evolved, Direct payments as a method of personalisation were introduced in 1996 by the Community Care (Direct Payments) Act 1996⁵²⁴. More recent

522 Glasby, J., 2017. Understanding health and social care. Policy Press.

523 Hudson, B., 2015. Dealing with market failure: A new dilemma in UK health and social care policy?. *Critical Social Policy*, 35(2), pp.281-292.

524 The Direct Payments scheme was a UK Government initiative in the field of Social Services that gave users money directly to pay for their own

updates, such as the Carers and Disabled Children Act 2000 and the Health and Social Care Act 2001, broadened and refreshed these approaches. There were many debates about whether the prior legislation to the Care Act did provide a legal basis for Self-directed support and personalisation. The local authorities through the ADASS said that A ‘personal budget’ is simply the name given to a sum of money which the person’s needs ought reasonably to be able to be met within⁵²⁵. The ADASS view was that in cases where the client is interested in a Direct Payment, that budget would be the net sum after the user’s contribution has been deducted⁵²⁶. In conventionally-arranged packages⁵²⁷ managed by local authority commissioners, the Personal Budget will also be the net sum, but the authority will pay the full cost of the package

care, rather than the traditional route of a Local Government Authority providing care for them. The Cabinet Office Strategy Unit called direct payments "the most successful public policy in the area of social care". See <http://www.cabinetoffice.gov.uk/upload/assets/www.cabinetoffice.gov.uk/strategy/disability.pdf>

525 ASS, A., 2009. Personalisation and the law: Implementing Putting People First in the current legal framework'. Association of Directors of Adult Social Services, available online at www.adass.org.uk.

526 ASS, A., 2009. Personalisation and the law: Implementing Putting People First in the current legal framework'. Association of Directors of Adult Social Services, available online at www.adass.org.uk.

527 ASS, A., 2009. Personalisation and the law: Implementing Putting People First in the current legal framework'. Association of Directors of Adult Social Services, available online at www.adass.org.uk.

and the disabled person's contribution recouped as happens at present, unless the provider agrees to collect it as the authority's collection agent⁵²⁸. While the disabled users and various carers organisations argued that self-directed support/Personalisation needed to be sited in legislation⁵²⁹ to protect their right to choice and control⁵³⁰. There was support for this stance from the Legal Professionals such as Belinda Schwehr⁵³¹, Sam Karim QC⁵³², and the Legal Action Group.⁵³³

4.2.3 Promote a disabled person's wellbeing

The golden thread running throughout the Act is the promotion of individual well-being: 'The general duty of a local authority, in exercising a function under this clause, is to promote the individual's well-being.'⁵³⁴

528 ASS, A., 2009. Personalisation and the law: Implementing Putting People First in the current legal framework'. Association of Directors of Adult Social Services, available online at www.adass.org.uk.

529 <https://www.kingsfund.org.uk/blog/2015/09/we-need-talk-about-social-care-providers>.

530 <http://www.in-control.org.uk/resources/legal/don't-be-fooled-by-the-law.aspx>

531 Schwehr, B., 2010. Safeguarding and personalisation. The Journal of Adult Protection, 12(2), pp.43-51.

532 <https://www.chambersandpartners.com/UK-Bar/person/409611/sam-karim>

533 <http://www.lag.org.uk/?id=203989&fromsearch=true#iosfirsthighlight>

534 Care Act 2014 section 1(1)

The Care Act sets out some 'key principles' on how health and local authority social services should work with People with disabilities, which can be summarised from the Act as: The person knows best; the person views, wishes, feelings and beliefs should always be considered; the person's well-being should be balanced with that of any involved family and friends; the main aim of the local authority should be on the person's well-being, on reducing the person's need for care and support, and on reducing the likelihood that the person will need care and support in the future; decisions made should take into account all relevant circumstances; any decisions should be made with the persons involvement; the local authority should always work to protect the person and other people from abuse and neglect; and the local authority should ensure that any actions are taken to support, protect you affect your rights and freedom as little as possible⁵³⁵. While a person with disabilities as a service user said that "in the past been a carer to a diverse group of individuals, I feel that had a lot of these changes been made in the past, many people's lives would have transformed sooner rather than later. That being said, we are now moving forward to enable individual lives to be more

535 Summarised from section 1-3 of Care Act 2014.
<https://www.legislation.gov.uk/ukpga/2014/23>

fulfilled.’⁵³⁶ As these examples show, the expectations were evaluated about what was going to be gained from the Act.

4.2.4 Financial Control and Austerity

The above summary of the 'key principles' shows that the outcomes were aimed high to meet the more savvy and consumerised populace⁵³⁷. However, this should be considered against the government requirements of controlling and capping the Social care Budget within local authorities⁵³⁸. It is worth reflecting what the international comparisons are with the Care Act. The King's Fund reviewed international comparisons for health and social care provision and type of funding.⁵³⁹ The report highlights that The Netherlands introduced a ‘universal’ (i.e. available to all) system of insurance for long-term care in 1968. In the 1990s it launched caps in response to rising costs, but this led to long waiting lists, and the caps were abolished⁵⁴⁰. Latterly, they have raised the threshold to access social care and outlined aspects

536 Barnes, D., Boland, B., Linhart, K. and Wilson, K., 2017. Personalisation and social care assessment—the Care Act 2014. *BJPsych Bull*, 41(3), pp.176-180.

537 Dustin, D., 2016. *The McDonaldization of social work*. Routledge.

538 Brimblecombe, N., Pickard, L., King, D. and Knapp, M., 2017. Barriers to receipt of social care services for working carers and the people they care for in times of austerity. *Journal of Social Policy*, pp.1-19.

539 Robertson, R., Gregory, S. and Jabbal, J., 2014. *The social care and health systems of nine countries*. The King's Fund. 2014

540 Ibid

of care that are expected to be delivered by families. Sweden established the right to tax-funded legislation in 1982/1983, whereas countries including Germany, France, Japan and South Korea all have mandatory long-term care insurance schemes⁵⁴¹. However, in July 2014 the Public Accounts Committee referred to the severe problems local authorities faced concerning adult social care funding and noted that the Department of Health accepted that it did ‘not know whether some preventative services and lower-level interventions are making a difference’.⁵⁴² The ADASS Budget Survey 2015⁵⁴³ noted that spending on preventative services fell between 2014 and 2015 by 6% and its 2016 Survey⁵⁴⁴ found that spending on preventative services had fallen by a further 4%. However, new approach to developing services need to be considered and alongside this is consider an alternative dispute resolution to maintain rising expectation caused by the conversations during the development of the Care Act.

541 Ibid

542 House of Commons Committee of Public Accounts Adult social care in England HC 518 (Stationery Office 2014) p.7 at www.publications.parliament.uk/pa/cm201415/cmselect/cmpubacc/518/518.pdf

543 The ADASS Budget Survey 2015
<https://www.adass.org.uk/media/4340/adass-budget-survey-2015-report-final-v2.pdf>

544 The ADASS Budget Survey 2016
<https://www.adass.org.uk/media/5379/adass-budget-survey-report-2016.pdf>

4.2.5 Promote Choice and Control

The Care Act was primarily introduced to enable people to have more control over their own lives ('choice and control') and where support should be less about being reactive to problems and more about prevention of problems (early intervention). The ultimate goal is helping people stay independent and to protect vulnerable adults from mistreatment and improve their quality of life⁵⁴⁵. This principle aim is to emphasise that everyone who receives support from a local authority is a human being with wants and needs. The Act defined how essential it is to involve a person with disabilities in the process of assessing their requirements and safeguarding needs⁵⁴⁶.

4.2.6 Safeguarding Principles

The Care Act 2014 reiterates the six principles of safeguarding, which apply to all sectors and settings of care and support services, with the standards should inform how local authorities work with adults⁵⁴⁷. The six principles may increase the autonomy of people with disabilities as service users through choice and

545 Clements, L., 2014. Caring as a human right? the Pauline Thompson memorial lecture 2014. *Elder Law Journal*, 4(4), pp.375-381.

546 Slasberg, C. and Beresford, P., 2014. Government guidance for the Care Act: undermining ambitions for change?. *Disability & Society*, 29(10), pp.1677-1682.

547 Separately, safeguarding of adults from abuse was dealt with by the Department of Health in No Secrets.⁵⁴⁷

control; and enhance a commitment to delivering the best support by taking a person-centred approach when safeguarding vulnerable people with disabilities⁵⁴⁸. The six principles of the Care Act are Empowerment; Protection; Prevention; Proportionality; Partnership; Accountability⁵⁴⁹. These principles aim to eliminate such a detached approach, and people receive the most appropriate care and feel in control⁵⁵⁰. The empowerment principle⁵⁵¹ encourages support for vulnerable adults so they can confidently make their own decisions and give informed consent regarding their care. The person with disabilities as a service user should decide what outcome they hope to see at the end of processes⁵⁵². To fulfil the principle of protection is the support and representation of those in greatest need. There should be a response immediately to concerns and take action to liberate a

548 Lonbay, S.P., Lonbay, S.P., Brandon, T. and Brandon, T., 2017. Renegotiating power in adult safeguarding: the role of advocacy. *The Journal of Adult Protection*, 19(2), pp.78-91.

549 Statement from the Law Commission on the publication of the government's response to our report on Adult Social Care and draft Care and Support Bill (2012)

550 Phelan, A., Fealy, G. and Downes, C., 2017. Piloting the older adult financial exploitation measure in adult safeguarding services. *Archives of Gerontology and Geriatrics*, 70, pp.148-154.

551 Law Commission, 2011. *Adult social care*. London: The Law Commission.

552 Lawson, J., Lewis, S. and Williams, C., 2014. *Making Safeguarding Personal*.

vulnerable person from a dangerous situation⁵⁵³. The principle of prevention⁵⁵⁴ is about the local authorities being proactive in stopping safeguarding concerns from developing. Therefore, the Care Act is written to pre-emptively protect vulnerable people with disabilities to reduce long-term harm⁵⁵⁵. Proportionality⁵⁵⁶ refers to ensuring that local authorities utilise preventative measures or respond to a safeguarding issue in the most unobtrusive way possible. Take into account the level of the vulnerable person's needs; do not apply a one-size-fits-all response⁵⁵⁷.

The partnership principle⁵⁵⁸ is about bringing together local services and communities to help provide services and inclusion, where local groups should collaborate and share with the person

553 Lawson, J., Lewis, S. and Williams, C., 2014. Making Safeguarding Personal.

554 Law Commission, 2011. Adult social care. London: The Law Commission.

555 Lawson, J., Lewis, S. and Williams, C., 2014. Making Safeguarding Personal.

556 Law Commission, 2011. Adult social care. London: The Law Commission.

557 Donnelly, S., O'Brien, M., Walsh, J., McInerney, J., Campbell, J. and Kodate, N., 2017. Adult Safeguarding Legislation and Policy Rapid Realist Literature Review.

558 Law Commission, 2011. Adult social care. London: The Law Commission.

with disabilities as a service user. Accountability⁵⁵⁹ is about being wholly transparent about, and take responsibility for, all the practices local authorities use to support the people with disabilities. It is intended that the disabled person, as well as their nominated individuals, are updated about any decisions the local authority make or changes in support and care⁵⁶⁰. At any given time, the person with disabilities or designated person should understand the role of everyone involved in the care plan and should be able to contact them if need be.

The next sections consider the main provisions within the Act to meet its aims and objections; then to review the pros and cons to the disabled person.

4.3 The essential Provisions

In the March 2016 guidance and regulations⁵⁶¹, Luke Clements says that the Guidance has the potential to metamorphose into the

559 Law Commission, 2011. Adult social care. London: The Law Commission.

560 Anka, A., Anka, A., Sorensen, P., Sorensen, P., Brandon, M., Brandon, M., Bailey, S. and Bailey, S., 2017. Social work intervention with adults who self-neglect in England: responding to the Care Act 2014. *The Journal of Adult Protection*, 19(2), pp.67-77.

561 The current version of the guidance can be accessed at [www.gov.uk/government/publications/care-act-statutory-guidance/care-](http://www.gov.uk/government/publications/care-act-statutory-guidance/care-act-statutory-guidance)

Code of Practice that the Law Commission and the Select Committee recommended and the English government rejected⁵⁶². The guidance is likely to be of considerable importance – in much the same way that the policy guidance accompanying the Community Care reforms in 1993⁵⁶³ proved to be highly influential in shaping that system. However, the argument is that the law commissioners should have learned from experience from how the previous care legislation evolved and from the inadequacies of the earlier legislation. This meant that there had to be a reliance on evolving statutory guidance, which is history repeating itself. By August 2014, the honeymoon period of consensus between the people with disabilities as service users, the local authorities and central government were over when an LGA survey revealed that 90% of authorities considered that the Care Act reforms were being put in jeopardy by the lack of adequate government funding.⁵⁶⁴

and-support-statutory-guidance and this includes and Update on final Orders under the Care Act 2014

562 Brooks, J., Mitchell, W., & Glendinning, C. (2017). Personalisation, personal budgets and family carers. Whose assessment? Whose budget?. *Journal of Social Work*, 17(2), 147-166.

563 Department of Health (1990) *Community Care in the Next Decade and Beyond: policy guidance*.

564 See Andy McNicoll Lack of funding could threaten Care Act reforms, councils warn in *Community Care* 7 August 2014 at www.communitycare.co.uk/2014/08/07/lack-adequate-funding-threaten-care-act-reforms-councils-warn/ accessed 11th August 2014.

The Care and Support Regulations⁵⁶⁵ that accompany the Act detail specific obligations relating to market oversight / business failure (three sets of regulations); the assessment of need; eligibility criteria; advocacy; charging; choice of accommodation; deferred payments; personal budgets; direct payments; the NHS interface; delayed hospital discharge; ordinary residence (2 sets of regulations); portability of care packages and cross-border placements; and registers for people with visual impairments. The longest set of regulations concern is charging, and there are none concerning some key questions – notably choice and control, safeguarding and personalisation⁵⁶⁶.

However, there are many enhancements to the legislation which provide choice to the disabled and positive. This enthusiasm needs to be balanced with the concerns and some recent directions and recommendations from the courts and ombudsman.

565 <https://www.legislation.gov.uk/ukdsi/2014/978011124185>

566 Stevens, M., Glendinning, C., Jacobs, S., Moran, N., Challis, D., Manthorpe, J., Fernández, J.L., Jones, K., Knapp, M., Netten, A. and Wilberforce, M., 2011. Assessing the role of increasing choice in English social care services. *Journal of Social Policy*, 40(2), pp.257-274.

4.3.1 Statutory Guidance

The starting point is the Statutory Guidance and Regulations 2016⁵⁶⁷. Clements believes that it has the potential to metamorphose into the Code of Practice that the Law Commission and the Select Committee recommended and the English government rejected⁵⁶⁸. The guidance was of importance – in much the same way that the policy guidance accompanying the Community Care reforms in 1993⁵⁶⁹ proved to be highly influential in shaping that system. However, it can be argued that the law commissioners should have learned from experience from how the previous care legislation evolved and how through inadequacies of the earlier legislation. Therefore, there was a reliance on evolving statutory guidance, which is history repeating itself.

The Care and Support Regulations⁵⁷⁰ that accompany the Act detail specific obligations relating to market oversight / business

567 The current version of the guidance can be accessed at www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance and this includes and Update on final Orders under the Care Act 2014

568 Brooks, J., Mitchell, W., & Glendinning, C. (2017). Personalisation, personal budgets and family carers. Whose assessment? Whose budget?. *Journal of Social Work*, 17(2), 147-166.

569 Department of Health (1990) *Community Care in the Next Decade and Beyond: policy guidance*.

570 <https://www.legislation.gov.uk/ukdsi/2014/9780111124185>

failure (three sets of regulations); the assessment of need; eligibility criteria; advocacy; charging; choice of accommodation; deferred payments; personal budgets; direct payments; the NHS interface; delayed hospital discharge; ordinary residence (2 sets of regulations); portability of care packages and cross-border placements; and registers for people with visual impairments. The weakness is that its longest set of regulations concern charging, and there are none concerning some key questions – notably choice and control, safeguarding and Personalisation⁵⁷¹. An additional weakness is that there is a casual approach to statutory formalities such as no official hard copy is printed with a seriously troubling intention that it will be subject to *ad hoc* changes⁵⁷², (not to say the ‘Rule of Law’) should be reconsidered. It certainly adds weight to the positive recommendations of the Law Commission and the Select Committee’ that the Act is the

571 Stevens, M., Glendinning, C., Jacobs, S., Moran, N., Challis, D., Manthorpe, J., Fernández, J.L., Jones, K., Knapp, M., Netten, A. and Wilberforce, M., 2011. Assessing the role of increasing choice in English social care services. *Journal of Social Policy*, 40(2), pp.257-274.

572 Penhale, B., Brammer, A., Morgan, P., Kingston, P. and Preston-Shoot, M., 2017. The Care Act 2014: a new legal framework for safeguarding adults in civil society. *The Journal of Adult Protection*, 19(4), pp.169-174.

subject of a Parliamentary Code of Practice (rather than departmental guidance)⁵⁷³.

4.3.2 Definitions and Terminology

Definitions and Terminology are little direct use to people with disabilities who are not generally familiar with legal terminology but are important regarding the interpretation of the law. Consideration needs to be given to the terms in the Act of ‘adult needing care’, carer and individual, as these will define who is protected in the legislation.

The Act positively does not talk of disabled, elderly or ill people: instead, it uses the word ‘adult’ – but this is generally qualified as being an adult ‘needing care’. The Eligibility Regulations 2015, however, stipulate that this is an adult who has ‘a physical or mental impairment or illness’⁵⁷⁴. These terms are not defined, although the revised Statutory Guidance advises (para 6.102) that they include ‘physical, mental, sensory, learning or cognitive disabilities or illnesses, substance misuse or brain injury’⁵⁷⁵. It is

573 Joint Committee on the Draft Care and Support Bill, ‘Draft Care and Support Bill’ Stationery Office (2013) HL Paper 143 HC 822 para 61 - 66.

574 The Care and Support (Eligibility Criteria) Regulations 2015 SI 313 reg 2.

575 The current version of the guidance can be accessed at www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance

therefore almost certain that ‘adults needing care’ will be given a very wide interpretation (as with the equivalent terms under the previous legislation⁵⁷⁶). Accordingly, it covers not only those whose illness is caused by the misuse of drugs or alcohol⁵⁷⁷ but also those with ‘any disorder or disability of the mind’.⁵⁷⁸ This latter category constructively would comprise such conditions as depression, dementia, learning disability, personality disorder as well as hyperactive / attention deficit disorders, ‘high functioning’ autism and Asperger’s syndrome. In this context, the revised Statutory Guidance advises (para 6.102) that authorities ‘should base their judgment on the assessment of the adult and a formal diagnosis of the condition should not be required’.

Another clear example of the definition of ‘adults needing care’ is ambiguous and inadequate as it will be given a wide interpretation upon a person with disabilities seeking care. An example is that an autistic person, will not be able to give a true picture of how their

576 Section 29 National Assistance Act 1948 defined disabled people as people who were ‘blind, deaf or dumb or who suffer from mental disorder of any description, and ... who are substantially and permanently handicapped by illness, injury, or congenital deformity’ and section 17(11) Children Act 1989 contains a similar definition.

577 See Schedule 20 NHS Act 2006 and the relevant Directions specific to drug and alcohol misusers, continued in Department of Health Circular LAC (93) 10 para 3(3)(g).

578 ie, within the ambit of section 1 Mental Health Act 1983.

disabilities affect them and fall through the net. Within Australia there is the use of functional capacity criteria undertaken before any assessment to inform on capabilities. However, on the positive side more disabled persons will qualify for support under this definition for an assessment; this will include drug misuse and lower level dementia. Thus, creating an additional problem of who provide funding – NHS or Social Services⁵⁷⁹. The Act does try to address joint-working between NHS and local authorities, but not joint funding. Personalised Health Budgets⁵⁸⁰ are being developed and may offer a solution to the perennial issues of ‘who funds what and when?’⁵⁸¹

The Act defines a carer as someone 18 or over⁵⁸² who provides or intends to provide care for someone but is not contracted to provide the care or to provide the care as formal ‘voluntary work’. This a positive undertaking is recognising the role of carers; however an analysis of the most recent government figures by *The Independent* shows that in May 2017 41,870 16-to-24-year-olds

579 *Montgomery v. Lanarkshire Health Board*, 2015 U.K.S.C. 11 (2015).

580 Raleigh, V.S., Cream, J. and Murray, R., 2018. Are the NHS national outcomes frameworks past their sell-by date?. *BMJ Qual Saf*, 27(2), pp.166-170.

581 Docherty, M. and Thornicroft, G., 2015. Specialist mental health services in England in 2014: overview of funding, access and levels of care. *International journal of mental health systems*, 9(1), p.34.

582 The Act has provisions for ‘young carers’ (ss63-64) – ie people who are under 18 – but these provisions use the term “‘young carers””.

qualified to receive the carer's allowance, compared with 31,080 in 2013 – an increase of 35 per cent in four years⁵⁸³. Laura Bennett, head of policy at Carer's Trust raised concerns that the Care Act 2014⁵⁸⁴, which placed a duty on local authorities to consider the needs of children and young people living in households where there is an adult who has a disability or impairment, was not being properly implemented because of a lack of financial resources available⁵⁸⁵. Therefore, there is a weakness in not accepting that a Carer can be under 18 years old; compared with Australia, where the threshold is eight years old.

Clarification is required when the Act uses the term 'individual' - it generally means either an adult 'in need' or a carer (see above)– although – just to cause confusion – on other occasions that the use of the word 'adult' also includes a carer (e.g. in relation to direct payments, s31 – see below). Again, there is no reference to a carer under the age of 18. The definitions have many positive but

583 The Sunday Independent - 28 January 2018: Number of young carers in UK soars by 10,000 in four years, figures show

<http://www.independent.co.uk/news/uk/home-news/young-carers-uk-numbers-rise-figures-support-family-social-care-benefits-community-a8177806.html>

584 Mitchell, W. and Glendinning, C., 2017. Allocating Personal Budgets/Grants to Carers. *Journal of Social Work*, 17(6), pp.695-714.

585 Aldridge, J., 2018. Where are we now? Twenty-five years of research, policy and practice on young carers. *Critical Social Policy*, 38(1), pp.155-165.

miss the opportunity to clarify some basis assumption which could help in legal challenges concerning funding and young carers.

4.3.3 Underpinning ‘principles’ (section 1)

The Act does not admit to being governed by any ‘principles’ although the revised Statutory Guidance (para 1.2) when referring to the obligation in section 1 to promote ‘individual well-being’ states that this ‘may sometimes be referred to as “the wellbeing principle” because it is a guiding principle that puts well-being at the heart of care and support’⁵⁸⁶.

The wellbeing obligation applies to every act of a local authority that relates to an adult in need or carer (when exercising ‘any function’ under Part 1 of the Act, i.e. sections 1-80) – from a telephone conversation to the setting by the authority of its social care budget. It will be maladministration⁵⁸⁷ for a local authority to impose ‘restrictive interpretations of Care Act outcomes’ that fail to take proper account of an adult’s well-being. The Act does not define ‘well-being’ merely stating in section 1(2) that it relates to a list of nine factors, that can be summarised in the following list:

586 The current version of the guidance can be accessed at www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance

587 Complaint 15 011 661 against London Borough of Hammersmith & Fulham 21 July 2016 para 25.

(a) personal dignity; (b) physical / mental health / emotional well-being; (c) protection from abuse and neglect; (d) control over day-to-day life inc nature of care provided; (e) participation in work, education, training or recreation; (f) social and economic well-being; (g) domestic, family and personal relationships; (h) suitability of living accommodation; (i) the adult's contribution to society.

In *R (JF) v Merton LBC*⁵⁸⁸ the High Court held that there was a statutory duty to have regard to the matters listed in section 1(2) in addition to those in section 1(3) (see below) for which an explicit duty 'have regard' exists. The emphasis on the importance of 'control' has been a cause for concern by some commentators⁵⁸⁹: noted that choice rather than control that is the key principle',⁵⁹⁰ even though choice' does not appear as a well-being principle.

588 *R (JF) v Merton LBC* [2017] EWHC 1519 (Admin) affirming (on this point) *R (Davey) Oxfordshire CC* [2017] EWHC 354 (Admin) para 136.

589 Such as Beresford in Beresford, P., 2016. *All our welfare: Towards participatory social policy*. Policy Press; Duffy in Duffy, S., 2017. *The value of citizenship. Research and Practice in Intellectual and Developmental Disabilities*, 4(1), pp.26-34; and Patrick in Patrick, R., 2017. *For whose benefit?: The everyday realities of welfare reform*. Policy Press.

590 Law Commission Adult Social Care Law Com No 326, Stationery Office HC 941 para 4.25

Choice and Control work hand in hand – person with disabilities, chooses her care provision and then has control of that care such as choosing a support worker or what domestic tasks may be required. Although wellbeing is articulated as relating to such a wide range of considerations, there is a risk that it may prove to be of little practical application. There are however a few ‘principles’ that are likely to be much asserted.

The first is section 1(3)(a) ‘assumption that the ‘individual’ is best placed to judge well-being’. This creates a default position which a local authority will have to produce evidence if it wishes to rebut. The revised Statutory Guidance indicates that this ‘principle’ should be given an expansive interpretation – for example at para 6.35⁵⁹¹, that inherent with this principle is the wider assumption that people with disabilities must also be ‘best placed to understand the impact of their condition(s) on their outcomes and wellbeing’. Positively, the person with disabilities has the right to judge their wellbeing if they have the capacity, but it does not cover people who may have a fluctuating capacity from day-to-day may be able to decisions concerning their care but may not have the capacity to control or self-manage their budgets on what they want to spend. If a person with

591 <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance> para 6.35

disabilities has no capacity, then the planning of care will fall on the local authority rather than families – conflict will arise⁵⁹².

A. The second is section 1(2)(e) identification of the importance of ‘participation in work, education, training or recreation’ which is of special relevance for carers; and

B. The third concerns the right to ‘independent living’ (which although absent from the Act⁵⁹³) is expressed with force in the revised Statutory Guidance, stating at para 1.19: The well-being principle is intended to cover the key components of independent living⁵⁹⁴, as expressed in the UN Convention on the Rights of Disabled People (in particular, Article 19 of the Convention). Supporting people with disabilities to live as independently as possible, for as long as possible, is a guiding principle of the Care Act.

592 As example of a person wanting to leave a care home without capacity. *R v. Islington London Borough Council ex parte Rixon*, 1998 C.C.L.R. 119 (1998).

593 See T Collingbourne ‘The Care Act 2014: a missed opportunity?’ in *Web JCLI* (2014) 20(3) at <http://webjcli.org/article/view/365/464>

594 This affirmation is repeated at para 23.28 where it is asserted that: The concept of ‘independent living’ is a core part of the wellbeing principle, and is detailed in the requirement to consider the person’s control over their day-to-day life, the suitability of their living accommodation and their contribution to society.

Such express statements are of positive and of considerable value – not least because the courts and Ombudsmen have shown a surprising willingness to have regard to the Convention⁵⁹⁵ including the 2015 Supreme Court judgment in *Mathieson v Sec State Work & Pensions*.⁵⁹⁶ The appeal succeeded because the Regulations infringed the claimant’s rights because the evidence was that the expenses of caring for a very sick child increased when he was admitted to hospital. This had been particularly so for Cameron, as his parents were now expected or indeed required to be with him. The Regulations were based upon the contrary assumption⁵⁹⁷.

It is noted also that Well-being is defined as including being protected from ‘abuse and neglect’ (s1(2)(c))⁵⁹⁸ and the revised Statutory Guidance gives emphasis to this stating that ‘it is not possible to promote wellbeing without establishing a basic foundation where people are safe, and their care and support is on

595 See for example *Burnip v. Birmingham City Council* [2012] EWCA Civ 629 and *R (Bracking and others) v. Secretary of State for Work and Pensions* [2013] EWCA Civ 1345.

596 *Mathieson v Sec State Work & Pensions* [2015] UKSC 47.

597 <http://swarb.co.uk/mathieson-v-secretary-of-state-for-work-and-pensions-sc-8-jul-2015/>

598 Whittington, C., 2016. Another Step towards the Promised Liberation of Adult Social Work under England’s 2014 Care Act? The Implications of Revised Statutory Guidance and the Politics of Liberation. *The British Journal of Social Work*, p.bcw155.

a secure footing’ (para 1.26). The problem, as is noted below, is that the eligibility criteria do not list “keeping safe’ as an outcome and so on one interpretation it is argued that being protected from ‘abuse and neglect’ will not in itself be an eligible need — clarification through the courts for an interpretation is necessary.

4.3.4 Information (section 4)

Section 4 obliges local authorities to have an enhanced duty to provide adults in need / carers with information about care and support arrangements, including:- how the care system operates; the care and support choices they have (including the choice of providers); how to access this support and how to raise safeguarding concerns. The information duty contained a significant ‘independent financial advice’ component – which would have advised ‘self-funders’ on the (now delayed) choices they had under the ‘cap on care cost’ reforms.⁵⁹⁹ The negative side of this is, and ADASS has expressed concern that the increased emphasis on the provision of independent financial advice may result in more people getting advice on how to avoid making contributions to care fees⁶⁰⁰.

599 Department of Health Care and Support Legal Reform (Part 1 of the Care Act) Impact Assessment 61067 October 2013 para 1.25.

600 LGA and ADASS Joint consultation response Care Act: regulations and guidance (August 2014) at para 31. It is also concerned that these reforms are taking place at a time when significant changes are being implemented to pensions (specifically the end of the requirement to purchase an annuity), and the choices that people make may also be directed at reducing their contributions to their care fees.

The revised Statutory Guidance explains that authorities ‘must establish and maintain a service for providing people with disabilities with information and advice relating to care and support’ (para 3.11)⁶⁰¹; that this must be provided for a variety of different formats; that the ‘duty in the Care Act will not be met through the use of digital channels alone’ and that the mix of provision will be expected to include ‘face-to-face contact’ (para 3.29⁶⁰²).

Increasingly information is only available on the internet and the effect of the so-called ‘digital divide’ is that significant sections of the population are thereby excluded – many of whom are disproportionately in need of care and support (e.g. older people, poor people, people with significant intellectual impairments). This negative needs to be reviewed and seems to be handed to the local authorities to decide how they meet this need. As an example, is Buckinghamshire County Council who have invested in a version of shop4support⁶⁰³ which uses eCommerce and catalogue information. However, this will only ever be utilised by

601 <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance> para 3.11

602 <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance> para 3.29

603

<https://www.careadvicebuckinghamshire.org/s4s/CustomPage/Index/46>

a minority of people with disabilities who are service users⁶⁰⁴. As an example, people with disabilities who are visually impaired may be researching on local authority websites and care catalogues, if it is in the correct format. The issue here is how can a person with disabilities have choice and control if they do not have information in the first place to make a choice.

4.3.5 Duty to promote high-quality provision (section 5)

Section 5 requires local authorities to promote a market in services; the Act (fleshed out by regulations⁶⁰⁵) contains a range of provisions designed to address the ‘supply-side’ problems of the social care market – ie (a) the problem of large providers collapsing (such as Southern Cross failure in 2011⁶⁰⁶); and (b) the increasing belief that the choice and quality of services is generally poor and deteriorating.

604 Power, A., Lord, J.E. and DeFranco, A.S., 2013. Active citizenship and disability: Implementing the personalisation of support. Cambridge University Press.

605 These include the Care and Support (Market Oversight Information) Regulations 2014 SI 2822; and The Care and Support (Market Oversight Criteria) Regulations 2015 SI 314 (as well as business failure regulations specific to cross-border placements).

606 The rise and fall of Southern Cross - The Guardian 01/06/2011 at: <https://www.theguardian.com/business/2011/jun/01/rise-and-fall-of-southern-cross>

Section 5 places a duty on local authorities to promote an efficient/effective local market ‘with a view to ensuring’ that there is a variety of providers and high-quality services to choose from. A key problem concerning the choice, diversity/quality is that councils hold a dominant position in this market and have (due to their chronic underfunding) been requiring providers to deliver the same quantity of services each year while concurrently imposing cuts to the amount paid. The National Audit Office considers that this relentless pressure by local authorities on fee rates is jeopardising the financial sustainability of some providers⁶⁰⁷ and the ADASS accept that local authorities do not always consider the profit margins of their suppliers, or the impact that reducing fees will have on their viability.⁶⁰⁸ The Select Committee⁶⁰⁹ considered that there had to be a mechanism that required local authorities to ‘properly take into account the actual cost of care when setting the rates they are prepared to pay providers’. Such a

607 Report by the Comptroller and Auditor General Adult social care in England: overview HC 1102 Session 2013- 14 (National Audit Office 2014) para 2.11-13.

608 House of Commons Committee of Public Accounts Adult social care in England HC 518 (Stationery Office 2014) p.13 at www.publications.parliament.uk/pa/cm201415/cmselect/cmpublicacc/518/518.pdf

609 Joint Committee on the Draft Care and Support Bill, ‘Draft Care and Support Bill’ Stationery Office (2013) HL Paper 143 HC 822 para 113.

mechanism is not to be found in the Act – but the revised Statutory Guidance is surprisingly direct and likely to be frequently cited in cases challenging arbitrary local authority rates. It reminds local authorities that the way they commission services is ‘a prime way to achieve effective market shaping’ (para 4.4) as these have a ‘significant influence on the market’ (para 4.7). The positive effect of the guidance will, inevitably, make the provider market fee levels ‘more transparent’ and this, together with the obligation to mitigate provider failure and have an overview of the market will – in the opinion of ADASS - ‘exacerbate providers’ concerns about the fee levels local authorities are willing’⁶¹⁰ and may, in consequence, lead to further litigation in this field.⁶¹¹ A recent example is Torbay Quality Care Forum Limited (an association representing independent care homes in Torbay), successfully challenged the decision of Torbay Council setting the fees it was prepared to pay for providing care to care home.⁶¹²

610 LGA and ADASS Joint consultation response Care Act: regulations and guidance (August 2014) at para 31.

611 For example, R (Sefton Care Association) v Sefton Council [2011] EWHC 2676 (Admin).

612 Torbay Council v Torbay Quality Care Forum Limited [2017] EWCA Civ 1605

The problem, of course, is not merely that of driving down standards as cost reductions are required, but of driving out smaller providers as only the larger corporations can compete on cost, thus reducing choice and control for the disabled person. The revised Statutory Guidance addresses this concern positively requiring that local authority commissioning procedures ‘must encourage a variety of different providers and different types of services’ (para 4.37), including ‘voluntary and community based organisations, including user-led organisations, mutual and small businesses’ (para 4.38) and should support people with disabilities who ‘micro-commission’ their own care (para 4.47). While the guidance envisages that local authorities may have ‘approved lists and frameworks that are used to limit the number of providers they work with’ it requires that they ‘must consider how to ensure that there is still a reasonable choice for people who need care and support’ (para 4.39).

The revised Statutory Guidance encourages ‘outcomes-based’ commissioning – i.e. that instead of a local authority simply commissioning ‘units of provision to meet a specified need (e.g. hours of care provided)’ in monetary terms. It moves towards specified outcomes for the individual which ‘emphasise prevention, enablement, ways of reducing loneliness and social isolation and promotion of independence as ways of achieving and exceeding desired outcomes, as well as choice in how people’s needs are met’ (para 4.16). Outcome-based commissioning may

not just focus on funded supports, but outcomes can be achieved by looking at informal support to achieve outcomes by paying for a gym membership for a friend to support the disabled person⁶¹³, while keeping the local authority budget sustainable. A new way of looking outside the box. However, the downside is that there is evidence that some local authorities are becoming more prescriptive of how the money can be spent.^{614 615}

One important element of this duty is for local authorities to publish details of what it wants from the market, sometimes referred to as ‘market position statements’ (MPS). Research⁶¹⁶ that analysed the fifteen learning disability MPS that existed in August 2016 suggested that these were materially defective and that authorities were not fulfilling their market shaping duties – noting that ‘Nowhere can this be seen more clearly than ... the persistent

613 Groene, O., 2017. From clinical commissioning to contracting for outcomes: prerequisites and facilitators to embed Accountable Care Organizations within the National Health Service in England. *International Journal of Integrated Care*, 17(5).

614 Smith, R., Darton, R., Cameron, A., Johnson, E.K., Lloyd, L., Evans, S., Atkinson, T.J. and Porteus, J., 2017. Outcomes-based commissioning for social care in extra care housing: is there a future?. *Housing, Care and Support*, 20(2), pp.60-70.

615 2017 POET Report for Adults in Receipt of Social Care Support In Control

616 S Broadhurst and K Landau, ‘Learning disability market position statements, are they fit for purpose?’ in *Tizard Learning Disability Review* (2017).

lack of appropriate options within the community to support them effectively'.⁶¹⁷ Quite simply – no mature market – no real choice and control.

4.3.6 Services/care and support responses (section 8)

Section 8 sets out an illustrative list of the types of services that could meet eligible assessed needs. The community care statutes⁶¹⁸ provided exhaustive lists of services that could be provided for people with disabilities, and the Carers and Disabled Children Act 2000⁶¹⁹ provided a generalised statement as to what a carer's 'service' might be. The Care Act repealed these statutes⁶²⁰ and avoided referring to the word 'service' when describing what may be provided to meet a person's needs. Instead, section 8(1) contains an illustrative list of what may be 'provided' to an adult in need or carer – namely: accommodation in a care home or in premises of some other type; care and support at home or in the

617 Citing Bubb, S. Time to Change – The Challenge Ahead (ACEVO 2016).

618 Primarily s2 Chronically Sick and Disabled Persons Act 1970 and ss 21 & 29 National Assistance Act 1948.

619 Clements, L. and Thompson, P., 2007. Community care and the law. London: Legal Action Group.

620 This was in keeping with its 'outcomes' rhetoric with the Car Act 2014.

community; counselling, advocacy and other types of social work; goods and facilities; information and advice⁶²¹.

However, the absence of such things as ‘adaptations’ ‘travel’; and ‘holidays’ was considered problematical by the Select Committee, and in response to a question, it asked the Department of Health, received confirmation that the Department considered that these services did fall within the ambit of the list.⁶²² Unfortunately, the revised Statutory Guidance does not make this sufficiently clear that this is not intended to limit how a local authority might meet any eligible needs or agreed outcomes.

Support such as home adaptations, equipment and transport is often vital to enable people with disabilities to live independently in the community ⁶²³ . The facilitation/provision of suitable adaptations/equipment requires explicit guidance, given that the overlap of responsibilities between Housing Trusts and local authorities remains (with such support being capable of being

621 Carers and Disabled Children Act 2000 at www.legislation.gov.uk/ukpga/2000/16/pdfs/ukpga_20000016_en.pdf

622 Joint Committee on the Draft Care and Support Bill, ‘Draft Care and Support Bill’ Stationery Office (2013) HL Paper 143 HC 822 para 168 - 170.

623 Fennell, L.A. and Keys, B.J., 2017. Introduction to Evidence and Innovation in Housing Law and Policy.

delivered under both the Housing Grants, Construction and Regeneration Act 1996 and the Care Act 2014). It is argued that there is a statutory duty on the Housing Trust under DDA 1995⁶²⁴ and DDA 2005⁶²⁵ with regards to reasonable adjustments. However, this subject has attracted a disproportionately high number of complaints to the Local Government Ombudsman⁶²⁶ – particularly the failure of local authorities to be aware of their responsibilities (which now rests in section 8). The guidance fails to reiterate and build on the current guidance on this question.⁶²⁷ This dispute resolution sphere needs to be improved, and especially regarding complaints and multi-agency working⁶²⁸.

624 Disability Rights Commission, 2004. Disability Discrimination Act 1995 (as Amended by the Special Needs and Disability Act 2001): Consultation on a New Code of Practice (schools). Disability Rights Commission.

625 Britain, G., 2005. Disability Discrimination Act 2005: Chapter 13: Explanatory Notes. Stationery Office,.

⁶²⁶ The Local Government Ombudsman was most likely to find fault in Adult Social Care cases (64% upheld), and least likely to find fault in complaints about Planning and Development (35% upheld); and the West Midlands area had the highest uphold rate for Adult Care Services at 73%, higher than the average of 64%.

627 Guidance that will of course cease to apply when the Care Act 2014 comes into force.

628 The importance of adaptations are central to eligibility determinations. Regulation 2(2) of the Eligibility Regulations, however, list as key outcomes (among others) ‘(e) being able to make use of the adult’s home safely’; and ‘(f) maintaining a habitable home environment’. The revised Statutory Guidance at para 6.107 gives examples of what these might mean – including consideration (in relation to (e)) of: the adult’s ability to move around the home safely, which could, for example, include getting up steps,

There is no clear authority in the provision of transport such as going out into the community, going to work or to a further education placement. The revised Statutory Guidance is also disappointing in relation to the responsibility to ensure: (1) adequate transport for individuals in need; and (2) the responsibilities of local authorities for the social care support needs of people with disabilities in education (formerly (for adults) the subject of specific duties under Chronically Sick and Disabled Persons Act 1970, s2). Many such ‘adults in need’ will not be eligible for a Plan under the Children and Families Act 2014 and it is troubling that the guidance fails to make it clear that these responsibilities remain and are implicit within the list in the Care Act 2014, section 8⁶²⁹.

Finally, local authorities can charge (under section 14) for the costs that they incur in providing care and support (under section

using kitchen facilities or accessing the bathroom. This should also include the immediate environment around the home such as access to the property, for example, steps leading up to the home accommodation, if owned by the Housing Trust will have a budget for adaptations. The dispute arises around what is reasonable – the handrail or a ramp is a common dispute.

629 Section 8(2) slips out of the ‘outcomes’ mode and gives examples of the ways need may be met which include the ‘service’ word – namely: by arranging for a person other than it to provide a service; by itself providing a service; by making direct payments. And need to have capacity to self-manage.

8) to meet the ‘needs’ of people with disabilities. The question arises therefore as to whether local authorities will start charging for support such as advocacy, social work⁶³⁰ and information. The question is all the more pressing since local authorities are now able to delegate assessments (and most of their other functions) to independent sector organisations⁶³¹ and large corporations such as Serco in Hertfordshire. In answer to a specific question on this point, the Minister (Norman Lamb) positively stated that these provisions do ‘not give power to local authorities to charge for carrying out a needs assessment in any circumstances’⁶³². It is positive that the Minister has stated this on record, but the fear is that the legislation is there for the future implementation.

630 If charging was developed, indeed how ‘social work’ is to be defined. The questions raised is whether Adult Social Workers only now do assessments rather provide therapeutic services?

631 section 79 – of the Care Act 2014. Local authorities are able to delegate all of their functions under the Act –with few exceptions (eg safeguarding (sections 42 – 47) and charging (section 14)). Section 79(6) makes it clear that ultimate responsibility in such cases will still rest with the local authority (any acts /omissions by the delegated body will be treated as done / omitted to be done by the local authority).

632 14 January 2014 column 154 Public Bill Committee.

4.3.7 Assessment of adults in need⁶³³ (section 9)

For the first time in statutory law, Section 9(3) provides that the duty to assess applies regardless of the authority's view of (a) the level of the adult's needs for care and support, or (b) the level of the adult's financial resources. Hearteningly, this effectively puts on a statutory footing the current position according to the common law and statutory guidance. The combination of these points, and their codification into statute, means that there will continue to be a very low threshold for assessments. However, we are seeing the case where a local authority must consider a service user's preference for how their care is provided when setting their personal budget⁶³⁴. Oxfordshire had reduced Mr Davey's budget from £1,651 to £950 on the basis that he could spend more time without carers and their wages could be reduced⁶³⁵. The first concern was the finding of Mr Justice Morris that when assessing the likely impact of cuts to Mr Davey's care package on his wellbeing, that Oxfordshire County Council was not compelled to

633 A number of guides have been published concerning the practicalities of assessing under the new legal regime - see for example, Think Local Act Personal Delivering Care & Support Planning - supporting implementation of the Care Act 2014.

⁶³⁴ *R (on the application of Luke Davey) v Oxfordshire County Council & anor* [2017] EWHC 354

⁶³⁵ *R (on the application of Luke Davey) v Oxfordshire County Council & anor* [2017] EWHC 354

make “judgements about the future”. There were additional challenges from the Equality and Human Right Commission because the person with disabilities was not at ‘the centre of all decisions’.⁶³⁶

Reassuringly, the Act, the Regulations and the Guidance create important and welcome obligations on local authorities concerning the advocacy needs of disabled persons that are identified during the assessment and care planning processes. As with the previous duty (under s47 NHS and Community Care Act 1990) the Care Act duty to assess adults in need is triggered by the ‘appearance of need’ and arises regardless of the ‘level’ of those needs or the person’s financial resources. The Care Act duty to assess adults in need is triggered by the ‘appearance of need’ and arises regardless of the ‘level’ of those needs or the person’s financial resources. The assessment must have specific regard to the well-being criteria (i.e. sections 1(2) and 1(3) above). Detailed Assessment Regulations⁶³⁷ have been issued concerning the process that must

⁶³⁶ The Equality and Human Rights Commission also intervened in the appeal, presenting arguments relating to the proper framing of the Care Act which the organisation said represented a re-focusing of the statutory framework for the provision of adult social care, in accordance with the UNCPRD and in particular Article 19, which puts the disabled person at the centre of all decisions.

⁶³⁷ The Care and Support (Assessment) Regulations 2014 2014 SI No. 2827.

be followed during an assessment, and in *R (JF) v Merton LBC*⁶³⁸ the High Court summarised the requirements, stating that an assessment will be unlawful if it (para 47):

- fails to assess the impact [of the adult's] needs for care and support upon the factors of wellbeing listed in section 1(2) of the Act;
- fails to assess the outcomes that [the adult] wishes to achieve in day-to-day life, and whether, and if so to what extent, the provision of care and support could contribute to the achievement of those outcomes;
- fails to have regard to the matters specified in Care and Support (Assessment) Regulations⁶³⁹, regulation 3(2) [their wishes and preferences; the outcomes they seek; the severity and overall extent of their needs]; The court held that in relation to people such as JF, inevitably this meant that the local authority must have regard to the views expressed by his parents; is neither appropriate nor proportionate.

638 *R (JF) v Merton LBC* [2017] EWHC 1519 (Admin) affirming (on this point) *R (Davey) Oxfordshire CC* [2017] EWHC 354 (Admin) para 136

639 The Care and Support (Assessment) Regulations 2014 2014 SI No. 2827.

The assessment must have specific regard to the well-being criteria (i.e. section 1(2) above) and must involve the adult and any carer. In this context 2015 ‘whole family’ guidance⁶⁴⁰ states that whatever assessment process is adopted: the assessment must include any carer, and there must be an assessment of their needs for support. The section 9(5) duty to ‘involve’ ‘any carer that the adult has’ requires some local authorities to rethink their approach – is based on the paradigm of there being ‘primary carers’.

There appears to be a welcome acceptance that the practical reality of ‘supported self-assessments’ does not always live up to their marketing fervour⁶⁴¹. Rhetorically they have promoted the notion of people with disabilities identifying their own needs and mapping out their support – with a social worker giving gentle guidance and the benefit of her or his wisdom⁶⁴². In practice, they have often been little more than Self-Assessment Questionnaires (SAQ) being posted to individuals, which (once returned) have

640 Department of Health (and others) The Care Act and Whole-Family Approaches (2015) at www.local.gov.uk/documents/10180/5756320/The+Care+Act+and+whole+family+approaches/080c323f-e653-4cea-832a-90947c9dc00c page 15.

641 Fernandez, J.L., Snell, T. and Marczak, J., 2015. An assessment of the impact of the Care Act 2014 eligibility regulations.

642 <http://www.in-control.org.uk/resources/procedures,-guidelines-and-templates/hartlepool-self-assessment-questionnaire-2008.aspx>

had their ‘tick boxes’ run through a Resource Allocation System (RAS): highly impersonalised and designed to reduce care costs: to ‘lower expectations’⁶⁴³. Although the revised Statutory Guidance requires individuals who are able and willing to undertake a supported self-assessment be offered one (para 6.44) it stresses that: (a) the local authority must assure itself that it ‘is an accurate and complete reflection of the person’s needs’ (para 6.46); and (b) that regardless of what the individual may think ‘the final decision regarding eligibility rests with the local authority’ (para 6.53). SCIE Guidance concerning supported self-assessments,⁶⁴⁴ emphasises that they must include: but ultimately it is the practitioner’s responsibility to determine if the supported self-assessment is complete and accurate, drawing on their experience and knowledge of the individual. The revised Statutory Guidance requires that assessments be ‘person-centred, involving the individual and any carer that the adult has, or any other person they might want to be involved’ (para 6.9) and that they must ‘establish the total extent of needs’ (para 6.10). Local authorities

643 Cameron, A., Lart, R., Bostock, L. and Coomber, C., 2014. Factors that promote and hinder joint and integrated working between health and social care services: a review of research literature. *Health & social care in the community*, 22(3), pp.225-233.

644 Social Care Institute for Excellence (SCIE) on line guidance - The Care Act 2014 Implications for practice - Supported self-assessment at www.scie.org.uk/care-act-2014/assessment-and-eligibility/process-map/

are also required to ‘provide in advance, and in an accessible format, the list of questions to be covered in the assessment’ (para 6.38).

4.3.8 Eligibility criteria (section 13)

Section 13 provides that there will be national eligibility criteria set by regulations. The position was established by *R v Gloucs C, ex p Barry*⁶⁴⁵ on a statutory footing, and will establish national standards for local authority care support. It will also, optimistically, end the current situation where some local authorities have limited themselves to only critical needs, or seek to establish new bands of “super-critical” needs to limit social care provision further. The Act sets out the national eligibility criteria, appear to be intended to reflect the current practice of most authorities, i.e. to set the eligibility threshold at the level of critical and substantial needs.

The pre-Care Act legislation contained no reference to ‘eligibility criteria’: locating them instead in guidance (commonly referred to as FACS⁶⁴⁶). The Care Act places eligibility criteria on a statutory

645(*R v Gloucestershire County Council ex parte Barry* [1997] AC 584, [1997] 2 All ER 1
<https://publications.parliament.uk/pa/ld199697/ldjudgmt/jd970320/barry01.htm>

646 ‘Fair Access to Care Services’ although the 2002 Department of Health guidance that bore this name was replaced in 2010 by Prioritising need in

footing (section 13) with the detail being spelt out in the Eligibility Regulations⁶⁴⁷ – which contain separate criteria for adults in need and for carers. Whether this change of status – or indeed the significant changes to the criteria themselves – will result in a material change in practice is difficult to predict. Research suggests that for both carers⁶⁴⁸ and people with disabilities,⁶⁴⁹ the content of national criteria is less influential than local managerial culture,⁶⁵⁰ ‘social work attitudes’ and local interpretations of the national criteria⁶⁵¹.

A fundamental concept to be seized with the new eligibility process concerns the interlocking nature of the various criteria.

the context of Putting People First: A whole system approach to eligibility for social care. Guidance on Eligibility Criteria for Adult Social Care, England 2010.

647 The Care and Support (Eligibility Criteria) Regulations 2015.

648 Wendy Mitchell How local authorities allocate resources to carers through carer personal budgets (National Institute for Health Research 2014).

649 See for example Jose-Luis Fernandez and Tom Snell Survey of Fair Access to Care Services (FACS) Assessment Criteria among Local Authorities in England PSSRU Discussion Paper 2825 (2012) and Jose-Luis Fernandez, Tom Snell and Gerald Wistow Changes in the patterns of social care provision in England: 2005/6 to 2012/13 PSSRU Discussion Paper 2867 (2013).

650 Colin Slasberg Resource allocation: Leaders’ Briefing (Dartington 2015).

651 Ibid pg12

Even if it is determined that the adult does not satisfy the adult criteria, she or he may still be entitled to support because their carer is deemed eligible – and even if this does not trigger a duty to provide support. Although the Care Act criteria have some similarities to the FACS guidance, a noticeable difference is an absence of ‘bands’ (the ‘critical’, ‘substantial’, ‘moderate’ and ‘low’ bands in FACS). Under the Care Act eligibility scheme, adults in need are either eligible, or they are not – and to be eligible three requirements must be satisfied: (a) their needs must be the result of a physical or mental impairment or illness; (b) as a result, they must be unable to achieve two or more specified outcomes; and (c) as a consequence, there is (or there is likely to be) a significant impact on their well-being.

A 2016 ombudsman complaint⁶⁵² concerned the reassessment of a person with disabilities with mental health difficulties who had been receiving a support package. The re-assessment found that it took her significantly longer than would generally be expected to achieve outcomes associated with work, accessing community services, maintaining hygiene, and maintaining a home environment due to her mental health conditions. Nevertheless (unlike the first assessment) it concluded that the difficulties did not significantly impact her wellbeing. In finding

652 Complaint no 15 001 422 against Milton Keynes Council dated 20th September 2016.

maladministration, the ombudsman noted the absence of any explanation as to why her wellbeing was not significantly impacted by her difficulties in achieving the specified outcomes and this is maladministration. This omission was compounded by the failure to provide reasons as to why she was no longer eligible for the support she had previously been assessed as needing.⁶⁵³

Para 6.106 of the revised Statutory Guidance provides examples of how local authorities should consider each of the outcomes⁶⁵⁴ – while emphasising that the guidance does not constitute an exhaustive list of examples. Some examples include:

- a) Managing and maintaining nutrition – a 2016 ombudsman complaint⁶⁵⁵ found it to be maladministration for a council to fail to recognise that ‘fresh food is essential to meet

⁶⁵³ Complaint no 15 001 422 against Milton Keynes Council dated 20th September 2016.

⁶⁵⁴ Regulation 2 details ‘outcomes’ as being: managing and maintaining nutrition; maintaining personal hygiene; managing toilet needs; being appropriately clothed; being able to make use of the adult’s home safely; maintaining a habitable home environment; developing and maintaining family or other personal relationships; accessing and engaging in work, training, education or volunteering; making use of necessary facilities or services in the local community including public transport, and recreational facilities or services; and carrying out any caring responsibilities the adult has for a child.

⁶⁵⁵ Complaint no. 15 011 661 against London Borough of Hammersmith & Fulham 21 July 2016 para 24.

nutritional needs’ and that ‘consumption of fresh food, once it has started to perish, carries a significant health risk’ (a complaint concerning a visually impaired adult who needed help to check the contents of her fridge, read cooking instructions and on occasions to be escorted to a local shopping centre.

b) Maintaining personal hygiene - a complaint⁶⁵⁶ concerning an adult who had been assessed as having eligible needs for support with showering, washing her hair and dressing. The ‘Funding Panel’ (see below) however refused all support. The ombudsman held this to be maladministration. While it was possible that her needs could be met in other ways, this could not be decided in direct contravention of the assessor’s recommendations by a panel who was not involved in the assessment.

c) being appropriately clothed - A finding ⁶⁵⁷ that it is maladministration for an LA to fail to recognise the importance to an adult’s personal dignity of wearing clean,

⁶⁵⁶ Complaint no. 15 017 591 against Brighton & Hove City Council 30th August 2016.

⁶⁵⁷ Complaint no. 15 014 893 against Dorset County Council 1st September 2016.

presentable and appropriate clothes (a complaint concerning a visually impaired adult who needed support to sort her clothes so that she did not wear stained or inappropriate clothing);

- d) Maintaining a habitable home environment - a 2016 ombudsman report⁶⁵⁸ concerned an adult who had been told by the assessor that the council ‘no longer fund domestic work generally’ and that he was not eligible because he could afford a cleaner: that the Care Act was “about what people can do for themselves”. In finding maladministration, the ombudsman held that the adult had an eligible need. Therefore he was entitled to receive such a service. The Care Act says “The local authority must also establish whether the individual wants to have their eligible needs met by the local authority. If the individual wishes to arrange their care and support, the authority does not have to meet those needs”.

Once more, the examples in the SCIE guide⁶⁵⁹ do not dramatically broaden the scope of this ‘outcome’ but again it is conceivable that the court or

658 Complaint no. 15 014 893 against Dorset County Council 1st September 2016.

659 SCIE has produced a Strengths-based approaches resource (accessible at www.scie.org.uk/care-act-2014/assessment-and-eligibility/strengths-based-approach/) which is designed to find ways of meeting a person’s needs through the use of informal community / social networks and it

Ombudsman could interpret the ‘ability to get around in the community safely’ as requiring consideration as to the provision of support workers and other measures to address the harms the adult may encounter in the local environment.

Enthusiastically, the pre-Care Act rule – that the eligibility criteria can be sidestepped for people whose needs are urgent⁶⁶⁰ – is carried forward into the new regime (section 19(3)). The revised Statutory Guidance advises that where ‘an individual with urgent needs approaches or is referred to the local authority [it] should provide an immediate response and meet the individuals care and support needs’ and it then provides as an example, ‘where an individual’s condition deteriorates rapidly, or they have an accident, they will need a swift response to ensure their needs are met’ (para 6.26). This is sensible and earnest in its approach, however, it does leave open the notion of ‘swift response’ and rapidly deteriorates to a challenge when cases are considered borderline. A dispute resolution method is required to solve issues before court proceedings⁶⁶¹. A complaint does not have a time limit to be resolved as ‘swiftly’ as the Act stands.

considers particularly relevant to ‘needs related to connecting with people, staying (physically) active, socialising, learning new skills and/or offering skills or knowledge to others in the community’ (although the one practical example it gives is of a person who has care needs and female neighbour agrees to provide this for her without charge www.scie.org.uk/care-act-2014/assessment-and-eligibility/strengths-based-approach/what-do-practitioners-need-to-consider.asp)

⁶⁶⁰ NHS and Community Care Act 1990 section 47(5) and see for example *R (Alloway) v Bromley LBC* [2004] EWHC 2108 (Admin), (2005) 8 CCLR 61

⁶⁶¹ See discussion in Chapter 5 – Dispute Resolution Recommendation

4.3.9 Care & support plans (section 25-26)

Sections 24 contains the provisions relating to support planning, to be set out in documents which will now be called “care and support plans”. Section 25 describes what such plans should contain, and this includes a personal budget.

The assessment process involves identifying ‘needs’ and then determining which of these (if any) are ‘eligible needs’. This stage is then followed by the development of a care and support plan that explains how the eligible needs will be met. These stages are two sides of an equation: on one side, there are the eligible needs that have to be met and on the other are the details of how this will be done. In order that the individual can determine whether their assessed needs are fully addressed in the care plan, the revised Statutory Guidance requires that they ‘must be given a record of their needs or carer’s assessment’ (para 6.96)⁶⁶² and also their final care plan (para 10.87).

662 Even if it is decided that none of their needs are eligible needs, the authority must nevertheless provide them with ‘information and advice in an accessible form, about what can be done to prevent, delay, or reduce development of their needs’ (para 2.52).

Section 25 details what must be in every care and support plan⁶⁶³ (i.e. for a carer or a disabled person) and this duty is analysed in the revised Statutory Guidance (para 10.36)⁶⁶⁴. The effect of section 25 is that the pre-Care Act requirements for care and support plans continue – but they are now statutory necessities rather than requirements of Department of Health guidance. Existing case law concerning care plans remains relevant – particularly so, given that it places great emphasis on the importance of local authorities following guidance⁶⁶⁵. In *R v Islington LBC ex p Rixon* (1997)⁶⁶⁶ it was held that central importance of a care plan was described as: the local authority hence affords good evidence to any inquirer of the due discharge of its statutory duties.

663 Unless excluded by the Care and Support (Personal Budget Exclusion of Costs) Regulations 2014 – which concerns the exclusion of costs associated with the provision of intermediate care (including reablement support) services.

664 These requirements include: the needs identified by the assessment; whether, and to what extent, the needs meet the eligibility criteria; the needs that the authority is going to meet, and how it intends to do so; for a person needing care, for which of the desired outcomes care and support could be relevant; for a carer, the outcomes the carer wishes to achieve, and their wishes around providing care, work, education and recreation where support could be relevant; the personal budget ...; information and advice on what can be done to reduce the needs in question, and to prevent or delay the development of needs in the future; where needs are being met via a direct payment ... , the needs to be met via the direct payment and the amount and frequency of the payments.

665 *R v Islington LBC ex p Rixon* (1997–98) 1 CCLR 119 at 128, QBD.

666 (1997–98) 1 CCLR 119 at 128, QBD.

It will be maladministration to fail to provide sufficient detail in an assessment and care plan.⁶⁶⁷ In *R (J) v Caerphilly CBC*⁶⁶⁸ it was held that care plans must ‘set out the operational objectives with sufficient detail – including detail of the “how, who, what and when” – to enable the care plan itself to be used as a means of checking whether or not those objectives are being met’. A 2014 Ombudsman’s report held (in similar terms) that an assessment must be more than merely a descriptive document: it must spell out with precision what the needs are, what the impact of the disability is on the carer(s) and whether the person with disabilities and the needs of the carer can be met and can continue to be met into the future. The assessment must result in a care plan that identifies the needs, what is to be done about these needs, by whom and when. If direct payment is made, it must specify precisely what need these payments are intended to meet, why this level of payment is considered appropriate, or what outcome will be.

The most significant and positive difference under the Act is that every such plan for a person with disabilities must have a

667 Complaint no 15 015 067 against Kent County Council 26 August 2016.

668 [2005] EWHC 586 (Admin); (2005) 8 CCLR 255. This case is discussed in detail at para 10.73.

‘personal budget’ (s25(1)(e) – discussed below) – this was place in Law that the person had access to ‘choice and control’ with their planning. However, since almost every local authority was already doing this in theory⁶⁶⁹ – it has made no practical difference.⁶⁷⁰ Many local authorities gave all people with disabilities a ‘personal budget’ in name but were directly managed by the authorities⁶⁷¹. The revised Statutory Guidance requires that the person being assessed must be ‘genuinely involved and influential throughout the planning process’ by the local authority and that: ‘it should be made clear that the plan ‘belongs’ to the person it is intended for, with the local authority role to ensure the production and sign-off of the plan to ensure that it is appropriate to meet the identified needs (para 10.2). The care and support plan ‘must take into consideration the individual’s preferences’ (para 10.20) may include helping the person to access some disability-related benefits and allowances (para 10.24).

669 Many local authorities gave all disabled people a ‘personal budget’ in name, but was directly managed by the authorities. It lead to many people calling a personal budget with self-management – a ‘Prue Personal Budget’.

670 Ismail, M., Hussein, S., Stevens, M., Woolham, J., Manthorpe, J., Aspinall, F., Baxter, K. and Samsi, K., 2017. Do personal budgets increase the risk of abuse? Evidence from English national data. *Journal of social policy*, 46(2), pp.291-311.

671 Williams, V. and Porter, S., 2017. The Meaning of ‘choice and control’ for People with Intellectual Disabilities who are Planning their Social Care and Support. *Journal of Applied Research in Intellectual Disabilities*, 30(1), pp.97-108.

It is self-evident that care and support must meet eligible needs. A 2016 ombudsman report⁶⁷² concerned a young man with Down's Syndrome who was assessed as having substantial needs, including outcomes to form 'peer group relationships' and prevent isolation. A supported housing placement was identified, which was considered suitable because it had a resident of a similar age. The local authority subsequently withdrew this offer, having found a cheaper placement but older people occupied this. The social worker, however, had noted that 'considering [Mr Z's] needs I do not believe another placement could be found at a lower cost to the one identified.' In finding maladministration, the ombudsman held that Care plans 'should not only cover how a person's physical needs will be met. They should also address the person's social needs and emotional wellbeing.'

Para 10.27 of the revised Statutory Guidance makes clear that pre-Care Act case law concerning the relevance of an authority's financial position remains – namely that although authorities can 'take into reasonable consideration' of their finances, they 'must comply' with their legal obligations.⁶⁷³ A local authority's finances

672 Complaint no. 15 019 312 against London Borough of Barking & Dagenham 08 June 2016.

673 i.e. the position identified by the House of Lords in *R v Gloucestershire County Council ex p Barry* 1 CCLR 40; [1997] 2 All ER 1;

are relevant when it decides how to meet the eligible needs of an individual ‘but not whether those needs are met’. The revised Statutory Guidance goes on to stress that authorities ‘should not set arbitrary upper limits on the costs [they are] willing to pay to meet needs through certain routes’ – although they may:

Take decisions on a case-by-case basis which weigh up the total costs of different potential options for meeting needs, and include the cost as a relevant factor in deciding between suitable alternative options for meeting needs. This does not mean choosing the cheapest option, but the one which delivers the outcomes desired for the best value. (para 10.27) This a positive progress within care planning and person-centred planning and should be commended. However, there is developing evidence that some local authorities are circumventing this but taking differing approaches. While *Ireneschild*⁶⁷⁴ is an important statement in this field⁶⁷⁵, it pre-dates the Care Act 2014 and has

and reiterated by the Supreme Court in *R (KM) v. Cambridgeshire County Council* (2012) [2012] UKSC 23.

⁶⁷⁴ *R (on the application of Ireneschild) v Lambeth London Borough Council* - [2007] All ER (D) 286 (Mar)

⁶⁷⁵ *Ireneschild* was dissatisfied with the community care assessment. She argued that it had failed to consider a relevant consideration, namely the Occupational Therapist analysis of falling risk, and, as a result, had underestimated her needs. She was successful in quashing the assessment in the High Court. Lambeth appealed to the Court of Appeal. The Court of Appeal also stressed that disputes of this sort should not normally end up in the courts. The statutory social services complaints procedure and the Local

never been considered alongside Lord Wilson’s statement⁶⁷⁶ in *R (KM) v Cambridgeshire CC*⁶⁷⁷ (concerning the heightened importance of social care decisions). That has now been done, and the Court has expressly approved the Ireneschild approach of Appeal, albeit its analysis is arguably obiter because this ground was academic in light of the judge’s findings of fact. In the Davey case the appellant ran an argument, following its argument in the High Court, that as existing personal assistants (PAs) stated that their rates of pay were insufficient, the budget needed to be raised to enable Mr Davey to pay his carers at a higher rate. Both the High Court and the Court of Appeal rejected this argument. Bean LJ at para 81 held that, while the PA concerned could not be criticised for being dissatisfied for regarding payment at minimum wage as a poor reward for her quality and experience, the Statutory Guidance at para 11.25 makes clear that the personal budget should reflect local market conditions. The council had submitted evidence as to local market conditions and rates of pay, and the court was entitled to accept that evidence. It was not unlawful for the council to decline to

Government Ombudsman should be used instead. The overall message, was that the business of assessing need and making service provisions is, ordinarily, for social workers and not lawyers.

⁶⁷⁶ Brammer, A., 2009. Social work law. Pearson Education.

⁶⁷⁷ *R (KM) v Cambridgeshire CC* [2011] EWCA Civ 682 and *R (KM) v Cambridgeshire CC* [2012] UKSC 23, [2012] MHLO 57

raise the budget to guard against the risk of PAs leaving because they were not prepared to work for the going rate. This in itself is quite worrying that the onus was transferred to the PAs on minimum wage – rather than have the issue of ‘choice’ and mediated with.

Finally, the Act also requires that a copy of the care and support plan be given to the adult in need/carer (and anyone else they request) (section 25(9) and (10)) and the revised Statutory Guidance at para 10.87 makes clear that the copy must be ‘in a format that is accessible to the person for whom the plan is intended’ and copies should also be given to any independent advocate involved. For many years the care and support plans, which are computer generated and incomprehensible to all but the initiated were not required to be accessible to the disabled person. The requirement that the copies be ‘in a format that is accessible’ must require that this practice ends and plain English, jargon-free plans are provided to those who request them. The negative issue here is in words ‘those who request them’ and does this include plan where a person with learning disabilities is given a simplified image document and help by an advocate? The next section to consider reviews and how they may work in the Act.

4.3.10 Review of care & support plans (section 27)

Section 27(1) of the Act places a general duty on local authorities to keep under review care and support plans (as well as when the adult makes a reasonable request in need of a carer) and section 27(4) requires a reassessment if they believe that those circumstances have changed materially. The revised Statutory Guidance creates an expectation that the care and support plans will be reviewed ‘no later than every 12 months, although a light-touch review should be considered 6-8 weeks after the plan and personal budget has been signed off’ (para 10.42 – and see also para 13.32). This good customer service practises and good quality control over the process.

In the original Act there were several weaknesses and these were addressed by revised Statutory Guidance requires that reviews (like assessments) must person-centred, accessible and proportionate: must involve the ‘person needing care and the carer where feasible’ (para 13.2) and their purpose is ‘identify if the person’s needs’ or any ‘other circumstances’ have changed (para 13.4). Very welcomed by the Disability Sector is the note in the revised Statutory Guidance that the ‘review must not be as a mechanism to arbitrarily reduce the level of a person’s budget’ (para 13.4). Progressively, the reviews should not be ‘overly-complex or bureaucratic’ and should cover the specified matters – which ‘should be communicated to the person before the review

process begins’ (para 13.12). These include: whether the person’s needs/circumstances have changed; what parts of the plan are working / not working/need changing; have the outcomes identified in the plan been achieved and are there any new outcomes they want to meet; is the person’s personal budget adequate and is there a need to change the way it is managed/paid; are there material changes in the person’s support networks which might impact negatively or positively on the plan; have any changes occurred which could give rise to a risk of abuse or neglect; and is the person, carer, independent advocate satisfied with the plan? All this is welcome; however, it has yet to be challenged further in court. In *R (Davey) v Oxfordshire CC* [2017]⁶⁷⁸ several further interesting points were dealt with by Morris J in the High Court, but which did not arise on appeal (the Court of Appeal’s judgment did not cast any doubt on those parts of Morris J’s judgment.) These include:

- para 121 (of Morris J’s judgment): the difference between “needs” and “wishes”, and the LA’s obligations in light of this distinction;
- para 122: whether the LA could regard “developing independence” (or as the claimant had put it, “spending more

678 *Davey v Oxfordshire CC* [2017] EWCA Civ 1308.

time alone”) as a “need” when it was said that Mr Davey himself did not want this

Regarding challenging reductions in care packages - a 2016 ombudsman report that reminded authorities that they must not assume a carer is willing or able to provide any care – including additional care arising from a reduction in the care package. It will be maladministration for such a reduction to occur without assessing the carer and explicitly clarifying (and recording) whether she/he is ‘able and willing’ to provide the additional care.⁶⁷⁹

In addressing an original weakness in the Act the revised Statutory Guidance goes into considerable and constructively detail about the different ways that a review may be triggered – i.e. as a result of a planned review (where the date is detailed in the care and support plan); an unplanned review (resulting from a change in needs / circumstances); and a requested review (ie by the person with the plan, or any interested party on their behalf) (para 13.13). An interesting case is a 2016 Ombudsman’s report⁶⁸⁰ concerned a person with disabilities as a service user, who requested that she

679 Complaint no. 15 020 384 against London Borough of Bromley 7th September 2016.

680 Complaint 15 011 661 against London Borough of Hammersmith & Fulham 21 July 2016 para 22.

have a direct payment (rather than the services being commissioned by the local authority). Instead of responding swiftly to this request, the authority stated that it would have first to undertake a review: an action that the ombudsman considered to be maladministration. Therefore, is it advantageous that the person with disabilities can ‘choose’ what method they wish to use for providing service delivery and not have to have a review? The review could lead to budget cuts as it is cheaper for a person with disabilities to buy support⁶⁸¹ than to purchase through an organisation with overheads.

4.3.11 Personal budgets

Section 26 prescribes what such budgets must contain. Under a personal budget, the local authority is required to set out the total sum of money a person is assessed as needing and the cost of services required to meet those needs. The local authority can still commission the services, but the rationale is that service-users will demand less if they know how much the services cost. Personal budgets have been in existence for several years, but the requirement to produce them in *every* case is novel. However, there are likely to be many cases in which there is no point of informing the service-user what the cost of services are: where

⁶⁸¹ Henwood, M., 2014. Self-funders: the road from perdition?. *Debates in Personalisation*, pp.75-86.

they lack capacity, for example. The extension of this requirement to all cases is thus likely to significantly increase the administrative burden on local authorities, to little effect.

The Select Committee expressed concern that this phrasing was different to the pre-Care Act 2014 requirement (in relation to direct payments) –that the amount be that which the ‘the authority estimate to be equivalent to the reasonable cost of securing the provision of the service concerned’: it considered that the word ‘reasonable’ was important and should be included in the Act. In response, the Government stated that the wording meant that the amount had to be ‘sufficient to meet’ the adult’s needs. This response did not reassure the Select Committee. The revised Statutory Guidance goes some way to allay these concerns, stating at para 11.10 that: the personal budget must always be an amount sufficient to meet the person’s care and support needs and must include the cost to the local authority of meeting the person’s needs which the local authority is under a duty to meet, or has exercised its power to do so. This overall cost must then be broken down into the amount the person must pay, following the financial assessment, and the remainder of the budget that the authority will pay. The guidance readdresses some of the earlier problems in the Act and clarifies what must be done.

The expectation is that (for non-self funders) the personal budget will change as the care and support planning process progresses.

At the start of the planning process, it will be an ‘indicative amount’ shared with the person, and anybody else involved, with ‘final amount of the personal budget confirmed through this process’ (para 11.7). This constructively means there is no need for a local authority to use a Resource Allocation System (RAS) to generate a figure at the commencement of the process – an authority might have (for example) a simple set of ‘bands’⁶⁸². Research suggests that most RAS generate incorrect figures which and have serious defects – not least their complexity and the rigidity with which some local authorities then apply them.⁶⁸³ In support of this heartening approach the revised Statutory Guidance advises that ‘complex RAS models of allocation may not work for all client groups’ (para 11.23) and that ‘regardless of the process used, the most important principles in setting the personal budget are transparency, timeliness and sufficiency’ (para 11.24).

A 2015 Ombudsman report concerning Cornwall Council⁶⁸⁴ has confirmed the legal position namely that the hourly rates on which personal budgets / direct payments are assessed must not be

682 Series, L. and Clements, L., 2013. Putting the cart before the horse: resource allocation systems and community care. *Journal of Social Welfare and Family Law*, 35(2), pp.207-226.

683 See for example Lucy Series and Luke Clements, ‘Putting the Cart before the Horse: Resource Allocation Systems and Community Care’ *The Journal of Social Welfare Law* [2013] (2) 207-226.

684 Report on Complaint against Cornwall Council (13 006 400) 26 February 2015

arbitrary and that the calculations must be shared with adults in need/carers. Where the individual lacks the necessary mental capacity to manage a personal budget (and to employ personal assistants), then the budget must be costed on the basis that an agency would have to be used.

The Act requires (it appears⁶⁸⁵) local authorities to include in a support plan a personal budget for carers. The revised Statutory Guidance (at para 11.7) states that ‘everyone whose needs are met by the local authority ... must receive a personal budget as part of the care and support plan, or support plan’ and at para 11.34⁶⁸⁶ suggests the pooling of budgets, for example, where an adult and a carer are living in the same household. The revised Statutory Guidance considers, however, the possible complexities that may arise when it is unclear as to whether a particular service is for a carer or the person with disabilities— para 11.38 advising that local authorities: should consider how to align personal budgets where they are meeting the needs of both the carer and the adult

685 Section 25 distinguishes between ‘adults’ and ‘carers’ but it would appear that the reference in section 25(1)(e) (the duty to include a personal budget) is intended to include both 'adults' and ‘carers’.

686 para 11.34

needing care concurrently. ... as well as being detailed in a care and support plan for the carer.⁶⁸⁷

4.3.12 Direct Payments (sections 31-33)

The Care Act provides for an almost identical ‘direct payments’ regime to that under the previous regime, and the detail is again to be found in the regulations⁶⁸⁸ and the revised Statutory Guidance. There are two material changes.

Firstly, concerns a ‘softening’ of the presumption against making payments to spouses/partners/ relatives living in the same house as the adult. Such payments can be made ‘if the local authority considers it is necessary to do so’⁶⁸⁹ – and the payment can cover either the cost of meeting the disabled person’s needs or the cost of providing ‘administrative and management support or services’ for the person to whom the direct payments are made. Concerning this latter category, the revised Statutory Guidance (para 12.36) explains that: [it is] where the local authority determines this to be necessary. ... the fact that in some cases, especially where there

687 para 11.38

688 The Care and Support (Direct Payments) Regulations 2014.

689 The Care and Support (Direct Payments) Regulations 2014 reg 3(2).

are multiple complex needs, the direct payment amount may be substantial⁶⁹⁰.

Undeniably, this was a positive step forward for ‘choice and control’ and for a person with disabilities wishes to be supported by, usually a person who knows themselves and their needs/wishes, and can support them through the self-management aspect of personal budgets. The negative is that the person with disabilities could be left vulnerable to the manipulation and abuse by a family member. The issue has been raised as an issue⁶⁹¹ in the *Journal of Adult Protection* as a potential issue⁶⁹².

The second positive change (which has now been postponed until 2020⁶⁹³) is that direct payments will be available for residential care placements. The local authorities who were piloting this

690 para 12.36

691 Dalley, G., Gilhooly, M.L., Gilhooly, K., Levi, M. and Harries, P., 2017. Researching the financial abuse of individuals lacking mental capacity. *The Journal of Adult Protection*, 19(6), pp.394-405.

692 Stark, E., 2018. Coercive control as a framework for responding to male partner abuse in the UK. *The Routledge Handbook of Gender and Violence*, p.15.

693 In late January 2016 the Government announced that it had decided to postpone the ‘national rollout of direct payments in residential care’ until 2020 - see www.local.gov.uk/web/guest/care-support-reform/-/journal_content/56/10180/7643648/ARTICLE.

programme will, however, be able to continue making such payments if they so choose.⁶⁹⁴

Therefore, Sections 31 to 33 provide that where a disabled person, or (in the case of a person with disabilities with intellectual disabilities) their guardian, request that a personal budget is paid by way of direct payment, the local authority must comply with that request provided certain conditions are met. Conditionally, this is positive with some hesitations about potential financial abuse. Nevertheless, some commentators believe that this is a risk worth taking⁶⁹⁵.

4.3.13 Independent advocacy (section 67)

The final section of the Act to be reviewed that has fundamental implications for choice and control in Section 67. The Act and the regulations place a duty on local authorities to arrange independent advocacy if the administration considers that: (1) an

694 These are listed in Schedule 2 to the Regulations – and see also Department of Health Policy Research Unit in Policy Innovation Research Direct Payments in Residential Care Trailblazer Programme Evaluation Preliminary report 2014 at www.piru.ac.uk/assets/files/DP%20Trailblazer%20Preliminary%20report.pdf.

695 Woolham, J., Daly, G., Sparks, T., Ritters, K. and Steils, N., 2017. Do direct payments improve outcomes for older people who receive social care? Differences in outcome between people aged 75+ who have a managed personal budget or a direct payment. *Ageing & Society*, 37(5), pp.961-984.

individual would experience ‘substantial difficulty’ in participating in (amongst other things) their assessment and/or the preparation of their care and support plan; and (2) there is no one appropriate available to support and represent the person’s wishes. However, of concern is the restriction (the existence of an appropriate representative) does not, however, apply to some ‘hospital discharge’ and ‘NHS continuing care’ disputes. The issue adds to the debate about the type of dispute resolution required and which is in nether in the Act or the Guidance.

The revised Statutory Guidance (para 3.9) defines advocacy as ‘supporting a person to understand information, express their needs and wishes, secure their rights, represent their interests and obtain the care and support they need’. Advocacy can be central to achieving well-being – particularly in identifying an individual’s views, wishes, feelings and beliefs – and maximising their control over their day-to-day life.⁶⁹⁶

In relation to the general advocacy duty the revised Statutory Guidance states at para 7.4: local authorities must arrange an independent advocate to facilitate the involvement of a person in their assessment, in the preparation of their care and support plan and the review of their care plan, as well as in safeguarding

⁶⁹⁶ CA 2014, (s1).

enquiries and SARs [Safeguarding Adults Reviews] if two conditions are met. The revised Statutory Guidance explains that a person experiences ‘substantial difficulty’ when this exists in relation to any one of four areas - namely (para by 6.33): understanding the information provided; retaining the information; using or weighing up the information as part of the process of being involved; and communicating the person’s views, wishes or feelings.

A 2016 ombudsman’s complaint⁶⁹⁷ provides an example of how the duty to appoint an advocate can be overlooked. A family member made a complaint about the support provided to her two siblings who lived with her and who had learning disabilities. During the complaints process, she lost confidence with the council and stopped responding to emails. As a result, the siblings received no support. The ombudsman found maladministration. Given the impasse between officers and the complainant, the duty under section 67 arose, and the siblings should have been provided with an advocate. A dispute resolution should and could have been used in this instance and highlights the weakness of the legislation but emphasises the need to solve disputes early.

⁶⁹⁷ Complaint no 16 004 955 Walsall MBC 8th December 2016.

The Government has advised local authorities about advocacy and how to comply with the new requirements of the Act'.⁶⁹⁸ The obligation that is regularly overlooked is to provide independent advocacy applies to all Care Act assessments: accordingly, the duty is engaged concerning most assessments for hospital discharge or to ascertain eligibility for NHS Continuing Healthcare funding.⁶⁹⁹ Dr Lucy Series, when commenting favourably on the advocacy provisions and the draft guidance suggested that what was being required went beyond advocacy and encompassed a duty of 'support and the duty to involve'.⁷⁰⁰ Her paper also highlighted the overlap between the Care Act 2014 duty and the more limited obligation under the Mental Capacity Act 2005⁷⁰¹ to appoint an Independent Mental Capacity Advocate (IMCA). She said that there is evidence to suggest that the Care

698 See SCIE Guidance on the Care Act 2014 (issued October 2014) Commissioning independent advocacy www.scie.org.uk/care-act-2014/advocacy-services/commissioning-independent-advocacy/.

699 If it is 'is likely to' result in the NHS funding the person in a hospital for a period of 28 days or more; or a care home for a period of 8 weeks or more - The Care and Support (Independent Advocacy Support) (No. 2) Regulations 2014 reg 4 (2)(a) – and see also the revised Statutory Guidance para 7.21.

700 Lucy Series Care Act 2014: Consultation on Draft Guidance & Regulations (2014) <http://thesmallplaces.wordpress.com>.

701 MCA, N.E.R. and DoLS, L.I.N., 2005. Mental Capacity Act 2005. See also, Hughes, R., 2009. Mental Capacity Act 2005. *British Journal of Healthcare Assistants*, 3(5), pp.233-233.

Act 2014 arrangements by which local authorities are required to refer people with disabilities as service users to advocates by local authorities is not working well, and research indicates that this is due to the lack of understanding of this duty by frontline social services staff.⁷⁰²

*R (SG) Haringey LBC (2015)*⁷⁰³ concerned a refugee with severe mental health problems, spoke no English, was illiterate and had significant memory difficulties. The local authority refused the Care Act 2014 support after an assessment which was completed without consideration of the need for an advocate. In striking down the decision, the court held that it was a: ‘paradigm case where such an advocate was required, as in the absence of one of the claimant was in no position to influence matters’⁷⁰⁴.

4.3.14 Final thoughts

The speed with which the Statutory Guidance has been produced has resulted in it having several material errors and omissions

702 K Newbigging, J Ridley & J Sadd Commissioning Care Act Advocacy Birmingham University Dec 2016.

703 [2015] EWHC 2579 (Admin) at para 40 Mr John Bowers QC, sitting as Deputy High Court Judge.

⁷⁰⁴ [2015] EWHC 2579 (Admin) at para 40 Mr John Bowers QC, sitting as Deputy High Court Judge.

(including some which must embarrass the government⁷⁰⁵). One omission is a section explaining the guidance's status at law. This obligation stems from section 78 of the 2014 Act – which replicates the current duty (in section 7(1) Local Authority Social Services Act 1970) and the removal of the reference to section 78 in the final guidance, and the many references in to its status as requiring local authorities to 'have regard' to it (rather than 'act under') suggests otherwise. The probability is that it is guidance intended to be issued under section 78 – and so 'binding' on local authorities – but this is a point that will be litigated as was the status of the guidance accompanying the 1993 reforms.⁷⁰⁶

4.4 Conclusion

The Care Act 2014 has changed the ability that a person with disabilities as a service user or carer has to influence the assessment of their own needs and eligibility. Whereas the FACS

705 As examples – para 14.4; para (first sentence); the footnote to para 7.26; the reliance on hyperlinks (which will inevitably change) without providing in additional basic information about the cited document – see for example the footnote to para 14.1.

706 The status of the 1990 guidance *Community Care in the Next Decade and Beyond: policy guidance* was contested in the Gloucestershire proceedings – only being agreed in the Court of Appeal – see *R v. Gloucestershire County Council exp Barry (CA)* 1 CCLR (1997) p24 B.

criteria⁷⁰⁷ considered the needs of the individual, they did not consider their whole well-being and how this fits into their everyday lives, meaning that some people with disabilities as service users may not have completely fitted into the specified categories. The criteria that the Care Act 2014 looks at the focus on the individual in context so that the impact on their well-being cannot now be overlooked or misjudged. The Care Act⁷⁰⁸ is allowing the person with disabilities as a service user to take control of everything that supports their specific needs and requirements.

The implications could have been quite dramatic; where a person with disabilities feels worthwhile and not a burden to anyone, and it allows a person with disabilities to take greater control of their own needs.⁷⁰⁹ This aspiration should be balanced against a casual approach to statutory formalities (not to say the ‘Rule of Law’). It certainly adds weight to the recommendations of the Law Commission and the Select Committee³ that the Act should be the subject of a Parliamentary Code of Practice (rather than

707 Social Care Institute for Excellence Fair Access to Care Services (FACS): Prioritising Eligibility for Care and Support. SCIE, 2013.

708 Waters J, Hatton C. Third National Personal Budget Survey: Experiences of Personal Budget Holders and Carers across Adult Social Care and Health. In Control, Lancaster University & TLAP, 2014.

709 Barnes, D., Boland, B., Linhart, K. and Wilson, K., 2017. Personalisation and social care assessment—the Care Act 2014. *BJPsych Bull*, 41(3), pp.176-180.

departmental guidance) to strengthen against challenges from local authorities who do not share the ambition of the Act.

It is hoped by many people with disabilities the Act will develop inclusive services, work in a person-centred way, and achieve specific outcomes in a way public services will be measured by⁷¹⁰. It will be through individual lives and stories that success will be realised. There will be many challenges both legal and procedural, that lie ahead. The next chapter reviews how the conflict resolution could and should have been legislated for in the Act.

⁷¹⁰ These include groups of disabled people such as Disability Rights UK at <https://www.disabilityrightsuk.org/policy-campaigns/proud-strong-and-visible-%E2%80%93-promoting-choice-control-and-participation-disabled>; Jonathan Lima-Matthews and Scope at <https://blog.scope.org.uk/2016/09/26/do-disabled-people-have-enough-choice-and-control-in-social-care/>; Simon Stevens in <https://www.disabilitynewsservice.com/stevens-comes-out-fighting-in-battle-with-anti-cuts-activists/>. Whilst In Control partnership has promoted this development for many years (see <http://www.in-control.org.uk/about-us.aspx>)

5 DISPUTE RESOLUTION: RECOMMENDATION FOR A MEDIATION SERVICE FOR THE CARE ACT

After almost five years of review of the Care Act, a decade of debate and development, and then three years of implementation, there has been and will be continued argument and deliberation to come. Undoubtedly, this will come with the added variety of litigation where disagreement arises between local authorities, commissioners, providers and individuals about what the statutory duties under the Act are and how they should be discharged in the current economic climate.

5.1 Introduction

The Care Act's principal aim was to bring together many of the existing provisions in the current law, which were until recently diffused across a complicated patchwork of statutes, regulations, and statutory guidance⁷¹¹. Even within this limited brief, the Government has not taken up one of the Law Commission's key recommendations, which was for there to be a single act,

⁷¹¹ Richards, B. and Williamson, L., 2015. Supporting Innovation in the UK: Care Act 2014. *Journal of bioethical inquiry*, 12(2), pp.183-187.

accompanied by a full Code of Practice⁷¹². The Care Act leaves much of the detail to be worked out in future regulations and/or statutory guidance ⁷¹³. Undeniably leading to more conflict, disputes and litigation in the courts. Likely, people with disabilities as service users and local authorities will still have to look at a variety of ‘documents’ to apprehend the full scope of community care law regarding ‘choice and control’. Correspondingly, the principal and likely most common challenge are how individual budgets can be spent, and secondary issues of whether self-funders can have a subsidised local authority rate for purchasing care services. This thesis has shown that the Care Act has left many gaps in its definitions that will leave local authorities and people with disabilities seeking clarification. These misunderstandings are increasingly leading to disputes and increased litigation.

There is no mechanism in the Act for issues to be resolved or understood at an early stage – only through a planned formal appeals process, which was to be enforced by April 2016 but has

⁷¹² Diaper, A. and Yeomans, P., 2016. Contribution to Society: A Footnote for the Care Act 2014. *Practice*, 28(5), pp.331-339.

⁷¹³ Anka, A., Sorensen, P., Brandon, M. and Bailey, S., 2017. Social work intervention with adults who self-neglect in England: responding to the Care Act 2014. *The Journal of Adult Protection*, 19(2), pp.67-77.

now been delayed until further notice⁷¹⁴. Therefore, the Act is still using the Complaints Procedure that was enacted under the Local Authority Social Services and National Health Service Complaints (England) Regulations 2009⁷¹⁵.

5.2 Complaints Process (now)

A person with disabilities(or carer/advocate) with disagreements must go through the Local Authority complaints procedure with an investigation before any court actions⁷¹⁶. After the investigation's response is not resolved, the person with disabilitiescan then complains to the Local Government Ombudsman (LGO) as a last resort. Local Authority does not have a legal obligation to comply with the Local Government Ombudsman's recommendations, even

⁷¹⁴ DHSC (2016) Factsheet 13: Appeals Policy Proposals at <https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets#factsheet-13-appeals-policy-proposals>

⁷¹⁵ Instrument, S., 2009. No. 309. The Local Authority Social Services and National Health Service Complaints (England) Regulations 2009.

⁷¹⁶ no time limit for the organisation to finish their investigation but the LA is expected to keep the disabled person informed of what is happening.

those in a published report,⁷¹⁷ though the Ombudsman states that less than two per cent of cases are not adhered to in full⁷¹⁸.

One risk of taking a complaint to the Local Government Ombudsman is that the complainant may run out of time to seek judicial review of a council's decision, missing the opportunity to raise the original matter in court.⁷¹⁹ In all the ombudsman, which acts as a last resort for disputes that have not been resolved locally, received 3,061 complaints and enquiries relating to adult social care, up slightly from 2,969 in 2015-16. The local government and social care ombudsman upheld 63% of adult social care complaints in 2016-17, 10% higher than the average across all sectors, the watchdog's annual review has revealed⁷²⁰.

The proportion of investigations upheld during 2016-17 rose 5% year on year, while the number of investigations completed –

717 Kirkham, R. and Martin, J., 2014. The creation of an English Public Services Ombudsman: mapping a way forward. Democratic Audit Blog.; and Cortes, P., 2015, August. The impact of EU law in the ADR landscape in Italy, Spain and the UK: time for change or missed opportunity?. In ERA Forum (Vol. 16, No. 2, pp. 125-147). Springer Berlin Heidelberg.

718 <http://www.communitycare.co.uk/2017/11/17/ombudsman-upholding-two-thirds-adult-social-care-complaints-annual-review-reveals/> and <https://www.lgo.org.uk/adult-social-care>

719 O'Brien, N., 2015. What Future for the Ombudsman?. The Political Quarterly, 86(1), pp.72-80.

720 <https://www.lgo.org.uk/information-centre/news/2017/nov/ombudsman-highlights-the-power-of-complaints-to-improve-social-care>

1,214 – was up 9%⁷²¹. Complaints relating to adult safeguarding saw the steepest climb, up 27% from 2015-16. Meanwhile, the number of complaints relating to independent care providers was up 16% to 447, continuing a steady rise from just 58 back in 2010-11⁷²².

Judicial Review must be requested within three months in the UK,⁷²³ whereas only 54% of 2014/5 Ombudsman cases were determined within this time.⁷²⁴ Under exceptional circumstances, the person with disabilities judicial review may be possible without going through the complaints procedure. However, the Judicial review only looks at the lawfulness of actions and decisions, and these can be challenged on many grounds, which are usually described as follows: illegality; irrationality; and unfairness. It is not concerned with the conclusions of that process and whether those were ‘right’, as long as the law has been correctly applied and the right procedures have been followed. The court will not substitute what it thinks is the 'correct' decision.

⁷²¹ <http://www.communitycare.co.uk/2017/11/17/ombudsman-upholding-two-thirds-adult-social-care-complaints-annual-review-reveals/>

⁷²² <http://www.communitycare.co.uk/2017/11/17/ombudsman-upholding-two-thirds-adult-social-care-complaints-annual-review-reveals/>

⁷²³ McIntyre, J. and Neudorf, L., 2016. Judicial review reform: avoiding effective review through procedural means?. Oxford University Commonwealth Law Journal, 16(1), pp.65-99.

⁷²⁴ "Judicial Review and Statutory Review". JUDICIAL REVIEW AND STATUTORY REVIEW. Ministry of Justice. Retrieved 8 September 2015.

This is an important consideration when considering dispute resolution under the Care Act 2014. The starting point is reviewing dispute Resolution within the Act, and there needs to be consideration of the ‘Rule of Law.’

5.3 Dispute Resolution and the Rule of Law

Improved financial wealth, wealth distribution and workforce participation fuelled greater social freedoms and more liberal attitudes towards (or at least the reality of) divorce, social contracts and social welfare⁷²⁵. Judge Harman argued that these societal changes in the latter half of the twentieth century saw the rise of an unseen legal phenomenon: the discussion and consideration of collective and universal rights⁷²⁶. Within these fertile soils, the seeds of mediation as an alternative form of dispute resolution were sown. This chapter will largely focus upon mediation law experience and the richly textured fabric of dispute resolution and mediation services for possible use with the Care Act 2014.

⁷²⁵ Hecló, H., 2010. Modern social politics in Britain and Sweden. ECPR Press.

⁷²⁶ Harman, J.J., 2016. Should mediation be the first step in all Family Law Act proceedings?. *AUSTRALASIAN DISPUTE RESOLUTION JOURNAL*, 27(1), pp.17-48.

Disputes involving such “*rights*” - disputes determined by reference to considerations not personal, or perhaps not even directly related, to the disputant litigants or their right to due process - represented fresh and novel challenges for legal processes. These disputes called for new approaches which recognised both the interests of persons not involved in the litigation or the “*dispute*” (although perhaps the subject matter of it) and the preservation of relationships by which those rights and interests might be addressed. This new rights-based landscape which called for disputes to be determined by reference to considerations, including primary or paramount considerations, not directly referable or personal to disputants was also, at least potentially, poorly served by adversarial dispute resolution processes that “*compensate*” or “*punish*”. Judge Harman to the National Mediation Conference Melbourne (2014) said that it is difficult to comprehend the utility or effectiveness of such considerations in a determination founded upon the “*best interests of the [disabled] person*”⁷²⁷. The extent to which provision is made for mediation of civil disputes and the enforcement of resulting awards may vary from jurisdiction to jurisdiction. The arrangements may adopt procedures very different from those that

⁷²⁷ *Harman JJ.* ‘From Alternate to Primary Dispute Resolution: The pivotal role of mediation in (and in avoiding) litigation’ *National Mediation Conference Melbourne 10 September 2014*

are utilised in court proceedings. For example, it is now not uncommon in mediations for the mediators to say that each side has a limited time in which to present the whole of its evidence and argument⁷²⁸ and that it is for the parties to decide how they will allocate that time⁷²⁹. If it is accepted that these arrangements are made willingly, they present no challenge to the rule of law principles. Therefore, more work is required concerning the Care Act and dispute resolution.

The rule of law has traditionally been contrasted with what was referred to as the "rule of men" in the maxim "the rule of law, not of men"⁷³⁰. Like all such maxims, the statement is more powerful than it is revealing. It has generated the creation of other, competing contrasts – the general rule of law as opposed to the personal discretion to do justice⁷³¹. It is a concept which has provoked great jurisprudential debate among English speaking scholars⁷³². To some⁷³³, the rule of law is a prerequisite for any

⁷²⁸ Moore, C.W., 2014. *The mediation process: Practical strategies for resolving conflict*. John Wiley & Sons.

⁷²⁹ Carter, A. and Watts, S., 2016. *The Role of Language Interpretation in Providing a Quality Mediation Process*. *Contemp. Asia Arb. J.*, 9, p.301.

⁷³⁰ Radin, M.J., 1989. *Reconsidering the rule of law*. *BUL Rev.*, 69, p.781.

⁷³¹ Scalia, A., 1989. *The rule of law as a law of rules*. *The University of Chicago Law Review*, 56(4), pp.1175-1188.

⁷³² See Segall, E.J., 1993. *Justice Scalia, Critical Legal Studies, and the Rule of Law*. *Geo. Wash. L. Rev.*, 62, p.991.; Chesterman, S., 2008. *An*

effective legal order. To others⁷³⁴, the rule of law is seen as advancing, even embodying, a particular view of desirable political values. It would be easy to become enmeshed in this debate. To do so would not serve any immediate purpose concerning the Care Act and 'choice and control'. It is, nonetheless, important to examine what the "rule of law" conveys to an English lawyer. Only by revealing the content of that expression, when an English lawyer uses it, can the relationship which that lawyer identifies between dispute resolution and the rule of law be adequately examined.

It is relevant to speak of the rule of law relating to dispute resolution only if the dispute concerns legally enforceable rights and duties and only if the parties to the dispute wish or are required to have their argument determined following those rights and duties. Not all conflicts concern legal rights and duties - not all disputes about legal rights, and duties must be resolved by reference to those rights and duties⁷³⁵. The two most essential

international rule of law?. The American Journal of Comparative Law, 56(2), pp.331-362. and Radin, M.J., 1989. Reconsidering the rule of law. BUL Rev., 69, p.781. – as examples

⁷³³ Fuller, L., 1986. The Morality of Law (rev. ed. 1969). 3. See Ronald Dworkin, Law's Empire.

⁷³⁴ For example, Rawls, A Theory of Justice, (1972) at 235-243; R Dworkin, A Matter of Principle, (1985) at 11-12

⁷³⁵ Sternlight, J.R., 2006. Is Alternative Dispute Resolution Consistent with the Rule of Law-Lessons from Abroad. *DePaul L. Rev.*, 56, p.569.

assumptions are, first, that each party may choose whether to submit the dispute to external resolution rather than reach an agreement with the opposite party, and, secondly, that there is an established and accessible body to resolve the conflict by application of what has been described as known and predictable laws⁷³⁶.

The freedom to choose external dispute resolution may not be absolute. It may come at a cost. In many, but not all legal systems, the party that loses a civil dispute must pay some or all of the other party's costs of resisting the claim. Even if the parties resort to the ordinary courts rather than some private or governmental form of dispute resolution, they may, in some systems, must contribute to the cost of providing the tribunal⁷³⁷. There comes the point at which the penalties for seeking resolution of a dispute are so substantial as to prevent all except the very rich or the very determined from doing that.⁷³⁸ At the other end of the spectrum, if there is no detriment suffered,

⁷³⁶ Hollander-Blumoff, R. and Tyler, T.R., 2011. Procedural justice and the rule of law: Fostering legitimacy in alternative dispute resolution. *J. Disp. Resol.*, p.1.

⁷³⁷ Delgado, R., 2017. Alternative Dispute Resolution: A Critical Reconsideration. *SMUL Rev.*, 70, p.595.

⁷³⁸ Delgado, R., 2017. Alternative Dispute Resolution: A Critical Reconsideration. *SMUL Rev.*, 70, p.595.

trivial and frivolous claims may occupy too much court time, at the expense of more substantial disputes⁷³⁹. How and where to strike a balance between the two extremes remains one of the more pressing problems for some legal systems. This would be a challenge for mediation for community care disputes in understanding the issues and boundaries.

Therefore, the second premise is that there is an established and open body to resolve the dispute and to which the dissatisfied party can go. A court system created by the State must be and remain the centrepiece of dispute resolution under the rule of law⁷⁴⁰. The application of public power in enforcing society's rules must ultimately find its roots in structures established by society. That has several consequences. Some of those results concern the structure of the system that must be developed. Other effects involve the relationship between dispute resolution that occurs outside the court system and the courts themselves.

The structural consequences which draw attention are those which arise about the resolution of civil rather than criminal disputes. The mediation of civil disputes is mostly, but not

⁷³⁹ Bingham, L., 2007. The rule of law. *The Cambridge Law Journal*, pp.67-85.

⁷⁴⁰ Reuben, R.C., 1997. Public Justice: Toward a State Action Theory of Alternative Dispute Resolution. *Cal. L. Rev.*, 85, p.577.

entirely, backwards-looking⁷⁴¹. It requires identification of what has happened. It involves the identification of what *are* the rights and duties of the parties. Seldom, at least for an English lawyer, does it concern the formulation of new rights and duties which are to govern the parties into the future. Of course, there will be cases where one side seeks to prevent the other from doing something in the future which, if it were done, would be in breach of that party's obligations. Further, in cases affecting the status of parties (as, for example, in community care and family disputes), the judgment of the court will directly affect the future rights and duties of the parties. Nonetheless, civil law is primarily backwards-looking in its resolution of disputes⁷⁴².

That is an inevitable result of the rule of law. Because the parties have made some relevant transaction, or one stands in some identified relationship to the other, each of the parties has certain rights and duties. The rights and duties which each has may be enforced, and it is no answer to that claim to say that it would have been better if the rights and duties had been structured differently. The most critical institutional consequence of the

⁷⁴¹ Hirschl, R., 2000. Looking Sideways, Looking Backwards, Looking Forwards: Judicial Review vs. Democracy in Comparative Perspective. *U. Rich. L. Rev.*, 34, p.415.

⁷⁴² Moore, C.W., 2014. The mediation process: Practical strategies for resolving conflict. John Wiley & Sons.

proposition that the application of public power to the resolution of disputes must be rooted in structures established by society is that the mediator must be independent of the parties. Not only must the mediator be independent of the parties, but the mediator must also be independent of other influences. At first sight, the proposition is paradoxical⁷⁴³. Why should the mediator who is applying *public* power in resolving a dispute be free from control by other elements of the structures by which society is governed? What would be wrong with the mediator taking account of what those who have charge of the economic or other policy say would further that policy in the interests of the society as a whole?

The answer lies in the requirement that the law should be predictable and capable of being ascertained before parties act or undertake obligations one to another. If the mediator is not independent of external influence, the rules which are given effect in resolving the dispute are not the known and predictable rules upon which the parties were and must be entitled to act. A new and different consideration has intruded in the conflict. A requirement will ordinarily assist independence of mediation that

⁷⁴³ Coley, D., 2015. The Mediator as an Evaluator: An Analysis of Evaluation as a Method for the Lawyer's Reform to Mediation. *World Academy of Science, Engineering and Technology, International Journal of Law and Political Sciences*, 2(11).

proceedings for the resolution of the dispute take place in public. The public performance of the task tends to expose the existence of preconceptions about a disagreement and tends to reveal the presence of any inappropriate external influence on the process. However, with the use of the Care Act 2014, the likelihood that this could happen is unlikely owing to personal confidentiality and confidence issues of the people with disabilities.

Two other institutional consequences should be noticed. Whatever may be the procedures adopted in a court system (adversarial, inquisitorial or as is increasingly the case, a mixture of the two⁷⁴⁴) representation of parties by skilled lawyers permits an mediator to consider competing contentions with a degree of detachment that is not possible if the mediator has had to be responsible for identifying and formulating the competing claims⁷⁴⁵. The more complicated the dispute, the more necessary it is for the mediator to be assisted by the parties in expressing not only the issues to be decided but also the arguments that are advanced in support.

⁷⁴⁴ Sevier, J., 2014. The truth-justice tradeoff: Perceptions of decisional accuracy and procedural justice in adversarial and inquisitorial legal systems. *Psychology, Public Policy, and Law*, 20(2), p.212.

⁷⁴⁵ Langer, M., 2015. In the Beginning Was Fortescue: On the Intellectual Origins of the Adversarial and Inquisitorial Systems and Common and Civil Law in Comparative Criminal Procedure.

It cannot be assumed that a court will always be right. The distinguished English judge, Sir Robert Megarry, said⁷⁴⁶: "No human being is infallible, and for none are there more public and authoritative explanations of their errors than for judges." The legal system, being a human system, is inevitably fallible⁷⁴⁷. A system of appeal or review is, therefore, necessary to deal with some of the errors that are made. The point to notice is that I say "some" of the errors that are made, not all. It is the human capacity to achieve absolute perfection.

Further, not only is it unrealistic to attempt to achieve such perfection; the finality of judicial decision-making is essential. Statutes or other principles which limit the time within which claims may be made or limit the circumstances in which a dispute may be reopened are fundamental to the proper ordering of society. Another distinguished English judge, Lord Wilberforce⁷⁴⁸, said⁷⁴⁹:

⁷⁴⁶ Miles, W.J. and Swan, N.K., 2017. Climate Change and Dispute Resolution. *Dispute Resolution International*, 11(2); and "DISPUTE RESOLUTION AND THE RULE OF LAW" SINO-AUSTRALIAN SEMINAR, BEIJING, 20-22 NOVEMBER 2002

⁷⁴⁷ Lewis, O.C., 1969. Systems theory and judicial behaviourism. *Case W. Res. L. Rev.*, 21, p.361.

⁷⁴⁸ Lord Wilberforce spoke about the importance of law reform, urging simplification and reduction in the amount of legislation and greater consolidation of our existing laws. He often spoke of the role of the judiciary in society, commenting in a debate in 1996 on the way that judges "have become much more outward-looking and much more concerned with

"Any determination of disputable fact may, the law recognises, be imperfect: the law aims at providing the best and safest solution compatible with human fallibility and having reached that solution it closes the book. The law knows, and we all know, that sometimes fresh material may be found, which perhaps might lead to a different result, but, in the interest of peace, certainty and security it prevents further inquiry. It is said that in doing this, the law is preferring justice to the truth. That may be so: these values cannot always coincide. The law does its best to reduce the gap. However, there are cases where the certainty of justice prevails over the possibility of truth, and these are cases where the law insists on finality. For a policy of closure to be compatible with justice, it must be attended with safeguards: so the law allows appeals: so the law, exceptionally, allows appeals out of time: so the law still more exceptionally allows judgments to be attacked on the ground of fraud: so limitation periods may, exceptionally, be extended. However, these are exceptions to a general rule of high public importance, and as all the cases show,

social needs and social imperatives", adding characteristically that there are "signs now of a rather more cautious attitude" in the area of public law.

⁷⁴⁹ Bradley, A.W. and Ewing, K.D., 2007. Constitutional and administrative law (Vol. 1). Pearson Education; and *Re Amptill Peerage* [1977] AC 547 at 569.

they are reserved for rare and limited cases, where the facts justifying them can be strictly proved."

The decision about how many appeals, or reviews,⁷⁵⁰ a case may have is not without difficulty. The general rule adopted in many legal systems is that the parties should have a right to seek one review of what has been decided but that any later review should be only with the permission of the higher court⁷⁵¹. Whatever may be the detail of the rules that are adopted, the institutional consequence which it is important to recognise is that there must be some system for appeal or review of decisions in all but exceptional cases. This is an important justification for disability rights but has to be considered against people resisting finding a solution.

The structural considerations to which have been referred are those which affect the mediation of civil disputes by courts. What if both parties choose to resolve their conflict by some other means? First, it must be the voluntary decision of both parties. Secondly, if it is done, there may come the point in that process where a party seeks to have the State give effect to the outcome that is achieved. That can be done only if the procedures

⁷⁵⁰ Dalton, H.L., 1985. Taking the right to appeal (more or less) seriously. *The Yale Law Journal*, 95(1), pp.62-107.

⁷⁵¹ Daly, S., 2017. *Public Law in the Tribunals and the Case for Reform*.

which the parties employ lead to rights and obligations which can be enforced or do not affect pre-existing rights and responsibilities.

The remaining part of this chapter will focus on the theory of dispute resolution and alternative forms. The rule of law is a concept that, in some respects, reflects the society to which it applies, and is, therefore, open and accessible to people with disabilities.

5.4 What difference to litigation does mediation offer?

Laurence Boulle has argued that traditionally dispute resolution processes have had system-maintenance functions: in broad terms, they maintain the societal status quo through their functions of compensating, punishing, distributing and restoring.⁷⁵²

If this statement is accurate, then we can see that “*traditional*” dispute resolution processes (i.e. litigious adversarial processes)

⁷⁵² Laurence Boulle, ‘Minding the gaps: reflecting on the story of Australian mediation’ (2000) 3(1) ADR Bulletin 1,

have significant shortcomings for any relational rather than transactional disputes. It is well recognised that the costs of litigation go well beyond financial costs and include emotional expenditure and damage of relationships between disputants (local authorities and people with disabilities). This perhaps gives some insight into the bases for greater community embrace of mediation over time. A convenient starting point for considering the differences between litigation and mediation is to identify the perceived failings, in the present day and age, of litigation as a form of dispute resolution. A succinct analysis is contained in the United Kingdom's *Woolf Report*.⁷⁵³

[i]t is too expensive in that the costs often exceed the value of the claim; too slow in bringing cases to a conclusion and too unequal: there is a lack of equality between the powerful, wealthy litigant and the under-resourced litigant. It is too uncertain: the difficulty of forecasting what litigation will cost and how long it will last induces the fear of the unknown; it is incomprehensible to many litigants.⁷⁵⁴

⁷⁵³ Access to Justice: Final Report (HMSO, July 1996) 2 [2]. Available at: <http://webarchive.nationalarchives.gov.uk/+/http://www.dca.gov.uk/civil/final/contents.htm>

⁷⁵⁴ Similarly the Jackson Report advocates strongly in favour of non-litigious dispute resolution and mandatory pre action procedures and for a comprehensive and erudite discussion of both Australian and UK review, consultations and recommendations see 'Resolving Disputes without Courts: Measuring the Impact of Civil Pre-action Obligations', Background

In contradistinction Bridge (2012)⁷⁵⁵ identifies the attractions of mediation over litigation as including - It is usually a far more economical means of dispute resolution; it is fast; it is confidential; it is almost infinitely flexible; because the parties themselves make the ultimate decision, in most instances the parties perceive both the process and the result to be fair; it minimises risk for the parties whether the risk be financial, cultural or risk of any other sort.

An additional area of potential difference is confidentiality, which is vital for people with disabilities as service users. Thus, there is potentially a valid argument that anything raised in mediation and should be disclosed by the parties in their litigation. Indeed, as regards “*information*” known to a party already involved in litigation addressing the same subject matter at or preceding mediation, the argument is irresistible. As regards confidentiality Justice Bergin of the Supreme Court of NSW, she observed that a

Paper, Australian Centre For Court And Justice System Innovation, Monash University, March 2012).

⁷⁵⁵ Campbell Bridge, ‘Comparative ADR In The Asia-Pacific – Developments In Mediation In Australia, Paper presented at the 5Cs of ADR Alternative Dispute Resolution Conference, Singapore, 4-5 October 2012.

most important tenet of mediation in Australia is that it is confidential⁷⁵⁶. Justice Bergin, in common with most authors on the topic, identifies that “mediation is a cost-effective and efficient mechanism for resolving disputes”⁷⁵⁷.

The American Bar Association,⁷⁵⁸ in directly addressing the benefits of mediation in their public education materials identifies nine such advantages, namely that the person with disabilities gets to decide the focus is on needs and interests; for a continuing relationship; Mediation deals with feelings; higher satisfaction; informality; faster than going to court; lower cost and privacy. Recent academic research supports those benefits regarding family law – McGowan (2018)⁷⁵⁹ in Ireland and the UK; and Anderson (2017)⁷⁶⁰

⁷⁵⁶ Patricia Bergin, ‘The objectives, scope and focus of mediation legislation in Australia’ (2013) 2 *Journal of Civil Litigation Practice* 49.

⁷⁵⁷ *Ibid*

⁷⁵⁸ *See*

http://www.americanbar.org/groups/public_education/resources/law_related_education_network/how_courts_work/mediation_advantages.html

⁷⁵⁹ McGowan, D., 2018. Reframing the mediation debate in Irish all-issues divorce disputes: from mediation vs. litigation to mediation and litigation. *Journal of Social Welfare and Family Law*, pp.1-14.

⁷⁶⁰ Anderson, J.L., 2017. *Divorcing Couples' Experience With Child Custody Mediation and Litigation* (Doctoral dissertation, Walden University).

Of these benefits perhaps, those who might most starkly differentiate mediation from litigation are the preservation of relationships and self-determination. While the preservation of relationships is often the focus of twenty-first-century litigation, especially but not exclusively in addressing family law disputes, less formal and less adversarial court processes⁷⁶¹ and objects for the conduct of litigation can only go so far. Despite increasing use and popularity of therapeutic jurisprudence principles, even this cannot preserve a relationship (nor meet the needs of those involved in a dispute) as successfully as the avoidance of litigation altogether through needs-based self-determination of the dispute.

The next stage is to review the various Models of Mediation and choose which one would be appropriate – or at least the most advantageous to use concerning the Care Act 2014 and dispute resolution.

5.5 Models of Mediation

One of the most common forms of alternative dispute resolution authorised is mediation. As seen above, the reasons this thesis has recommended that the use of mediation is principally savings in

⁷⁶¹ See

http://www.lrc.justice.wa.gov.au/_files/P92_Consultation_Papers_voll.pdf

cost, person-centred focus and time⁷⁶², but many other significant reasons have been highlighted. These include: studies showing the high level of satisfaction⁷⁶³; arrangements may be made quickly; the process usually takes one day or less; simple and easy process; confidentiality; process non-binding and "without prejudice"⁷⁶⁴ and parties can leave it at any time and continue with litigation. Importantly, the outcome is within the control of the parties; and agreement resulting from mediation forms a binding contract between the parties like any other negotiated agreement. However, no one can be compelled to reach an agreement, and a decision is not imposed in mediation⁷⁶⁵. Mediation is not 'a one-size-fits-all' dispute resolution process but one which needs to be adaptive to its users – in our case people with disabilities as service users and local authorities.

⁷⁶² Clark, B., 2015. Can courts enhance the use of mediation?. *Asian Journal on Mediation*, 2015, pp.49-59.

⁷⁶³ Slater, A., Shaw, J.A. and Duquesnel, J., 1992. Client satisfaction survey: A consumer evaluation of mediation and investigative services. *Family Court Review*, 30(2), pp.252-259. They surveyed 557 people who had received mediation services in Orange State, California between 1987-1988 which included satisfaction of the process, the outcomes such as visitation rights; and how the parent felt that the children had processed.

⁷⁶⁴ Andrews, N., 2016. Mediation in England: organic growth and stately progress. *Revista Eletrônica de Direito Processual*, 9(9).

⁷⁶⁵ Goldberg, S.B., Sander, F.E., Rogers, N.H. and Cole, S.R., 2014. *Dispute resolution: Negotiation, mediation and other processes*. Wolters Kluwer Law & Business.

Mediation, defined here as a social process in which a third party helps people in conflict understand their situation and decide for themselves what, if anything, to do about it, has a long history and roots in many cultures⁷⁶⁶. Mediation began to develop as a distinct social institution in the U.S. during the 20th century,⁷⁶⁷ with the earliest organised use of mediation in the employee relations arena. This was followed by various efforts to introduce mediation to the courts and in civil rights disputes,⁷⁶⁸ as well as attempts to use community mediation to further agendas of legal and social

766 For various perspectives on the history of mediation describing the history and current trends in the "informal justice" arena are: Rogers, N.H., Cole, S.R. and McEwen, C.A., 2001. *Mediation: Law, policy, practice* (Vol. 1). Clark Boardman Callaghan; Folberg, J. and Taylor, A., 1986. *Mediation: A comprehensive guide to resolving conflicts without litigation.*; Kovach, K.K. and Love, L.P., 1998. *Mapping Mediation: The Risks of Riskin's Grid.* *Harv. Negot. L. Rev.*, 3, p.71.; Bush, R.A.B., 1994. *The promise of mediation: Responding to conflict through empowerment and recognition.* Jossey-Bass.; Folger, J. and Bush, R.A.B., 2014. *Transformative Mediation.* *International Journal of Conflict Engagement and Resolution*, 2, p.62.; Della Noce, D.J., 2001. *Mediation Theory and Policy: The Legacy of the Pound Conference.* *Ohio St. J. Disp. Resol.*, 17, p.545. ; McCorkle, S. and Reese, M.J., 2014. *Mediation theory and practice.* SAGE Publications.

767 Rogers, N.H., Cole, S.R. and McEwen, C.A., 2001. *Mediation: Law, policy, practice* (Vol. 1). Clark Boardman Callaghan

768 Merry, S.E. and Milner, N. eds., 2010. *The possibility of popular justice: A case study of community mediation in the United States.* University of Michigan Press.

reform.⁷⁶⁹ In recent decades mediation has entered many areas of British life. Some Government agencies and private businesses offer both in-house mediation programs and outside referrals in order to handle disputes. Court-connected mediation programs are increasing, as courts look to mediation to control and reduce the Legal Aid budgets and improve the public's satisfaction with the judicial system.⁷⁷⁰

5.5.1 Development of Mediation Frameworks and Theories

The impressive growth in the *use* of mediation in the U.S, Europe and Australia, while this stands in marked contrast to the slower growth in the explanation and understanding of mediation practice.⁷⁷¹ More than one scholar has criticised the mediation field for its lack of an articulated theoretical framework - a coherent description of "the when and why" of mediator intervention.^{772 773} There is an examination of the developments in

769 Hensler, D.R., 2003. Our courts, ourselves: how the alternative dispute resolution movement is re-shaping our legal system. Penn St. L. Rev., 108, p.165.

770 Flynn, A. and Hodgson, J., 2017. Access to Justice and Legal Aid Cuts: A Mismatch of Concepts in the Contemporary Australian and British Legal Landscapes. Access to Justice and Legal Aid: Comparative Perspectives on Unmet Legal Need, p.1.

771 Della Noce, D.J., 2001. Mediation Theory and Policy: The Legacy of the Pound Conference. Ohio St. J. Disp. Resol., 17, p.545.

772 Scimecca, J.A., Avruch, K. and Black, P.W. eds., 1998. Conflict resolution: Cross-cultural perspectives. Praeger.

explaining and understanding "the when and why" of mediation practice - from the "lay theories" that have informed much of the field, to Bush and Folger's⁷⁷⁴ articulation of three distinct and coherent ideologically based theoretical frameworks: the problem-solving framework, the harmony framework, and the transformative framework.

According to Bush and Folger's analysis, the problem-solving framework is based on Individualist ideology, the harmony framework is found on organic ideology, and the transformative framework is found in Relational ideology^{775 776}. We then trace the development of the transformative framework since its formulation in 1994⁷⁷⁷ and share the insights gained along the way regarding the impact of increasing intellectual clarity and differentiation in the mediation field. We conclude with a

773 Kolb, D.M. and Porter, J.L., 2015. *Negotiating at work: Turn small wins into big gains*. John Wiley & Sons.

774 Folger, J. and Bush, R.A.B., 2014. Transformative Mediation: A Self-Assessment. *International Journal of Conflict Engagement and Resolution*, 2, p.20.

775 Wilson, B., 2017. 'Leave no footprints': on the role of influence in mediation.

776 Folger, J.P. and Bush, R.A.B., 1996. Transformative mediation and third-party intervention: Ten hallmarks of a transformative approach to practice. *Conflict Resolution Quarterly*, 13(4), pp.263-278.

777 Moore, C.W., 2014. *The mediation process: Practical strategies for resolving conflict*. John Wiley & Sons.

discussion of the implications of ideologically based academic distinctions for mediation practice and policy, and recommendations for a fresh, theoretically informed, approach to policy initiatives with the framework of the Care Act 2014.

While scholars may criticise the mediation field for its lack of articulated, scholarly mediation theory⁷⁷⁸, this should not be confused with a complete absence of theoretical grounding in the mediation field. If "theory" is understood as "the when and why" of intervention,⁷⁷⁹ it is apparent that mediators must have a theory underlying their practices, no matter how naive or obscured.⁷⁸⁰ While mediators may indeed draw upon articulated, scholarly theories to construct their explanatory and interpretive frameworks

⁷⁷⁸ Chowdhury, J.A., 2012. *Gender Power and Mediation: Evaluative Mediation to Challenge the Power of Social Discourses*. Cambridge Scholars Publishing. It investigates the practice of family mediation and some of the challenges that may hinder its effective use by marginalised groups in a society. Those challenges include gendered power disparity and family violence, especially towards women, and the discussion extends to how the challenges can be overcome through a practice of evaluative mediation to provide fair outcomes for women.

⁷⁷⁹ Scimecca, J.A., 1993. Theory and alternative dispute resolution: A contradiction in terms. *Conflict resolution theory and practice: Integration and application*, pp.211-221.

⁷⁸⁰ Empirical analysis of the discourse of mediators as they conducted their sessions, and as they explained their in-session practices during interviews, has illustrated that mediators either drew upon articulated scholarly theoretical frameworks for mediation practice or constructed their own theoretical frameworks in order to explain their practices, and that they drew upon those same frameworks as they engaged in practice.

for "the when and why" of practice,⁷⁸¹ they are not limited to such theoretical frameworks. Even if not drawing upon articulated scholarly frameworks for mediation practice, mediators can and do actively construct their theoretical frameworks to give meaning and order to their work.⁷⁸² This is because mediators, like all other social actors, are "lay theorists" - people with their vocabularies, frames of meaning, interpretive schemes and resources, and explanations for their social worlds and activities.⁷⁸³ As mediators interact with the parties during the mediation process, they regularly draw upon their preferred theoretical frameworks - whatever the source - to interpret the unfolding interactions and to make choices about when and how to intervene based upon their interpretations.⁷⁸⁴ In turn, those decisions reflect the mediators'

⁷⁸¹ See, e.g., the analysis of how mediators drew upon the transformative framework articulated by Bush & Folger Ibid, both as they conducted their mediation sessions and as they later explained what they were doing in their sessions and why. Della Noce Ibid, at 148-97, 251-304.

⁷⁸² for example, the analysis of how mediators constructed problem-solving frameworks by drawing on the language, metaphors and practices of problem-solving itself, as well as the complementary "imported" theories of negotiation and systems therapy, both as they conducted their mediation sessions and as they later explained what they were doing in their sessions and why. See Della Noce Ibid

⁷⁸³ Giddens, A., 1991. *Modernity and self-identity: Self and society in the late modern age*. Stanford university press.

⁷⁸⁴ Della Noce Ibid

goals for intervention, embedded in their own fundamentally ideological explanations of the social world and social activities.⁷⁸⁵

As mediation practice has developed, mainly in the absence of scholarly and theoretical frameworks explaining mediation as a distinct social process, practising mediators⁷⁸⁶ have tended to construct and express their own "lay" theoretical frameworks by relying upon "imported" theories, and "skills and techniques" that were presumed to be theory-free.

5.5.2 "Imported Theories"

Another response to the absence of articulated mediation theory has been the marked tendency in the mediation field to "import" theories from other domains: primarily negotiation theory,⁷⁸⁷ but also various therapeutic theories⁷⁸⁸ and even various theories from

⁷⁸⁵ See Bush & Folger, *Ibid* 236-59. See also Della Noce, *Ibid* for an empirical discourse study illustrating the links between mediators' goals, practices and ideologies.

⁷⁸⁶ Goldberg, S.B., Sander, F.E., Rogers, N.H. and Cole, S.R., 2014. *Dispute resolution: Negotiation, mediation and other processes*. Wolters Kluwer Law & Business.

⁷⁸⁷ It is quite common for scholars and practitioners in the mediation field to draw upon negotiation theory as an explanation for the mediation process and grounding for the mediator's work. For examples of mediation literature that imports negotiation theory, see Lewicki, R.J., Saunders, D.M., Minton, J.W., Roy, J. and Lewicki, N., 2011. *Essentials of negotiation*. Boston, MA: McGraw-Hill/Irwin.

⁷⁸⁸ When used as grounding for mediation practice, therapeutic theories are typically blended with negotiation theory. For an example from the

the physical sciences.⁷⁸⁹ Imported theories are useful because they, too, provide a certain amount of much-needed grounding for the practitioner. However, because none of these theories was developed expressly to explain third-party interventions in conflict, the theories became somewhat distorted when imported and adapted to the goals of third-party intervention.⁷⁹⁰ For example, interest-based negotiation theory provides one useful explanation of two-party bargaining that parties directly engaged in a negotiation can choose to draw upon (or not) in order to understand the behaviour of the other party and to strategise their behaviour. However, when imported into the mediation process and applied prescriptively by a third party, the fundamental character of interest-based negotiation is changed: the third party imposes the framework on both parties, structures their

mediation literature, see, Joel, L. and Shien, L.M.T. eds., 2016. *Contemporary Issues in Mediation* (Vol. 1). World Scientific and Irving, H.H. and Benjamin, M., 1995. *Family mediation: Contemporary issues*. Sage Publications.

⁷⁸⁹ Benjamin, R.D., 1990. The physics of mediation: Reflections of scientific theory in professional mediation practice. *Conflict Resolution Quarterly*, 8(2), pp.91-113.

⁷⁹⁰ Della Noce, D.J., 2001. Mediation Theory and Policy: The Legacy of the Pound Conference. *Ohio St. J. Disp. Resol.*, 17, p.545. At the same time, Della Noce has argued elsewhere that importing theoretical frameworks from other disciplines has distorted the mediation process -detracting from its character as a distinct social process and institution, and instrumentalising it in service of the goals and values of such processes as adjudication, litigation, negotiation, and therapy.

interactions accordingly, assumes the power to determine what the parties' hidden interests are and when they have been uncovered, and becomes as invested in the production of a "win-win" solution as the parties themselves are presumed to be.⁷⁹¹

5.5.3 “Theory-free” skills and Techniques

Finally, the lack of scholarly mediation theory has produced an overemphasis on skills and techniques in the field of mediation, or what Scimecca calls "blind faith in the *how* of the processes"⁷⁹² The "how to" emphasis frames mediation practice as a simple matter of skills application, uncomplicated by deeper theoretical considerations.

As a consequence, mediator development is framed as a matter of technical "training" and skills acquisition rather than education. "How to" workshops and publications, devoid of articulated theoretical grounding, proliferate. In these workshops and publications, experts typically focus on *how* to intervene and avoid the deeper questions of *when* and *why*. Skills, "tricks" and "tools"

⁷⁹¹ Folger, J. and Bush, R.A.B., 2014. Transformative Mediation. *International Journal of Conflict Engagement and Resolution*, 2, p.62.

⁷⁹² Scimecca, J.A., 1993. Theory and alternative dispute resolution: A contradiction in terms. *Conflict resolution theory and practice: Integration and application*, pp.211-221.

are emphasised, while goals and underlying values are either obscured or presumed merely.

This "how-to" viewpoint is quite popular in the mediation field, and remarkably far-reaching. For example, the popular explanation for observed differences in mediators' practices - that mediators are assumed to be working toward the same goals, but with individual "style" variations in how they apply their specific skills⁷⁹³ - is based on the "how-to" view. Similarly, numerous mediator competency-testing initiatives are also based on this view, as evidenced by the focus on the evaluation of the "how," that is, the observed performance of specific skills according to various checklists that are assumed to be theory-free.⁷⁹⁴ These initiatives generally fail to consider the relationship of mediator goals and values to the observed performance, or the likelihood that there could be very different goals and values among mediators that could shape competent performance in fundamentally different ways.⁷⁹⁵

⁷⁹³ Krivis, J. and McAdoo, B., 1997. A style index for mediators. *Alternatives to the High Cost of Litigation*, 15(11), pp.157-168.

⁷⁹⁴ Scoliere, D., 2014. Is the Lack of Credentialing for Mediators Jeopardizing the Future of the Profession. *Geo. J. Legal Ethics*, 27, p.875.

⁷⁹⁵ Bush, R.A.B., 2003. One Size Does Not Fit All: A Plualistic Approach to Mediator Performance Testing and Quality Assurance. *Ohio St. J. on Disp. Resol.*, 19, p.965.

Reliance on importing theories from other disciplines, and an emphasis on skills and techniques that are presumed to be theory-free, all represent related responses by mediators to the relative lack of meaningful articulated theories of mediation. This fails to encourage a thoughtful examination of the reality that mediator practices can and do influence the parties' conflict, the questions of what kinds of influence are appropriate and why, the nature of differences in mediators' motives and orientations, and how different underlying ideologies shape mediators' goals, and therefore, their influence on the conflict, in very different ways.

5.5.4 Clarification of Conflict Theory

In *The Promise of Mediation*, Bush and Folger⁷⁹⁶ tried to move beyond lay theories, grounding their analysis of mediation practice in clearly articulated theoretical models of both conflict in general and mediation in particular. Building on the body of research findings regarding mediators' practices noted above, their own experiences as mediators, and their insights as legal and communication scholars respectively, they acknowledged the inevitability of some mediator influence on the parties' interactions and the outcome of the mediation.⁷⁹⁷ They did not reject the

⁷⁹⁶ Bush, R.A.B. and Folger, J.P., 2004. *The promise of mediation: The transformative approach to conflict*. John Wiley & Sons.

⁷⁹⁷ *Ibid* 75-77

mounting body of empirical research that defied the mythology of mediation practice but sought a framework in which it could be explained.⁷⁹⁸ The challenge was to identify the social forces and interpretive frameworks underlying the exercise of mediator influence and determine how those forces and frameworks might shape mediator influence in different ways, with different social consequences. This led to the insight that mediator influence on the parties' conflict took different forms and had different social consequences depending upon the mediator's underlying ideology and how that ideology shaped the mediator's goals and practices.⁷⁹⁹ Building on this insight, Bush and Folger clarified that three models of practice shared the mediation field: *problem-solving*, *harmony*, and *transformative*.⁸⁰⁰ Each model of mediation practice assumes a particular view of the nature of the conflict, which in turn is built upon and reflects the underlying values and assumptions of a particular ideology.⁸⁰¹ Bush and Folger also

⁷⁹⁸ Ibid 75-77, 104-108.

⁷⁹⁹ Eagleton, T., 2014. Ideology. Routledge.

"Ideologies" are the socially constructed, socially shared, meaning systems that members of social- groups use to view, organize, interpret and judge their surrounding world.

⁸⁰⁰ Bush & Folger, Ibid at 236-259.

⁸⁰¹ While some may suggest that there is a much wider variety of practice in the field than three models can capture, many of the other "models" put forth can actually be explained as variations on one of these fundamental theoretical frameworks. For example, "

argued that a mediator's preferred framework for practice was less a matter of situational strategy or personal style than it was a matter of his or her fundamental ideology.⁸⁰² The two most prevalent models, problem-solving and transformative, are outlined in the sections that follow.⁸⁰³

5.5.5 The Problem-Solving Model

Bush and Folger argued that the *problem-solving* model of mediation was based upon an essentially psychological/economic view of the human conflict.⁸⁰⁴ According to this model, conflict represents a problem in solving the parties' incompatible needs and interests⁸⁰⁵. Because a problem solved is a conflict resolved, the model presumes that a solution-typically represented by a

therapeutic" mediation as described in Benjamin, M. and Irving, H.H., 1995. Research in family mediation: Review and implications. Conflict Resolution Quarterly, 13(1), pp.53-82.

⁸⁰² Bush & Folger, Ibid at 236-259.

⁸⁰³ Pinto, J., 2016. Peacemaking as ceremony: The mediation model of the Navajo Nation. Creating the Third Force: Indigenous Processes of Peacemaking, p.163. The harmony model, based in Organic ideology, is not widely relied upon in contemporary Western society.

⁸⁰⁴ Cobb, S., "Einsteinian Practice and Newtonian Discourse: An Ethical Crisis in Mediation"(1991). Negotiation J., 7, p.87. For works by other scholars who have noted and explored the psychological / economic basis of a problem-solving approach to conflict in general, and to mediation practice in particular, see Della Noce Ibid; Cobb, S., 1993. Empowerment and mediation: A narrative perspective. Negotiation Journal, 9(3), pp.245-259.

⁸⁰⁵ Bush & Folger, Ibid, at 55-75.

tangible settlement agreement - is "what the parties want."⁸⁰⁶ Therefore, the mediator's goal is to generate an agreement that solves tangible problems on fair and realistic terms, and good mediator practice is a matter of issue identification, option creation, and effective persuasion to "close the deal." In this model, there is a heavy reliance on mediator initiative and direction because both are useful in generating settlement.⁸⁰⁷ The problem-solving framework is based on and reflects an *individualist* ideology, in which human beings are assumed to be autonomous, self-contained, atomistic individuals, each motivated by the pursuit of the satisfaction of his or her separate self-interests.⁸⁰⁸ The problem-solving model, while seldom going by that precise name, and seldom acknowledging or exposing its

⁸⁰⁶ Della Noce, *Ibid*, at 148-186, for an analysis of the importance to mediators of this concept of "what the parties want." She observed that mediators used this concept to address the fundamental dilemma of their own agency in mediation. That is, they "untroubled" the nature and extent of their own influence in a mediation session by aligning their influence with "what the parties want." Specifically, she found through her interviews with mediators that problem-solving mediators described a solution to the problem as "what the parties want."

⁸⁰⁷ Folger, J.P. and Bush, R.A.B., 1994. *Ideology, orientations to conflict, and mediation discourse. New directions in mediation: Communication research and perspectives*, pp.3-25.

⁸⁰⁸ Noce, D.J.D., Bush, R.A.B. and Folger, J.P., 2002. *Clarifying the theoretical underpinnings of mediation: Implications for practice and policy. Pepp. Disp. Resol. LJ*, 3, p.39.

ideological roots, is the dominant model in the mediation field.⁸⁰⁹ The predominance of this model also explains, in part, the persistence of the lay theories that have emerged in the mediation field - all partake of the same individualist ideology, and psychological/economic view of the conflict, underlying the problem-solving model.⁸¹⁰

5.5.6 The Transformation Model

In contrast to problem-solving, Bush and Folger articulated the *trans- formative* model of mediation.⁸¹¹ This model takes a fundamentally social/communicative view of the human conflict.⁸¹² According to this model, a conflict represents first and

⁸⁰⁹ For empirical evidence of the dominance of the problem-solving model, drawn from the discourse of mediators, see Della Noce, *Ibid*

⁸¹⁰ The various lay theories discussed above are all compatible with, and can be used to further, the problem-solving mediator's goal of producing a settlement agreement based on assumptions of individual self-interest. They are naive expressions of the dominant problem-solving theoretical framework of the field. But the lay theories have an befuddling dimension. They obscure the nature, extent and underlying value-base of mediator influence, whereas an articulated theoretical framework exposes these features and thereby opens them to critical reflection, dialogue and informed choice.

⁸¹¹ Folger, J.P. and Bush, R.A.B., 1996. Transformative mediation and third-party intervention: Ten hallmarks of a transformative approach to practice. *Conflict Resolution Quarterly*, 13(4), pp.263-278.

⁸¹² Wodak, R. and Meyer, M. eds., 2009. *Methods for critical discourse analysis*. Sage. The roots of this view of conflict can be found in the postmodern and social constructionist literature of the social sciences, particularly in the discipline of communication science.

foremost a crisis in some human interaction - an interactional turmoil with a somewhat standard and predictable character.⁸¹³ Specifically, the occurrence of conflict tends to destabilise the parties' experience of both self and other, so that the parties interact in ways that are both more vulnerable and more self-absorbed than they did before the conflict.⁸¹⁴ Further, these negative dynamics often feed into each other on all sides as the parties interact, in a vicious circle that intensifies each party's sense of weakness and self-absorption.⁸¹⁵ As a result, the interaction between the parties quickly degenerates and assumes a mutually destructive, alienating, and dehumanising character.⁸¹⁶ For most people, according to transformative theory, being caught in this kind of harmful interaction is the most significant negative impact of conflict.⁸¹⁷ However, the transformative model posits that, despite conflict's potentially destructive impacts on interaction, people can change the quality of their interactions to reflect relative personal strength or self-confidence (the empowerment shift) and relative openness or responsiveness to the

⁸¹³ Pope, S.G. and Baruch Bush, R.A., 2000. UNDERSTANDING CONFLICT AND HUMAN CAPACITY The Role of Premises in Mediation Training. *Family Court Review*, 38(1), pp.41-47.

⁸¹⁴ Bush & Pope Ibid

⁸¹⁵ Ibid

⁸¹⁶ Ibid

⁸¹⁷ Ibid

other (the recognition shift).⁸¹⁸ Moreover, as these positive dynamics feed into each other, the interaction can regenerate and assume a constructive, connecting, and humanising character.⁸¹⁹ The model assumes that the transformation of the interaction itself is what matters most to parties in conflict - even more than a settlement on favourable terms.⁸²⁰ Therefore, the model defines the mediator's goal is helping the parties to identify opportunities for empowerment and recognition shifts as they arise in the parties' conversation, to choose whether and how to act upon these opportunities, and thus to change their interaction from destructive to constructive.⁸²¹ In transformative mediation, success is measured not by settlement *per se* but by party shifts toward personal strength, interpersonal responsiveness and productive interaction.⁸²² Efficient practice is focused on supporting

818 Ibid

819 Ibid

820 Folger, J. and Bush, R.A.B., 2014. Transformative Mediation. *International Journal of Conflict Engagement and Resolution*, 2, p.62.

821 Folger, J.P. and Bush, R.A.B., 2005. A response to Gaynier's "Transformative mediation: In search of a theory of practice". *Conflict Resolution Quarterly*, 23(1), pp.123-127.

822 Settlement is certainly possible in this model, and is not discouraged. The distinction is that settlement is not the mediator's goal, but rather one of the many choices that might open to the parties as an incidental benefit of improved inter- action. If mediators do their job, parties are likely to make positive changes in their interactions with each other and, as a result, find acceptable terms of resolution

empowerment and recognition shifts, by allowing and encouraging party deliberation and decision-making, and inter-party perspective-taking, in various ways. The transformative framework is based on and reflects *relational* ideology, in which human beings are assumed to be fundamentally social - formed in and through their relations with other human beings, mainly connected to others, and motivated by a desire for both personal autonomy and constructive social interaction.⁸²³

5.5.7 Developments in Transformative Theory

The articulation of these different theoretical frameworks and the distinctions between them generated significant interest among scholars and practitioners⁸²⁴. Practitioners who resonated with

for themselves where such terms genuinely exist. But the possibility is also left open that parties may voluntarily choose, and be satisfied, to leave the mediation with new insights on their choices and new interpersonal understandings but no agreement, or even to take the conflict to a different forum such as litigation. Settlement remains a distinct possibility - one choice available to the parties depending upon how their own goals and insights develop through the mediation conversation -but it is no longer the single outcome privileged by the mediator or the mediator's single measure of a successful mediation. See Della Noce, D.J., 1999. Seeing theory in practice: An analysis of empathy in mediation. *Negotiation Journal*, 15(3), pp.229-244.

⁸²³ Della Noce, D.J., 1999. Seeing theory in practice: An analysis of empathy in mediation. *Negotiation Journal*, 15(3), pp.229-244.

⁸²⁴ See Della Noce, *supra* note 12, at 65-73, for a review of the literature that has developed in response to Bush & Folger's analysis of theoretical frameworks for the mediation field.

transformative theory sought greater clarification about the realities and implications of this framework for their practices. Several major theory-building initiatives followed.

Bush and Folger began the Training Design Consultation (TDC) Project in 1996, which supported the development of a wealth of new training materials, exercises and models, and new insights on the transformative model.⁸²⁵

Bush and Folger began another initiative intending to disseminate the transformative framework for those who were drawn to it and to preserve a genuine opportunity for practitioners to engage in this form of practice. It had three critical dimensions: developing pictures of transformative practice via videos and transcripts, improving research methods to assess the progress of mediators building their competency in the transformative framework, and developing ways of analysing mediation policy to determine underlying assumptions and their effects on practice. The work of the PEI, coupled with the earlier work described here, ultimately led to the establishment of the Institute for the Study of Conflict Transformation, affiliated with Hofstra University Law School. The Institute functions as a "think tank," devoted to advancing the understanding of transformative mediation through research,

⁸²⁵ Umbreit, M. and Lewis, T., 2015. *A Humanistic Approach to Mediation and Dialogue: An Evolving Transformative Practice*.

policy analysis and consulting, and the development of resources for practitioners and program administrators.⁸²⁶

5.6 The Impact of promoting theoretical clarity

The initiatives described above show the process of clarification and further development of one particular conceptual framework for the mediation field. These actions have had a significant substantive impact on the field themselves, particularly among those who are drawn to, and wish to, practice from the transformative framework. At the same time, we observed that the very process of pursuing intellectual clarity by engaging in these initiatives had had an impact of its own, which also deserves to be articulated. Specifically, we have noted that: (1) pursuing intellectual clarity requires that value-based distinctions between models be highlighted; (2) there is a substantial incentive for mediators to deny value-based academic differences; and (3) conceptual differences have policy implications.

When Bush and Folger tried to clarify the values, goals and practices of transformative mediation⁸²⁷, they did so by also

⁸²⁶ Information about the Institute, its mission, history, and current projects, can be found at <http://www.transformativemediation.org>.

highlighting where, how and why these differed from those of problem-solving mediation ⁸²⁸ . Further clarifications of the theoretical framework of transformative mediation have also employed comparisons for the sake of clarity, concerning the structure of the transformative mediation process,⁸²⁹ the meaning of empathy in each framework,⁶⁹ approaches to training,⁷⁰ approaches to opening the mediation session,⁸³⁰ and approaches to assessing mediator competency.⁸³¹

Such comparative clarifications are immensely helpful to scholars and practitioners. An important part of clarifying any theoretical framework is clarifying not just what it *is* but also what it is *not*.⁸³² At the same time, however, these comparative clarifications at the

⁸²⁷ Folger, J.P. and Bush, R.A.B., 1996. Transformative mediation and third-party intervention: Ten hallmarks of a transformative approach to practice. *Conflict Resolution Quarterly*, 13(4), pp.263-278.

⁸²⁸ Umbreit, M. and Lewis, T., 2015. *A Humanistic Approach to Mediation and Dialogue: An Evolving Transformative Practice*.

⁸²⁹ Antes, J.R., Hudson, D.T., Jorgensen, E.O. and Moen, J.K., 1999. Is a stage model of mediation necessary?. *Conflict Resolution Quarterly*, 16(3), pp.287-301.

⁸³⁰ Bush, R.A. and Pope, S.G., 2004. *Transformative mediation. Divorce and family mediation: Models, techniques, and applications*, pp.53-71.

⁸³¹ Moore, C.W., 2014. *The mediation process: Practical strategies for resolving conflict*. John Wiley & Sons.

⁸³² Glaser, B., 2017. *Discovery of grounded theory: Strategies for qualitative research*. Routledge. comparative analysis is an important feature of various bodies of empirical research, such as grounded theory research, institutional discourse analysis, analysis of gender and discourse, and ideological discourse analysis.

theoretical and ideological level moved the mediation field to an unfamiliar place - a place where value-based distinctions among mediators' practices demanded to be acknowledged, discussed and accommodated.⁸³³ It is worth noting, in this context, that what the lay theories in the field accomplish is an obscuring and minimising of such important distinctions; each serves to perpetuate and reinforce the false image of a unitary or monolithic field of practice⁸³⁴. The articulation and clarification of the transformative framework posed a particular challenge for the mediation field, because accepting the distinctions on which it is based required the field to acknowledge that differences among mediators' practices are a matter of deeply-held values and assumptions.⁸³⁵ It also forced practitioners to grapple with the

⁸³³ Alfini, J.J., 2006. Mediation theory and practice. Lexis Nexis Matthew Bender. Noting differences among mediators' approaches to practice was not new to the mediation field. Historically, distinctions have been found between mediators' approaches in one empirical study after another. e.g., Alfini identifying "rashers," "bashers," and "hashers");

⁸³⁴ Field, R., 2017. Proposing A System of Contextual Ethics for Mediation for A Range of Mediation Models and in Both Ad Hoc and Institutional Environments.

⁸³⁵ Huang, H.X., 2016. Mediation under the Employment Relations Act 2000: Has the promise been fulfilled?. In *The Promise of Mediation*, Bush and Folger argue that mediation can bring about social transformation to create a better society for all. Huang inspired by Bush and Folger's argument and the success of REDRESS, she believes that mediation has brought about social transformation in the Australia and New Zealand employment context.

associated practical and policy implications. Hence, a response we have encountered frequently in the mediation field is that practitioners accept that differences among themselves exist at the level of "style" of practice, but deny that these differences exist at the level of theory, values or ideology. At first, we were puzzled by the impulse seen in some mediators and scholars to deny that fundamental value-based differences in theoretical frameworks for mediation practice were of any consequence or even that they existed.⁸³⁶ However, as we have continued to engage with the field around these and other issues, we have gained some insight into why this is so.

Finally, we have come to realise that the clarification of value-based theoretical distinctions in the field is fundamentally threatening because, ironically enough, the field of mediation cannot yet deal constructively with a difference. If some mediators examine their own fundamental beliefs and assumptions about practice, and in doing so, identify with a sub-community of practitioners that could be called an "us," in distinction to another sub-community that could be called a "them," the process of drawing this distinction is considered inherently provocative. This

⁸³⁶ Menkel-Meadow, C., 2017. *Dispute processing and conflict resolution: theory, practice and policy*. Routledge. She says that the impulse to deny theoretical and ideological distinctions has taken several different forms (although we have also seen some people take the rather inconsistent approach of arguing two or three at the same time.)

reflects the dominant problem-solving theoretical framework of the field: "us" and "them" must have competing self-interests, and conflict will exist as long as those interests are not mutually satisfied through finding common ground, compromising, and reaching a "win-win" agreement.⁸³⁷ There is not yet a field-wide discourse that accommodates and nurtures meaningful difference; on the contrary, the dominant discourse of the field operates on many levels to obscure, marginalise or even eliminate essential differences. This has become most apparent to us in the realm of mediation policy, a subject we take up in the next section.

5.7 Theoretical distinctions have policy implications

Mediation policy is continuously shaping, and being formed by, mediation practice. Typical policy topics in the mediation field include who can practice mediation, how to determine mediator competency, how the process should and should not be conducted, who is capable of participating in mediation as a client, the ethical obligations of the mediator, grounds for termination of the mediation process, whether the mediator should have reporting obligations to various agencies, whether mediation is the practice of law, and whether mediation should be

⁸³⁷ Bush & Folger, *Ibid*, for a description of markers of the predominant problem-solving framework.

confidential.⁸³⁸ Policy statements regarding these and other topics can be found in legislation, regulations, court rules, standardised forms, training standards, and codes of ethics, to name but a few places.⁸³⁹ Typically, policy statements directly address “mediation” in the generic, as if it is a unitary process. Of course, this is not true.

To some extent, this is understandable, as a great deal of mediation policy was developed before the clarification and differentiation of underlying theoretical frameworks.

Nonetheless, differences in the theory and practice of mediation are generally being ignored or minimised by policy-makers to this day⁸⁴⁰, and policy-makers continue to try to craft policies that treat mediation generically. However, efforts to craft theory-free, value-free system (or to interpret and enforce existing policies in a theory-free, value-free way) are useless. The underlying theory and values will emerge, because every policy that defines or limits mediation in any way is built on a particular value-based vision of

⁸³⁸ Rogers, N.H., Cole, S.R. and McEwen, C.A., 2001. *Mediation: Law, policy, practice* (Vol. 1). Clark Boardman Callaghan for extensive references to, and examples of, policy topics in the mediation field.

⁸³⁹ Sarah R. Cole in Goldberg, S.B., Sander, F.E., Rogers, N.H. and Cole, S.R., 2014. *Dispute resolution: Negotiation, mediation and other processes*. Wolters Kluwer Law & Business.

⁸⁴⁰ Menkel-Meadow, C.J. and Porter-Love, L., 2014. *Mediation: Practice, policy, and ethics*. Wolters Kluwer Law & Business.

what mediation is and should be, and by its very existence reproduces that vision. Through policy analysis, participation in various policy-making initiatives, and our encounters with mediators in the field, we have come across much direct evidence supporting this argument⁸⁴¹.

Many current mediation policies make certain types of practice normative, and others marginal, based on an unarticulated, underlying vision of "good" mediation - often without ever intending that this be so. Each policy that has this effect is significant in itself for the way it contributes to shaping the field. Many such policies have a cumulative effect. If predominantly based on a single vision of "good" mediation, they create an unspoken (and often fundamentally unexamined) norm. On the other hand, is based on a variety of unarticulated, possibly inconsistent, underlying visions, they have the additional unintended effect of creating a general state of confusion in policy affairs and the impasse in policy initiatives.⁸⁴² This is especially

⁸⁴¹ Rubinson, R., 2016. Indigency, Secrecy, and Questions of Quality: Minimizing the Risk of Bad Mediation for Low-Income Litigants. *Marq. L. Rev.*, 100, p.1353 and also, Della Noce, *Ibid* suggests that the idea that human interaction can and should be made to fit an organized, linear sequence, implicates a web of value-based assumptions about the nature of human interaction that are embedded in individualist ideology at 75-76.

⁸⁴² For an analysis of this dynamic with respect to performance-based assessment standards for mediators, see Bush, R.A.B., 1989. *Mediation*

true when we consider the tendency of some policy-making bodies to import, borrow, or cut-and-paste policy statements from other bodies without examining the underlying value-based vision of "good" mediation, a practice that results in internally inconsistent policy statements built on competing visions⁸⁴³.

There is a great deal of work to be completed regarding policy and procedures. It has been seen above in the earlier part of the chapter that there is a great fit between Mediation and dispute resolution under the Care Act 2014. However, there is the much enterprise required to develop the policy such as accreditation, funding, confidentiality, fir with legislation, statutory regulations, court rules, standardised forms, training standards, Rule of Law and codes of ethics. These are a few issues that need to be considered and developed for mediation to be appropriate and useful for people with disabilities, the Care Act, dispute resolution.

and adjudication, dispute resolution and ideology: An imaginary conversation. *J. Contemp. Legal Issues*, 3, p.1. and Alrø, H. and Dahl, P.N., 2015. Dialogic group coaching–inspiration from transformative mediation. *Journal of Workplace Learning*, 27(7), pp.501-513.

⁸⁴³ Lovan, W.R., Murray, M. and Shaffer, R. eds., 2017. *Participatory governance: planning, conflict mediation and public decision-making in civil society*. Routledge.

5.8 Advancing the Care Act through Clarity: A Proposal

Mediation policy is continuously shaping, and being formed by, mediation practice. As seen above, the reasons this thesis has recommended the use of mediation for dispute resolution is predominantly savings in cost (both financial and emotionally), person-centred focus and the fast time to resolve issues⁸⁴⁴. However, many other significant reasons have been highlighted why mediation would be useful for the Care Act 2014.

Further work is required to include who can practice mediation within a disability setting, how to determine mediator competency to practice with disability services, how the process should and should not be conducted, who has the capacity to participate in the mediation process as a client – and how is this resolved, the ethical obligations of the mediator, grounds for termination of the mediation process, whether the mediator should have reporting obligations to local authorities, whether mediation is the practice of law, and whether mediation should be confidential.⁸⁴⁵ At the

⁸⁴⁴ Clark, B., 2015. Can courts enhance the use of mediation?. *Asian Journal on Mediation*, 2015, pp.49-59.

⁸⁴⁵ Rogers, N.H., Cole, S.R. and McEwen, C.A., 2001. *Mediation: Law, policy, practice* (Vol. 1). Clark Boardman Callaghan for extensive references to, and examples of, policy topics in the mediation field.

moment for other uses such as commercial and family mediation, policy statements regarding these and other topics can be found in legislation, regulations, court rules, standardised forms, training standards, and codes of ethics, to name but a few places.⁸⁴⁶ The view I will offer is that questions and their answers will lie in the policy documents will need to be written with only the person with disabilities as a service user in mind. This is because of the power relationships between a local authority and the disabled person; the obligation for the process to empower rather than disempower; and the requirement for social justice to be achieved.

On the other hand, if the mediation policy for the Act is based on a variety of unarticulated, possibly inconsistent, underlying visions, they have the additional unintended effect of creating a general state of confusion in the Care Act's policy affairs and the impasse in dispute resolution policy initiatives.⁸⁴⁷ This is especially true when we consider the tendency of some policy-making bodies to import and borrow. However, cut-and-paste policy statements

⁸⁴⁶ Sarah R. Cole in Goldberg, S.B., Sander, F.E., Rogers, N.H. and Cole, S.R., 2014. *Dispute resolution: Negotiation, mediation and other processes*. Wolters Kluwer Law & Business.

⁸⁴⁷ For an analysis of this dynamic with respect to performance-based assessment standards for mediators, see Bush, R.A.B., 1989. Mediation and adjudication, dispute resolution and ideology: An imaginary conversation. *J. Contemp. Legal Issues*, 3, p.1. and Alrø, H. and Dahl, P.N., 2015. Dialogic group coaching—inspiration from transformative mediation. *Journal of Workplace Learning*, 27(7), pp.501-513.

from other bodies without examining the underlying value-based vision of "good" mediation for people with disabilities as service users are bound to fail, because a practice that results in internally inconsistent policy statements built on competing visions⁸⁴⁸.

Over the past twenty years, mediation has become a central feature of the Australian dispute resolution landscape. Just over thirty years ago, mediation could be found only in Community Justice Centres, or in specific contexts such as family, environmental and planning disputes. By contrast, Federal legislation in Australia now requires parties to pursue alternative methods of dispute resolution as a rule, before commencing civil litigation.⁸⁴⁹ Similar legislation has been enacted in New South Wales and Victoria.⁸⁵⁰ There is no doubt that the significant cultural shift in favour of alternative dispute resolution (ADR) has contributed to a more efficient and robust civil justice system in Australia. Could this process work in England? With some adaption, there is a principled framework in place.

⁸⁴⁸ Lovan, W.R., Murray, M. and Shaffer, R. eds., 2017. *Participatory governance: planning, conflict mediation and public decision-making in civil society*. Routledge.

⁸⁴⁹ Civil Dispute Resolution Act 2011 (Cth).

⁸⁵⁰ Part 2A of the Civil Procedure Act 2005 (NSW). Civil Procedure Act 2010 (Vic).

The success of mediation is in part dependent upon the abilities of the mediator, whatever country you are in. In Australia, private mediation is generally conducted by former judicial officers, lawyers and other professionals with particular expertise in the nature of the relevant dispute⁸⁵¹. In England, we need to ask who would be the ideal people to mediate between a local authority and a disabled person? Can the mediator, who is an impartial third party to support and find a resolution, be someone with both the knowledge of the Care Act and Disability rights - to help the sides agree? I believe yes, but there should be an independent body⁸⁵² to oversee the process of mediation and be acknowledged under statutory guidance. There is more work required in this aspect to assess the feasibility.

A most important tenet of mediation in Australia is that it is confidential.⁸⁵³ The willingness of parties to voluntarily settle their

⁸⁵¹ Gutman, J., 2017. Mediation and its uses in the legal process. *Legaldate*, 29(2), p.3.

⁸⁵² The Australian Human Rights Commission oversees mediation for discrimination issues has provided by many ADR courses which focus on a mediation process model and interest-based negotiation skills. The AHRC has, for example, developed a statutory mediation training course which is run for AHRC staff, staff of other Australian anti-discrimination agencies and some overseas agencies. This course, which in AHRC is conducted in conjunction with an on-the-job program of observation, supervision and mentoring, aims to provide essential knowledge and skills for the conduct of mediation in the anti-discrimination and human rights environment (See Ball & Raymond 2000).

⁸⁵³ CPA, s 31.

differences through mediation depends in large part on the confidentiality of the process. If parties fear that their disclosures to mediators or other parties during a mediation may be used against them or published outside the mediation session, the use of the process will likely decline, or the process will be weakened by parties manipulating their presentation to ensure that the mediator and/or the other parties are not provided with certain information that might otherwise be pivotal to a settlement being reached at the mediation.

In the vast majority of cases in Australia, mediation is voluntary.⁸⁵⁴ Although there may be a mandatory requirement to attend mediation, the outcome is always voluntary. The parties alone determine whether they will settle their dispute and the terms upon which they will settle their dispute, albeit that they are assisted in this regard by the mediator.

Finally, mediation is a cost-effective and efficient mechanism for resolving disputes. Mediation is pursued in large part because of its potential to significantly reduce the practical and financial burden of a dispute. This principle has an important corollary that mediation should not be recommended if it is likely to prolong

⁸⁵⁴ There are some disputes in which mediation is mandatory

proceedings and lead to increased client costs. However, assessing whether this is likely to occur is not free from complexity.

An example from Australia and which is not directly related to disabled people but one which we could review is that of Farm debt disputes. The Farm Debt Mediation Act 1994 (NSW) (FDMA) established a mediation regime “for the efficient and equitable resolution” of disputes arising in connection with debts incurred to conduct farming operations.⁸⁵⁵ A creditor cannot take any action to enforce a debt without first notifying the farmer of its intention to do so, as well as the availability of mediation.⁸⁵⁶ A creditor may apply for a certificate exempting it from this requirement. However, such a certificate will only be granted if there has been “satisfactory mediation”, the farmer has declined to mediate, or the creditor has attempted to mediate in good faith for a period of three months.⁸⁵⁷

In *Waller v Hargreaves Secured Investments Limited*,⁸⁵⁸ mediation had taken place following the FDMA following default by the borrower. At mediation, a further loan agreement was entered into. After further default, the parties entered into a third loan

⁸⁵⁵ FDMA, s 3.

⁸⁵⁶ FDMA, s 8.

⁸⁵⁷ FDMA, s 11

⁸⁵⁸ *Waller v Hargreaves Secured Investments Limited* [2012] HCA 4.

agreement. A certificate under the FDMA was subsequently issued to the lender after which it successfully brought proceedings against the borrower. The High Court held that the legislation barred the lender from obtaining a money judgment or possession of the borrower's property. Mediation had been conducted, and a certificate had been granted in respect of the original loan agreement. Since the subsequent agreements had discharged that agreement, the lender was not exempted from its statutory obligations to propose and pursue mediation concerning the later agreement before commencing court proceedings against the borrower. The legislation required the lender to again notify the borrower of the availability of mediation, despite mediation having already been conducted concerning the initial agreement. The legislative preference for mediation in this context is underpinned by a desire to temper the perceived structural imbalance between large lending institutions and small agribusiness borrowers. Actions taken by financiers concerning farm debts almost inevitably lead to severe consequences for farmers, including repossession of their property, which is generally both their family home and place of business. Besides, drought and other seasonal factors may result in temporary default of a farm loan. For these reasons, there is a clear policy imperative to encourage and assist parties to reach a negotiated resolution through mediation. The interesting point here is the fact that it is David and Goliath scenario – the big institution versus the

individual – where all the power is with the Bank. It is a similar power situation to local authorities and people with disabilities in England under the Act.

The most common criticism of these mandatory pre-litigation requirements is that they conflict with the essentially voluntary nature of mediation. The force of this complaint is reduced by the fact that compulsory mediation has existed for many years, both in the Courts' powers to refer proceedings to mediation without the parties' consent and in the pre-action mediation mandated for certain types of dispute. Furthermore, experience demonstrates that a referral to mediation is often the initial stimulus that otherwise, non-communicative parties need to move towards a voluntary and successful process of mediation.⁸⁵⁹ The CDRA requires parties to take "genuine steps" to resolve their dispute, while the legislatures in the two States opted for the criteria of "reasonable steps".⁸⁶⁰ The Chair of the National Alternative Dispute Resolution Advisory Council (NADRAC), an advisory body to the Federal Attorney-General, suggested that the New South Wales and Victorian legislation "missed the point" by adopting an objective test of reasonableness that "lawyerised a piece of non-lawyer legislation and caused a pre-litigation tool to

⁸⁵⁹ Bergin PA, "Mediation in Hong Kong: The way forward – Perspectives from Australia" (2008) 82 ALJ 196 at 203-204.

⁸⁶⁰ CPA, s 18E(1); *Civil Procedure Act* 2010 (Vic), s 34(1) (repealed).

be drawn away from the disputant and thrust into the fray of litigation”.⁸⁶¹ Measuring a party’s efforts to resolve a dispute by reference to objective criteria may present as a flawed exercise.

Legislation prescribing compulsory pre-litigation mediation involves a delicate balance between ensuring that parties attempt to settle their disputes before litigating and preserving the right of access to the Courts. The characteristics of certain disputes justify legislation deeming that good faith involves a requirement to mediate first in the context of those disputes. It is another thing entirely to conclude that good faith requires disputants actually to mediate first in all cases.

Other issues we could consider is that of legal action against mediators may threaten the efficacy of mediation in two ways. This may require the Court to investigate the content of mediation sessions, which may undermine confidence in the process of mediation itself and discourage participants from engaging in a completely honest and open manner.⁸⁶² Exposure to legal liability

⁸⁶¹ Gormly J, “The Children of the Revolution: A Change in Dispute Culture” (Speech delivered at Dispute Resolution Conference, *Dispute Resolution in the Next 40 Years: Repertoire or Revolution*, University of New South Wales, 2 December 2011).

⁸⁶² National Alternative Dispute Resolution Advisory Council, *Legislating for Alternative Dispute Resolution: A Guide for Government Policy Makers and Legal Drafters* (2006) at 63.

may force mediators to adopt a more legalistic course of conduct in order to protect themselves, increasing formality and cost.⁸⁶³ In Australia, mediators enjoy broad protection from civil proceedings because of a rather piecemeal system of immunity, predominantly provided by legislation and supplemented by exclusions. Some mediators enjoy protection equal to that of a judicial officer, which is known as “unqualified mediator immunity”. This affords mediators a complete immunity from civil proceedings without the need to first establish the impugned conduct was carried out in good faith. This kind of immunity applies to mediations connected to the highest courts in New South Wales, Victoria, Queensland, Western Australia and South Australia.⁸⁶⁴ Such protection is also applied to the higher courts in the federal jurisdiction, including court-appointed mediators in the Federal Court, Federal Magistrates Court and the Administrative Appeals Tribunal⁸⁶⁵; plus the Human Rights and Equal Opportunity Commission.⁸⁶⁶ There has been some debate about the current state of mediators’

⁸⁶³ National Alternative Dispute Resolution Advisory Council, *Legislating for Alternative Dispute Resolution: A Guide for Government Policy Makers and Legal Drafters* (2006) at 63.

⁸⁶⁴ Boule L, *Mediation: Principles, Process, Practice* (3rd ed, 2011) at 738; Carroll R, “Mediator Immunity in Australia” (2001) 23 *Sydney Law Review* 185 at 189-190.

⁸⁶⁵ Boule L, *Mediation: Principles, Process, Practice* (3rd ed, 2011) at 740.

⁸⁶⁶ Human Rights and Equal Opportunity Commission Act 1986 (Cth), s 48.

immunity in Australia, which has formed part of a wider debate as to role for immunities. The view has been expressed that immunities need to be strongly justified as a matter of public policy, as they are a privilege bestowed on very few professions, and that the case for mediators' immunity has not yet been sufficiently made out. It has also been suggested that mediator immunity from civil action is superfluous because a sufficient level of protection for mediators can be achieved using more moderate mechanisms, such as professional insurance and indemnity schemes. With the increasing use of such schemes, it remains to be seen whether the Australian mediation regime will continue to rely on and provide for broad statutory immunities.

Long gone are the days when mediation could be accurately described as "alternative" dispute resolution and is now an integral component of the civil justice system in Australia. The legislation goes even further, requiring that civil litigants will always take reasonable or genuine steps to settle their dispute (including by mediation) before instituting proceedings. It will be critical to monitor whether this significant change supports the already positive impact of ADR on civil justice in Australia. However, this gives the English legal system a chance to review what is possible and how this could be used for disputes under the Care Act 2014.

5.9 Conclusion

In this chapter, we have provided an overview of the progress toward the theoretical development in the field of mediation and our insights on why that has sometimes been an arduous journey. Academic development challenges the arena to come to terms with fundamental differences in mediators' practices at a meaningful level, and to come to terms with what it means to embrace different values, goals and practices within one field. Historically, the mediation field has lacked an openly value-based discourse that accommodates and nurtures such fundamental differences.⁸⁶⁷

The field can move to an understanding of mediation as a value-based practice rooted in different theoretical frameworks for understanding conflict. In an openly value-based dialogue, the field can constructively address differences in practice and policy, rather than minimising, obscuring or trying to eliminate those disparities in the hope of preserving the illusion of uniformity. This dialogue would offer unique and untapped promise for advances in any number of policy initiatives. We believe that

⁸⁶⁷ Smithson, J., Barlow, A., Hunter, R. and Ewing, J., 2017. The Moral Order in Family Mediation: Negotiating Competing Values. *Conflict Resolution Quarterly*, 35(2), pp.173-196.

whether the field opens itself to this kind of conversation will shape the future and the continued viability of the field.

6 GENERAL CONCLUSIONS

6.1 Summary

The work of Nancy Fraser is useful in considering what ‘socially just’ community care provision in the UK might look like. Her work has focussed on considering how the sometimes competing demands of economic justice and cultural justice can be worked together to provide a comprehensive theory of justice⁸⁶⁸. In more recent times, Fraser has embedded a concern with political justice into her theoretical framework. Within Fraser’s framework, economic injustice refers to an inequitable distribution of resources and the damaging effects of this ‘maldistribution’. Cultural injustice refers to how various groups are have become ‘despised’, for example, on the grounds of sexuality, gender, or race/ethnicity. This ‘misrecognition’ occurs when people are forced to suppress their cultural ways of being and communicating to the (often hostile) norms of the dominant culture, are rendered invisible or are disrespected as a result of belonging to a particular cultural group. Political injustice, which Fraser refers to as ‘misrepresentation’, occurs in those instances when people are deprived of an opportunity to make justice claims when they are experiencing economic, cultural injustice or

⁸⁶⁸ Fraser, N. (1997). *Justice interruptus: Critical reflections on the ‘postsocialist’ condition*. New York: Routledge.

when they are unable to contribute to the decisions that impact upon their lives. She contends that misrepresentation can occur (although unlikely) in the absence of economic and cultural injustices. Fraser argues that all such aspects of injustice have to be attended to in order to achieve a socially just society where there is ‘parity⁸⁶⁹ of participation’. Her work has not been without its critics⁸⁷⁰. However, having found this framework a useful device for considering how economic, cultural and political injustices, and their respective solutions of distribution, recognition and representation, relate to contemporary Social Care, both in the mainstream and alternative sectors. UK Social Services have a long history of not serving particular groups of people with disabilities well. Using Frasers’s terminology and defining ‘culture’ in its broadest sense to include gender, sexuality, race/ethnicity, religion, language background and so on, it is clear that people with disabilities who belong to marginalised ‘cultures’ habitually encounter Local Authorities with a less than positive experience. This ‘cultural injustice’ can

⁸⁶⁹ (McGregor, G., Mills, M., te Riele, K., & Hayes, D. (2015). Excluded from school: Getting a second chance at a ‘meaningful’ education. *International Journal of Inclusive Education*, 19(6), 608-625.; Mills, M., Renshaw, P., & Zipin, L. (2013). Alternative education provision: A dumping ground for 'wasted lives' or a challenge to the mainstream? *Social Alternatives*, 32(2), 13-18.

⁸⁷⁰ Olsen, K. (Ed.) (2008). *Adding insult to injury: Nancy Fraser debates her critics*. London: Verso.

be shaped by a lack of resources to the person with disabilities, but also by harassment and violence, by being ignored, silenced or having one's existence denied, by active and hidden discrimination at multiple levels, and it can be perpetrated by care managers and social workers⁸⁷¹. Thus, it is contended that a socially just care provision for people with disabilities attends to Fraser's dimensions of social justice in respect of economic, cultural and political inequities⁸⁷². Finally, drawing upon the work of Lynch⁸⁷³ and Sayer⁸⁷⁴, these dimensions are enhanced by the inclusion of effective and contributive forms of justice, which pay attention to inequities in relational care and individual potential for meaningful participation.

With an acknowledgement of Fraser's work, 2017 saw for the first time, an overdue public acknowledgement of the severe crisis in England's adult social care. The Parliamentary Health Committee

⁸⁷¹ Smyth, J. (2006). Educational leadership that fosters 'student voice'. *International Journal of Leadership in Education: Theory and Practice*, 9(4), 279-284.

⁸⁷² Fraser, N. (1997). *Justice interruptus: Critical reflections on the 'postsocialist' condition*. New York: Routledge; Fraser, N. (2009). *Scales of justice: Reimagining political space in a globalizing world*. New York: Columbia University Press.

⁸⁷³ Lynch, K. (2012). Affective equality as a key issue of justice: A comment on Fraser's 3- dimensional framework. *Social Justice Series*, 12(3), 45-64.

⁸⁷⁴ Sayer, A. (2009). Contributive justice and meaningful work. *Res Publica*, 15, 1-16.

flagged the critical impact of underfunding, not only on social care but on the broader NHS.⁸⁷⁵ The Care Quality Commission concurred.⁸⁷⁶ So did NHS England's chief executive.⁸⁷⁷ The King's Fund produced a searing analysis of the extent and impact of social care cuts.⁸⁷⁸ Getting to this has taken years of policymakers and politicians making decisions about people with disabilities and their needs and requirements, whilst hiding when long-term funding decisions need to be made.

Our essentially arbitrary divide of "free at point" NHS healthcare from means-tested (often self-funded) social care goes back to

875 Health Committee. Statement on social care following Liaison Committee. 22 Dec 2016.

www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/news-parliament-20151/social-care-chairs-statement-16-17/

876 Campbell D. Social care cuts take English services to tipping point, regulator warns. Guardian 13 Oct 2016.

<https://www.theguardian.com/society/2016/oct/13/social-care-cuts-take-english-service-to-tipping-point-regulator-warns>.

877 Bingham J. NHS chief: bus passes and pensions must be up for discussion to tackle social care crisis. Daily Telegraph 14 Dec 2016

878 King's Fund, Nuffield Trust. Social care for older people: home truths. Nov 2016.

https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/Social_care_older_people_Kings_Fund_Sep_2016.pdf.

1948.⁸⁷⁹ The Cameron/Clegg government of 2010-15 deliberately cut funding to local authorities. These local authorities, not the NHS, have statutory responsibilities to assess individual needs and to commission means-tested care for people with disabilities. At the same time, Local government funding fell by 28-40%.⁸⁸⁰ Local authority social care spending is not formally ringfenced, but most local authorities have protected it concerning spending on other services. The Care Act 2014 set out a national framework and people with disabilities' rights to support⁸⁸¹. However, tighter allocating (which is possibly illegal) had already excluded many people with “moderate” needs from the support they would previously have received.⁸⁸² Around 900 000 fewer now receive care than in 2010, and fewer than 5% of carers for people with

879 Thane P. Lecture: King's College London history of social care policy in England. www.kcl.ac.uk/sspp/policy-institute/scwru/swhn/pthane5dec11swhn.pdf.

880 Local Government Association. Under pressure: how councils are planning for future cuts. Apr 2014. www.local.gov.uk/documents/10180/5854661/Under+pressure.pdf; and National Audit Office. The impact of funding cuts on local authorities. Nov 2014. <https://www.nao.org.uk/wp-content/uploads/2014/11/Impact-of-funding-reductions-on-local-authorities.pdf>.

881 Department of Health. Care Act 2014—easy read version. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/365345/Making_Sure_the_Care_Act_Works_EASY_READ.pdf.

882 Mortimer J, Green M. Briefing: the health and care of older people in 2015. Age UK. Oct 2015. www.cpa.org.uk/cpa/docs/AgeUK-Briefing-TheHealthandCareofOlderPeopleinEngland-2015.pdf.

disabilities receive statutory support ⁸⁸³ . These are the circumstances in which the Care Act 2014 is being manipulated in – and one which we should judge it by. The obvious effect is that there will many legal challenges to decisions by Local Authorities to cut funding and services — many leading to the Courts to resolve rather than an Alternative Dispute Resolution procedure.

Already stressed people with disabilities navigating a fragmented system (with the NHS) are bewildered by different rules, and by multiple assessments. People with disabilities have expressed their wants for responsive support that works—not unfunded, not one based on market-forces, or wild promises about what personalisation can give for choice and control. It is time to simplify the system, which was the primary aim of the Care Act; and develop a dispute resolution process which is accessible to all and will help people with disabilities as service users to express their requirements and objections – in a constructive way.

Many people with disabilities have welcomed the promise of increased choice and control. However, the speed and nature of the Acts implementation and its coupling with the marketisation of

883 BMJ 2017; David Oliver: Social care crisis needs meaningful solutions, not tinkering and soundbites

the disability service sector has produced well documented, but still unresolved tensions. These are located in broader debates regarding the strain between the disabled rights and neoliberal market narratives upon which the broader personalisation agenda is based (Needham 2011⁸⁸⁴ ; Kendall & Cameron 2013⁸⁸⁵ ; Lymbery 2014⁸⁸⁶ ; Mladenov et al. 2015⁸⁸⁷). The conflation of marketisation and self-directed approaches change the nature of relationships between people with disabilities, the state and the market yet the consequences of these shifting accountabilities and the inherent risk, as well as opportunity that sit within these new frameworks, have yet to be fully unpacked (Dickinson et al. 2014⁸⁸⁸). The “citizen consumer” construct that places the person with disabilities and their choices at the centre of service delivery systems reflects neoliberal governments’ values and

884 Needham, C. (2011) *Personalising public services: Understanding the Personalisation Narrative*, Bristol, Policy Press.

885 Kendall, S. and Cameron, C. (2013) ‘Personalisation of adult social care: self-directed support and the choice and control agenda’, *British Journal of Learning Disabilities*, 42, 264–71.

886 Lymbery, M. (2014) ‘Understanding personalisation: implications for social work’, *Journal of Social Work*, 14 (3), 295–312.

887 Mladenov, T., Owens, J. and Cribbs, A. (2015) ‘Personalisation in disability services and healthcare: a critical comparative analysis’, *Critical Social Policy*, 35 (3), 1–20.

888 Dickinson, H., Needham, C. and Sullivan, H. (2014) ‘Individual funding for disability support: what are the implications for accountability?’, *Australian Journal of Public Administration*, 73 (4), 417–25.

priorities (Clarke et al. 2007⁸⁸⁹). However, the assumptions underpinning the notion of the person with disabilities as a service user as a key player in, and shaper of a human services market, have been critiqued as problematic and contradictory. Many are concerned that true market forces may not operate well in a human service context and that the “profit motive” associated with market competition is “antithetical” to human services values and purpose (Meagher & Goodwin 2015⁸⁹⁰; Quiggan 2016⁸⁹¹).

Despite these concerns, the market is developing and responding to the opportunities triggered by the personalisation, through the self-management options. These include the emergence of new service and business models such as online Uber-style⁸⁹² service

889 Clarke, J., Newman, J., Smith, N., Vidler, E. and Westmarland, L. (2007) *Creating Citizen-Consumers: Changing Publics and Changing Public Services*, London, Paul Chapman Publishing

890 Meagher, G. and Goodwin, S. (2015) ‘Introduction: capturing marketization in Australian social policy’. In G. Meagher and S. Goodwin (eds) *Markets, Rights and Power in Australian Social Policy*, Sydney, University Press, pp. 1–27

891 Quiggan, J. (2016) ‘Face the facts: competition and profit don't work in health, education or prisons’, *The Guardian*, <https://www.theguardian.com/commentisfree/2016/sep/12/face-the-facts-competition-and-profit-dont-work-in-health-education-or-prisons>(accessed 9 November 2017).

892 The term “uber” is used to describe any person or thing that is outstanding, supreme, cool or edgy. In this case, the term is used to describe the newly emerging online disability service platforms which mirror the uber taxi model and have the potential to disrupt the traditional

platforms that provide personalisation people with disabilities with direct access to support workers via the “gig” economy and direct employment initiatives (Rold 2014⁸⁹³). These innovations have the potential to offer some people with disabilities as service users unprecedented levels of flexibility and autonomy in their support service choices.

The literature has revealed many important factors, which need to be considered if people with disabilities are to be supported in the process (and not just the tasks) of personalisation. Themes in the literature focus on critical issues to do with choice, control, independence and autonomy. Although the results of the study reveal little empirical evidence about outcomes of personalisation, these important debates form an essential backdrop to its contemporary rapid implementation. They also confirm the need to extend knowledge about its impact.

Consequently, more evidence is needed to guide social care practice and promote independence, autonomy, choice and control for people with disabilities. Further studies are required which compare and contrast the relative benefits of using personal budgets against the traditional funding model of services provided

disability service provider market. i.e. shop4support, PlanMyCare and slivers of care.

893 Rold, A. (2014) ‘The Gig Economy’, *Diplomatic Courier*, 8 (1), 6.

directly by local authorities. The comparison will enable a more critical judgement about reported improvements to the quality of life resulting from personalisation as compared with other care arrangements. If we are willing to narrow the range of reasonable and necessary conceptions of the good, we may be able to identify the broad categories of activity that are central to social participation and individual flourishing, that can help with social justice and the care act.

We can then turn to the issues of how a just society can create or modify environments and practices in ways that permit all, or almost all, its members to engage in these activities. Rather than seeing the ramp, the flexible work schedule, the audiobook, or the visual display of words spoken at a meeting as “accommodations” to individual deficits, they are the conventional components of Gliedman and Roth's⁸⁹⁴ inclusive society.

Theories of justice, and the politicians and policy-makers, who might apply such approaches to the community, can then squarely and forthrightly confront how much energy, imagination, and money they are prepared to expend for inclusion in an age of

894 Gliedman, J. and Roth, W., 1980. The unexpected minority-Handicapped children in America. *International Journal of Rehabilitation Research*, 3(4), pp.601-604.

austerity and public spending cuts, particularly in social care. The next consideration is the ‘choice and control’ for the person with disabilities within the Care Act 2014⁸⁹⁵. The Care Act 2014 has changed the ability that a person with disabilities as a service user or carer has to influence the assessment of their own needs and eligibility. Whereas the FACS criteria⁸⁹⁶ considered the needs of the individual, they did not consider their whole well-being and how this fits into their everyday lives, meaning that some people with disabilities as service users may not have completely fitted into the specified categories. The criteria that the Care Act 2014 looks at the focus on the individual in context so that the impact on their well-being cannot now be overlooked or misjudged. The Care Act⁸⁹⁷ is allowing the person with disabilities as a service user to take control of everything that supports their specific needs and requirements.

The implications could have quite dramatic; where a person with disabilities feels worthwhile and not a burden to anyone, and it allows a person with disabilities to take greater control of their

895 Duffy, S., 2017. The value of citizenship. *Research and Practice in Intellectual and Developmental Disabilities*, pp.1-9.

896 Social Care Institute for Excellence Fair Access to Care Services (FACS): Prioritising Eligibility for Care and Support. SCIE, 2013.

897 Waters J, Hatton C. Third National Personal Budget Survey: Experiences of Personal Budget Holders and Carers across Adult Social Care and Health. In *Control*, Lancaster University & TLAP, 2014.

personal needs.⁸⁹⁸ This aspiration should be balanced against a casual approach to statutory formalities (not to say the ‘Rule of Law’). It certainly adds weight to the recommendations of the Law Commission and the Select Committee³ that the Act should be the subject of a Parliamentary Code of Practice (rather than departmental guidance) to strengthen against challenges from local authorities who do not share the ambition of the Act.

Many people with disabilities anticipate that the Act will develop inclusive services, work in a person-centred way, and achieve specific outcomes in a way public services will be measured. It will be through individual lives and stories that success will be realised. There will be many challenges, both legal and procedural that lie ahead. The next chapter reviews how the conflict resolution could and should have been legislated for in the Act.

The final consideration is that of dispute resolution. The present process is not ‘fit-for-purpose’ owing to being controlled with the local authority, and they do not have to give a time-limit. The future should be about the partnership between the person with disabilities and the local authority. The recommendation from this thesis is the use of Mediation. Mediation policy is continuously

898 Barnes, D., Boland, B., Linhart, K. and Wilson, K., 2017. Personalisation and social care assessment—the Care Act 2014. *BJPsych Bull*, 41(3), pp.176-180.

shaping, and being formed by, mediation practice. Typical policy topics in the mediation field include who can practice mediation, how to determine mediator competency, how the process should and should not be conducted, who is capable of participating in mediation as a client, the ethical obligations of the mediator, grounds for termination of the mediation process, whether the mediator should have reporting obligations to various agencies, whether mediation is the practice of law, and whether mediation should be confidential.

Bush and Folger argued that the *problem-solving* model of mediation was based upon an essentially psychological/economic view of the human conflict.⁸⁹⁹ According to this model, conflict represents a problem in solving the parties' incompatible needs and interests⁹⁰⁰. Therefore, the mediator's goal is to generate an agreement that solves tangible problems on fair and realistic terms, and good mediator practice is a matter of issue identification, option creation, and effective persuasion. In this

899 Cobb, S., "Einsteinian Practice and Newtonian Discourse: An Ethical Crisis in Mediation" (1991). *Negotiation J.*, 7, p.87. For works by other scholars who have noted and explored the psychological / economic basis of a problem-solving approach to conflict in general, and to mediation practice in particular, see Della Noce *Ibid*; Cobb, S., 1993. "Empowerment and mediation: A narrative perspective." *Negotiation Journal*, 9(3), pp.245-259.

900 Bush & Folger, *Ibid*, at 55-75.

model, there is a heavy reliance on mediator initiative and direction because both are useful in generating settlement.⁹⁰¹

This problem-solving framework is based on and reflects an *individualist* ideology, in which human beings are assumed to be autonomous, self-contained, atomistic individuals, each motivated by the pursuit of the satisfaction of his or her separate self-interests.⁹⁰² The thesis believes the model fits in closest with the requirements of people with disabilities with disputes under the Care Act. The predominance of this model also explains, in part, the persistence of the lay theories that have emerged in the mediation field - all partake of the same individualist ideology, and psychological/economic view of the conflict, underlying the problem-solving model.⁹⁰³ However, more empirical research

901 Folger, J.P. and Bush, R.A.B., 1994. Ideology, orientations to conflict, and mediation discourse. *New directions in mediation: Communication research and perspectives*, pp.3-25.

902 Noce, D.J.D., Bush, R.A.B. and Folger, J.P., 2002. Clarifying the theoretical underpinnings of mediation: Implications for practice and policy. *Pepp. Disp. Resol. LJ*, 3, p.39.

903 The various lay theories discussed above are all compatible with, and can be used to further, the problem-solving mediator's goal of producing a settlement agreement based on assumptions of individual self-interest. They are naive expressions of the dominant problem-solving theoretical framework of the field. But the lay theories have an befuddling dimension. They obscure the nature, extent and underlying value-base of mediator influence, whereas an articulated theoretical framework exposes these features and thereby opens them to critical reflection, dialogue and informed choice.

work is required within English local authorities – that could guide the development of mediation to be part of future statutory guidance of the Act.

6.2 Conclusion

There is more research required on the types of mechanisms that might mediate between different stakeholders' interests to ensure the implementation of the personalisation, through the Care Act 2014 is rights-promoting for all rather than just for some. The types of regulation required to “tame” increased complaints, litigation and reviews to the ombudsman; while improving services provision for disabled people is being driven by necessity at the moment rather than social justice motives as required.

While in Australia, the National Disability Insurance Agency and its NDIS Act 2013 mirrors the UK Care Act 2014. In 2018 the NDIA spent over \$12m to fight people with disabilities claims for better support. They realised there was a better way and are developing an ‘Early Resolution Team’ to mediate and understand the reasons for the disputes. Fraser would recognise some of the challenges for people with disabilities in which there is a power relationship. Further academic work is required to analyse the methodology and successful outcomes. One of mediation’s strengths is to neutralise any power imbalances by allowing a ‘weaker’ party, like the patient, to air his or her feelings in confidentiality, during private caucus sessions with the mediator,

where he or she might otherwise not have been comfortable in doing so in the presence of the doctor, let alone in a public hearing. Through this mechanism, the actual root of a dispute can be exposed and dealt with by allowing a ‘weaker’ party to be heard and listened to.

The contribution the thesis makes to the academic community/literature is one where there is a consideration of addressing injustices while developing a balanced framework where each a party has a path/process to follow before court challenges on community and social care disputes. This process will avoid the situation where a legal team gathered the necessary information from the person with disabilities, and then further negotiations are conducted exclusively by the legal team which leaves the client without a ‘voice’ or control over the direction of the matter.

The mediation discussed is specifically structured to empower participating parties to voice their concerns and interests and in full control of the direction and duration of the whole process without ever being sidelined. Considering the complex, delicate nature of community and social care disputes, imminent power imbalances, financial risks and the adversarial nature of litigation, mediation offers a much needed and very productive alternative

method of dispute resolution and should be put forward as the dispute resolution process in the Care Act 2014.

7 Bibliography

- Abberley, P. (1992) Counting us out: a discussion of the OPCS disability surveys. *Disability, Handicap & Society*, 7(2): 139-55.
- Adorno, T.W. (1992) *Negative Dialectics*. New York: Continuum International.
- Anderson, J., Sapey, B. and Spandler, H. (eds.) (2012) Distress or disability? Proceedings of a symposium held at Lancaster University, 15-16 November 2011. Centre for Disability Research, Lancaster University, Lancaster.
- Andrews, M. (2007) *Shaping history*. Cambridge: Cambridge University Press.
- Barker, C. and Cox, L. (2002) "What have the Romans ever done for us?" Academic and activist forms of movement theorizing, *8th Annual Conference on Alternative Futures and Popular Protest*. Manchester Metropolitan University, Manchester, pp 1 - 27 [Online]. Available: <http://eprints.nuim.ie/428/1/AFPPVIII.pdf> [12 July 2014].
- Barnes, C. (1990) 'Cabbage Syndrome': The social construction of dependence. Brighton: The Falmer Press
- Barnes, C. (1991) *Disabled people in Britain and discrimination*. London: Hurst & Co.
- Barnes, C. (2003) What a difference a decade makes: reflections on doing 'emancipatory' disability research. *Disability & Society*, 18(1): 3-17.
- Barnes, C. (2008) An ethical agenda in disability research: rhetoric or reality? In: Mertens, D.M. and Ginsberg P E. (eds.) *The handbook of social research ethics*. London: Sage.
- Barnes, C. and Mercer, G. (2006) *Independent futures: Creating user-led disability services in a disabling society*. Bristol: Policy Press.
- Barnes, C. and Sheldon, A. (2007) 'Emancipatory' disability research and special educational needs. In: Florian, L. (ed.) *The Sage handbook of special education*. London: SAGE.
- Barnes, M. (2008) Is the personal no longer political? *Soundings*, 39 (1): 152-9.
- Beckett, A. (2006) Understanding social movements: theorising the disability movement in conditions of late modernity. *The Sociological Review*, 54 (4): 734-752.
- Benstead, S., Marsh, S., Richardson, C., Cartwright, J., Hale, C., Barnet-Cormack, S. and Smithet,
- R. (2014) *Beyond the barriers: a Spartacus Network report into Employment Support Allowance, the Work Programme and recommendations for a new system of support* [Online]. Available: <http://www.spartacusnetwork.org.uk/images/reports/BeyondTheBarriers.pdf> [11 August 2014].
- Berlin, I. (1969). *Four essays on liberty*. Oxford: Oxford Paperbacks.
- Bevington D, and Dixon, C. (2005) Movement-relevant theory: rethinking social movement scholarship and activism. *Social Movement Studies*, 4 (3): 185-208.
- Bhaskar, R. (1986) *Scientific realism and human emancipation*. London: Verso.

Bhaskar, R. and Danermark, B. (2005) Meta-theory, Interdisciplinarity and disability research: a critical realist perspective. *Scandinavian Journal of Disability Research*, 8(4): 278-297.

Blumer, H. (1951) Social Movements. In: McClung Lee, A. (ed.), *Principles of Sociology*, 2nd edition. New York: Barnes and Noble.

Blyth, M. (2013) The austerity delusion, *Foreign Affairs* [Online]. Available: <http://www.foreignaffairs.com/articles/139105/mark-blyth/the-austerity-delusion> [3 February

2014].

Bonefeld, W. (1987) Open Marxism. *Common Sense*, 1: 34-38.

Bonefeld, W. (1994) Human practice and perversion: beyond autonomy and structure. *Common Sense*, 15: 43-52.

Bonefeld, W., Gunn, R. and Psychopedis, K. (1992) *Open Marxism, volume 1: dialectics and history*. London: Pluto Press.

Bornat, J. (2006) Introduction. In: J. Leece and J. Bornat (eds) *Developments in Direct Payments*. Bristol: The Policy Press.

Bott, S. (2014) *We need a new vision for independent living* [Online]. Available: <http://disabilityrightsuk.blogspot.co.uk/2014/07/we-need-new-vision-for-independent.html> [20 July 2014].

Boxall, K., Dowson, S., and P. Beresford. (2009) Selling individual budgets, choice and control: Local and global influences on UK social policy for people with learning difficulties. *Policy & Politics*, 37 (4): 499–515.

Brawn, E., Bush, M., Hawkings, C. and Trotter, R. (2013) The other care crisis: making social care funding work for disabled adults in England. Report by Scope, Mencap, National Autistic Society, Sense, and Leonard Cheshire Disability [Online]. Available: <https://www.scope.org.uk/Scope/media/Documents/Publication%20Directory/The-other-care-crisis-1.pdf?ext=.pdf> [13 August 2014].

Briant, E., Watson, N. and Philo, G. (2013) Reporting disability in the age of austerity: the changing face of media representation of disability and disabled people in the United Kingdom and the creation of new ‘folk devils’. *Disability & Society*, 28(6): 874-889.

Burnip, L. (2012) Threats to the Disabled People’s Movement from the austerity cuts [Online]. Available:

http://www.inclusionlondon.co.uk/domains/inclusionlondon.co.uk/local/media/downloads/threats_to_the_disabled_people.doc [11 August 2014].

Burchardt, T. (1999) The evolution of disability benefits in the UK: Reweighting the basket, *CASE Paper 26*, London: London School of Economics and Political Science.

Cabinet Office - Prime Minister’s Strategy Unit (2005) *Improving the life chances of people with disabilities*. London: Prime Minister’s Strategy Unit.

Calder, G. (2007) Disability and misrecognition. In: Thompson, S. and Yar, M. (eds) *The politics of misrecognition*. Aldershot: Ashgate.

Campbell, J and Oliver, M. (1996) *Disability politics: understanding our past, changing our future*. London: Routledge.

Campbell, J. (1997) "Growing pains' disability politics - the journey explained and described". In: Barton, L. and Oliver, M. (ed.) *Disability Studies: Past Present and Future*. Leeds: The Disability Press.

Campbell, S. J., Anon, S. Marsh, K. Franklin, D. Gaffney, Anon, M. Dixon, L. James, S. Barnett- Cormack, R. Fon-James, D. Willis, and Anon. (2012). *Responsible reform: A report on the proposed changes to Disability Living Allowance*. [Online]. Available: <http://www.rcpsych.ac.uk/pdf/Responsible%20Reform.pdf> [20 October 2014].

Clarke, J., Newman, J., Westmarland, L. (2007) The antagonisms of choice. New Labour and the reform of public services. *Social Policy & Society*, 7(2): 245–53.

Clarke, J., Smith, N., and Vidler, E. (2006) The indeterminacy of choice. Political, policy and organisational implications. *Social Policy & Society*, 5(3): 327–36.

Clegg, N. (2012) *Speech to Liberal Democrat spring conference March 2012* [Online]. Available:

http://www.libdems.org.uk/nick_clegg_s_speech_to_spring_conference_march_2012 [20 July 2014].

Clifford, E. (2014) *Re-forging the disability movement* [Online]. Available: <http://socialistreview.org.uk/391/re-forging-disability-movement> [20 July 2014].

Collier, A. (1994) *Critical Realism*. London: Verso.

Crow, L. (1996) Including all of our lives: renewing the social model of disability. In: Barnes, C. and Mercer, G. (eds.) *Exploring the divide: illness and disability*. Leeds: The Disability Press.

Danermark, B., and Gellerstedt, L. C. (2004) Social justice: redistribution and recognition—a non-reductionist perspective on disability. *Disability & Society*, 19(4) 339-353.

Davis, K. (1993). *Disability issues resource notes: "Power, oppression and disability"* [Online]. Available: <http://disability-studies.leeds.ac.uk/files/library/DavisK-resourcenotes.pdf> [10

October 2014].

Deal, M. (2003) People with disabilities's attitudes toward other impairment groups: a hierarchy of impairments. *Disability & Society*, 18 (7): 897-910.

DeJong, G. (1983) 'Defining and implementing the independent living concept'. In: N. Crewe and I. Zola (eds.) *Independent Living for Physically People with disabilities*. London: Josey-Bass.

Department for Work and Pensions (2012) *Housing Benefit: under-occupation of social housing. Impact assessment* [Online]. Available:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214329/soci al-sector-housing-under-occupation-wr2011-ia.pdf [23 July 2014].

Department for Work and Pensions (2014) *Closure of the Independent Living Fund: equality analysis. Impact assessment* [Online]. Available:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214329/social-sector-housing-under-occupation-wr2011-ia.pdf [23 July 2014].

People with disabilities Against the Cuts (DPAC) (2012) *A question of intent: DPAC's response to comments from Disability Rights UK on DPAC's 'tactics'* [Online]. Available: <http://dpac.uk.net/2012/12/a-question-of-intent/> [21 August 2014].

Disability Rights UK (2012) *Response to PIP assessment criteria and thresholds consultation - Disability Rights UK response: May 2012* [Online]. Available: <http://www.disabilityrightsuk.org/sites/default/files/pdf/pipconsult.pdf> [23 July 2014].

Dodd, S. (2013) Personalisation, individualism and the politics of disablement. *Disability & Society*, 28(2): 260-273.

Dowse, L. (2001) Contesting practices, challenging codes: self-advocacy, disability politics and the social model. *Disability & Society*, 16(1): 123-141.

Duffy, S. (2013) *A fair society? How the cuts target people with disabilities* [Online]. Available: <http://www.centreforwelfareform.org/library/type/pdfs/a-fair-society1.html> [20 July 2014].

Duffy, S. (2014) *Counting the cuts – What the Government doesn't want the public to know* [Online]. Available: <http://www.centreforwelfareform.org/library/by-az/counting-the-cuts.html> [20 July 2014].

Evans, J. (2002) Independent Living Movement in the UK [Online]. Available: <http://disability-studies.leeds.ac.uk/files/library/evans-Version-2-Independent-Living-Movement-in-the-UK.pdf> [30 July 2014].

Evans, J. (2008) Independent Living in the UK - Developments, Accomplishments and Impact on Government Social Policy and Legislation. [Online] Available: <http://www.independentliving.org/25years2008evans#speech> [24 September 2014].

Evans, J. (2014) We can't give up on independent living, *Guardian* [Online]. 16 July 2014, Available: <http://www.theguardian.com/society/2014/jul/16/independent-living-fund-closure-disabled-people-residential-care> [14 August 2014].

Ferguson, I. (2005) Challenging a 'spoiled identity': mental health service users, recognition and redistribution. In: Riddell, S. and Watson, N., (ed.) *Disability culture and identity*. Harlow: Pearson.

Ferguson, I. (2007) Increasing user choice or privatizing risk? The antinomies of personalization. *British Journal of Social Work*, 37(3): 387-403.

Finkelstein, V. (1980) *Attitudes and people with disabilities: issues for discussion*. New York: World Rehabilitation Fund.

Finkelstein, V. (1996) Outside, inside out. *Coalition*, April: 30-36.

Finkelstein, V. (1999) Doing disability research. *Disability & Society*, 14 (6): 859-67.

Fraser, N. (1995) From redistribution to recognition? *New Left Review*, 212: 68-92.

Fraser, N. (2013) *Fortunes of Feminism*. London: Verso.

Fraser, N. and Honneth, A. (2003) Redistribution or recognition? A political-philosophical exchange. London: Verso.

Giddens, A. (1979) *Central problems in social theory*. London: Macmillan. Giddens, A. (1987) *Social theory and modern society*. Oxford: Blackwell.

Gleeson, B. (1997) Disability studies: a historical materialist view. *Disability & Society*, 12(2): 179-202.

- Gleeson, G. (1999) *Geographies of disability*. Abingdon: Routledge.
- Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. and Wilberforce, M (2008) *Evaluation of the individual budgets pilot programme: Final report*. York: Social Policy Research Unit, University of York.
- Goffman, E. (1963) *Stigma: some notes on the management of spoiled identity*. Harmondsworth: Penguin.
- Goodley, D. (2013) Dis/entangling critical disability studies. *Disability & Society*, 28(5): 631-644.
- Grim toll for work tests, *Guardian* [Online]. 3 March 2014, Available: <http://www.theguardian.com/society/2014/mar/03/grim-toll-fit-for-work-tests> [3 March 2014].
- Gunn, R. (1989) Marxism and philosophy: a critique of critical realism. *Capital & Class*, 13 (1): 87-116.
- Hardt, M. and Negri, A. (2000) *Empire*. London: Harvard University Press
- Harris, J. & Roulstone, A. (2011). *Disability, Policy & Professional Practice*. Sage, London.
- Harvey, D. (1982) *The limits to capital*. Oxford: Blackwell.
- Harvey, D. 2005. *A brief history of neoliberalism*. Oxford: Oxford University Press.
- Hasler, F. (1993) Developments in the people with disabilities's movement. In: Swain, J., Finkelstein, V., French, S. and Oliver, M. (eds.) *Disabling barriers, enabling environments*, 3rd edition. London: Sage.
- HM Treasury (2013) *Autumn statement 2013* [Online]. Available: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/263942/350_62_Autumn_Statement_2013.pdf [25 July 2014].
- Hoare, Q. and Nowell-Smith, G.N. (eds.) (1998) *The Intellectuals*. In: Gramsci, A. *Selections from the Prison Notebooks*. London: Lawrence and Wishart.
- Holloway, J. (1991) In the beginning was the scream. *Common Sense*, 11: 69-78.
- Holloway, J. (1993a) Open Marxism, history and class struggle. *Common Sense*, 13: 76-86.
- Holloway, J. (1993b) The freeing of Marx. *Common Sense*, 14: 17-21.
- Holloway, J. (2002) *Change the world without taking power*. London: Pluto Press.
- Holloway, J. (2005) No. *Historical Materialism*, 13(4): 265-284.
- Holloway, J. (2011) *Why Adorno? Part 2* [Online]. Available: <http://www.johnholloway.com.mx/2011/07/30/negative-and-positive-autonomism/#sdfootnote1sym> [25 July 2014].
- Honneth, A. (1995) *The struggle for recognition: the moral grammar of social conflicts*. Cambridge: Polity.
- Houston, S., (2010) Beyond homo economicus: Recognition, self-realization and social work. *British Journal of Social Work* 40: 841–57.
- Houston, S. (2014) Beyond individualism: Social work and social identity. *British Journal of Social Work*, 1–17 [Online]. Available:

- <http://bjsw.oxfordjournals.org/content/early/2014/09/17/bjsw.bcu097.short> [20 November 2014].
- Hughes, B. (2009) Disability activism: social model stalwarts and biological citizens. *Disability & Society*, 24(6): 677-688.
- Hunt, P. (ed.) (1966) *Stigma: The experience of disability* [Online]. Available: <http://disability-studies.leeds.ac.uk/files/library/Hunt-critical-condition.pdf> [12 July 2014].
- Hunt, P. (1981), Settling accounts with the parasite people: a critique of 'A life apart' by E.J Miller and G.V. Gwynne. *Disability Challenge* 1: 37-50.
- Ikaheimo, H. (2010) Personhood and the social inclusion of people with disabilities. A recognition theoretical approach. In: Kristiansen, K., Vehmas, S. and Shakespeare, T. (eds.) *Arguing about disability: philosophical perspectives*. Abingdon: Routledge.
- Inclusion London (2013) UK people with disabilities's manifesto: reclaiming our futures [Online]. Available: http://www.inclusionlondon.co.uk/domains/inclusionlondon.co.uk/local/media/downloads/U_K_Disabled_People_s_Manifesto_Reclaiming_Our_Futures.pdf [12 July 2014].
- Inglehart, R. (1971) The silent revolution in Europe: Intergenerational change in post-industrial societies. *American Political Science Review*, 65 (4): 991-1,017.
- Joint Committee on Human Rights (2012) *Implementation of people with disabilities's right to independent living* [Online]. Available: <http://www.publications.parliament.uk/pa/jt201012/jtselect/jtrights/257/257.pdf> [14 July 2014].
- Kelly, C. (2010) Wrestling with group identity: disability activism and direct funding. *Disability Studies Quarterly*, 30(No ¾).
- Korzybski, A. (2010) *Selections from science and sanity*. Fort Worth: Institute of General Semantics.
- Lawson, T. (1999) Feminism, realism, and universalism. *Feminist Economics*, 5(2): 25-59. Lawson, T. (2003) *Reorientating Economics*. Abingdon: Routledge.
- Lazard, T. et al. (2012) *Disabled workers fight to save Remploy factory jobs* [Online]. Available: <http://www.theguardian.com/society/2012/may/10/disabled-works-fight-remploy-jobs> [13 July 2014].
- Leadbeater, D (2004) *Personalisation through participation: A new script for public services*. London: Demos.
- Lincoln, Y.S. and Guba, E.G. (1985) *Naturalistic inquiry*. Newbury Park, CA: Sage Publications.
- Lister, R. (1998) Citizenship and Difference: Towards a Differentiated Universalism. *European Journal of Social Theory*, 1(1): 71-90.
- Loja, E., Costa, M, E., Hughes, B., & Menezes, I. (2013) Disability, embodiment and ableism: stories of resistance. *Disability & Society*, 28 (2): 190-203.

- Mason, M. (2010) Sample size and saturation in PhD studies using qualitative interviews. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, 11(3): art. 8 [Online]. Available: <http://www.qualitative-research.net/index.php/fqs/article/view/1428/3027> [5 June 2014].
- Meekosha, H., and Shuttleworth, R. (2009) What's so 'critical' about critical disability studies?
Australian Journal of Human Rights 15(1): 47–76.
- Miller, E. J. and Gwynne, G.V. (1972) *A life apart*. London: Tavistock. Morris, J. (1991) *Pride against prejudice*. London: Women's Press.
- Morris, J. (1992) Personal and political: a feminist perspective on researching physical disability. *Disability, Handicap & Society*, 7(2): 157-66.
- Morris, J. (1993) *Independent lives? Community care and people with disabilities*. Basingstoke: Macmillan.
- Morris, J. (1994) The shape of things to come? User led social services. Social Services Policy Forum paper No 3. London: National Institute for Social Work.
- Morris, J. (2005) *Citizenship and Disabled People: a scoping paper prepared for the disability rights commission* [Online]. Available: <http://disability-studies.leeds.ac.uk/files/library/morris-Citizenship-and-disabled-people.pdf> [3 February 2014].
- Morris, J. (2011) *Rethinking Disability Policy*. York: Joseph Rowntree Foundation [Online]. Available: <http://www.jrf.org.uk/sites/files/jrf/disability-policy-equality-summary.pdf> [22 January 2012].
- Morris, J. (2014a) *Independent Living Strategy: A review of progress* [Online]. Available: <http://disabilityrightsuk.org/sites/default/files/pdf/IndependentLivingStrategy-A%20review%20of%20progress.pdf> [18 July 2014].
- Morris, J. (2014b) *Personal budgets and self-determination* [Online]. Available: <http://jennymorrisnet.blogspot.co.uk/2014/04/personal-budgets-and-self-determination.html> [24 April 2014].
- Morris, J. (2014c) *Independence* [Online]. Available: <http://jennymorrisnet.blogspot.co.uk/2014/09/independence.html> [2 October 2014].
- National Health Service and Community Care Act 1990. London: HMSO. Needham, C. (2011) *Personalising public services*. Bristol: Policy Press.
- Office for Disability Issues (2009) *Choice and control/access to goods and services - a rapid evidence assessment (REA) for the Office for Disability Issues* [Online]. Available: <http://webarchive.nationalarchives.gov.uk/20130812104657/http://odi.dwp.gov.uk/docs/res/rea/091119-choice-control-access.pdf> [12 July 2014].
- Office for Disability Issues (2009) *Independent living - A cross-government strategy about independent living for Disabled People*[Online]. Available:

<http://webarchive.nationalarchives.gov.uk/20130703133823/http://odi.dwp.gov.uk/docs/wor>

[/ind/ilr-executive-report.pdf](#) [1 September 2014].

Oliver, M. (1983) *Social Work with Disabled People*. Basingstoke: Macmillan

Oliver, M. (1988) *Walking into darkness: the experience of spinal cord injury*. Tavistock: Macmillan.

Oliver, M. (1990) *The politics of disablement*. London: Macmillan.

Oliver, M. (1992) Changing the social relations of research production? *Disability, Handicap & Society*, 7(2): 101-114.

Oliver, M. (1996a) Defining impairment and disability: issues at stake. In: Barnes, C. and Mercer, G. (ed.) *Exploring the divide: illness and disability*. Leeds: The Disability Press.

Oliver, M. (1996b) *Understanding disability, from theory to practice*. London: Macmillan.

Oliver, M. (1999a) *Disabled People and the inclusive society: or the times they really are changing*. Public lecture on behalf of Strathclyde Centre for Disability Research and Glasgow City Council [Online]. Available: <http://www.independentliving.org/docs4/oliver.html> [8 June 2014].

Oliver, M. (1999b) Final accounts and the parasite people. In: Corker, M. and French, S. (ed.) *Disability discourse*. Buckingham: Open University Press.

Oliver, M. (2004) The social model in action: if I had a hammer. In: Barnes, C. and Mercer, G. (ed.) *Implementing the social model of disability: theory and research*. Leeds: The Disability Press.

Oliver, M. (2009) *Understanding disability: from theory to practice*, 2nd edition. Basingstoke:

Palgrave Macmillan.

Oliver, M. (2011) *Old lessons for a new politics* [Online]. Available: <http://www.disabilitynow.org.uk/article/old-lessons-new-politics> [14 July 2014].

Oliver, M. (2012) *The politics of humility* [Online]. Available: <http://www.disabilitynow.org.uk/article/politics-humility> [14 July 2014].

Oliver, M. & Barnes, C. (2006) Disability politics and the disability movement in Britain: where did it all go wrong? *Coalition*, August, 8–13. [Online] Available: <http://disability-studies.leeds.ac.uk/files/library/Barnes-Coalition-disability-politics-paper.pdf> [20 January 2013].

Parckar, G. (2008) *Disability poverty in the UK*. London: Leonard Cheshire.

Paterson, K. and Hughes, B. (1999) Disability studies and phenomenology: the carnal politics of everyday life. *Disability & Society*, 14(5): 597-610.

Polanyi, K. (1944) *The great transformation*. Boston: Beacon Press.

Priestley, M. (1995) Commonality and difference in the movement: an 'Association of Blind Asians' in Leeds. *Disability & Society*, 10(2): 157-170.

- Priestley, M. (1997) Who's research? A personal audit. In: Barnes, C. and Mercer, G. (ed.) *Doing disability research*. Leeds: The Disability Press.
- Priestley, M. (1998) *Constructions and creations: idealism, materialism and disability theory*.
Disability & Society, 13(1): 75-97.
- Priestley, M. (1999) *Disability politics and community care*. London: Jessica Kingsley Publishers.
- Priestley, M. (2003) *Disability: A Life Course Approach*. Cambridge: Polity Press.
- Pring, J. (2012a) *Anger over government's new 'disability quango'* [Online]. Available: <http://disabilitynewsservice.com/2012/09/anger-over-governments-new-disability-quango/> [16 July 2014].
- Pring, J. (2012b) *Disability movement divided over Remploy closures* [Online]. Available: <http://disabilitynewsservice.com/2012/05/disability-movement-divided-over-remploy-closures/> [16 July 2014].
- Pring, J. (2012c) *Disability Rights UK fights back over new alliance, Capita and Remploy* [Online]. Available: <http://disabilitynewsservice.com/2012/11/disability-rights-uk-fights-back-over-new-alliance-capita-and-remploy/> [16 July 2014].
- Punton, R. (2014) *A plea from an ILF user to DRUK* [Online]. Available: <http://dpac.uk.net/2014/07/a-plea-from-an-ilf-user-to-druk/> [20 July 2014].
- Ramesh, R. (2012) 35 of 1,000 sacked Remploy workers have found new jobs, says Labour, *The Guardian*, 23 November 2012 [Online]. Available: <http://www.theguardian.com/society/2012/nov/23/remploy-workers-new-jobs-labour> [20 July 2014].
- Reed, H. and Portes, J. (2014) *Cumulative impact assessment: a research report by Landman Economics and the National Institute of Economic and Social Research (NIESR) for the Equality and Human Rights Commission* [Online]. Available: http://www.equalityhumanrights.com/sites/default/files/publication_pdf/Cumulative%20Imp%20act%20Assessment%20full%20report%2030-07-14.pdf [22 July 2014].
- Reeve, D. (2002) Negotiating psycho-emotional dimensions of disability and their influence on identity constructions. *Disability & Society*, 17(5): 493-508.
- Reeve, D. (2004) *Psycho-emotional dimensions of disability and the social model*. In Barnes, C., Mercer, G. (eds.) *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press.
- Riessman, C.K. (1993) *Narrative analysis*. Qualitative research methods series, no. 30. Newbury Park, CA: Sage.
- Riessman, C.K. (2008) *Narrative methods for the human sciences*. Thousand Oaks, CA: Sage.
- Robinson, J. (1962) *Essays in the theory of economic growth*, London: Macmillan.
- Roulstone, A. (2002) *Disabling pasts, enabling futures? How does the changing nature of capitalism impact on the disabled worker and jobseeker?* *Disability & Society*, 17 (6): 627-642.

- Roulstone, A. and Morgan, H. (2009) Neo-liberal individualism or self-directed support: Are we all speaking the same language on modernising adult social care? *Social Policy and Society*, 8(3): 333–45.
- Roulstone, A., and Mason-Bish, H. (2014) *Disability, hate crime and violence*. Abingdon: Routledge.
- Roulstone, A., Prideaux, S. (2012) *Understanding Disability Policy*. Bristol: The Policy Press.
- Sapey, BJ and Pearson, J (2004) Do *Disabled People* need social workers? *Social Work and Social Sciences Review*, 11(3): 52-70.
- Sayer, A. (1992) *Method in social science*. Abingdon: Routledge.
- Sayer, A. (1993) Postmodernist thought in geography: A realist view. *Antipode*, 25(4): 320-344. Sayer, A. (2000) *Realism and social science*. London: Sage.
- Sayce, L. (2011) Getting in, staying in and getting on: disability employment support fit for the future. London: The Stationery Office Limited.
- Scott-Hill, M. (2004) collectivising experience and rules of engagement: close(d) encounters in disability research. In: Barnes, C. and Mercer, G. (eds.) *Implementing the social model of disability: theory and research*. Leeds: The Disability Press.
- Shakespeare, T. (1993) *Disabled People* 's self-organisation: a new social movement? *Disability, Handicap & Society*, 8(3): 249-264.
- Shakespeare, T. (1996) Rules of engagement: doing disability research. *Disability & Society*, 11(2): 115-119.
- Shakespeare, T. (1997) Researching disabled sexuality. In: Barnes, C. and Mercer, G. (eds.) *Doing disability research*. Leeds: The Disability Press. Shakespeare, T. (2000) *Help*. Birmingham: Venture Press.
- Shakespeare, T. (2004) Social models of disability and other life strategies. *Scandinavian Journal of Disability Research*, 6(1): 8-21.
- Shakespeare, T. (2006) *Disability rights and wrongs*. Abingdon: Routledge.
- Shakespeare, T. (2014) *Disability rights and wrongs revisited*. London: Routledge.
- Shakespeare, T. and Watson, N. (2002) The social model of disability: an outdated ideology? *Research in Social Science and Disability*, 2: 9–28.
- Shildrick, M. (2012) Critical Disability Studies: Rethinking the Conventions for the Age of Postmodernity. In: Watson, N, Roulstone, A., and Thomas, C. (eds.) *Routledge handbook of disability studies*. London: Routledge.
- Slasberg, C., Beresford, P., and Schofield, P. (2013) The increasing evidence of how self- directed support is failing to deliver personal budgets and personalisation. *Research, Policy and Planning*, 30(2): 91-105.
- Spandler, H. (2004) Friend or foe? Towards a critical assessment of Direct Payments. *Critical Social Policy*, 24 (2): 187–209.
- Social Security Advisory Committee (2014) *The cumulative impact of welfare reform: a commentary* [Online]. Available:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/324059/sac

_occasional_paper_12_report.pdf [22 July 2014].

Soldatic, K. (2013) The transnational sphere of justice: disability praxis and the politics of impairment. *Disability & Society*, 28 (6):744-755.

Stevens, M., Glendinning, C., Jacobs, S., Moran, N., Challis, D., Manthorpe, J., Fernandez, J.L., Jones, K., Knapp, M., Netten, A., and M. Wilberforce, M. (2011) Assessing the role of increasing choice in English social care services. *Journal of Social Policy*, 40 (2): 257–74.

Stone, E. and Priestley, M. (1996) Parasites, pawns and partners: disability research and the role of non-disabled researchers. *British Journal of Sociology*, 47(4): 699-716.

Strauss, A. and Corbin, J. (1998) Basics of qualitative research: techniques and procedures for developing grounded theory, 2nd edition. Thousand Oaks, CA: Sage.

Touraine, A. (1974) *Post-industrial society*. London: Wildwood House.

Touraine, A. (1981) *The voice and the eye: an analysis of social movements*. Cambridge: Cambridge University Press.

Thomas, C. (1999) *Female forms*. Maidenhead: Open University Press.

Thomas, C. (2004) How is disability understood? *Disability & Society*, 19(6): 569-583.

Thomas, C. (2007) *Sociologies of disability and illness*. Basingstoke: Palgrave

Macmillan. Thomas, C. (2008) Disability: getting it “right”. *Journal of Medical Ethics*, 34: 15-17.

Thomas, C. (2010) Medical sociology and disability theory. In: Scambler, G. and Scambler, S. (eds.) *New directions in the sociology of chronic and disabling conditions*. Basingstoke: Palgrave Macmillan.

Thomas, C. (2012) Theorising disability and chronic illness: where next for perspectives in medical sociology? *Social Theory and Health*, 10(3): 209-228.

Tyler, I. (2013) *Revolting Subjects: Social Abjection and Resistance in Neoliberal Britain*. London: Zed Books.

UK People with disabilities's Council (UKDPC) (ND) *About us* [Online]. Available: <http://www.ukdpc.net/ukdpc/pages/who.php> [22 July 2014].

Union of the Physically Impaired Against Segregation (UPIAS) (1976) *Fundamental principles of disability*. London: UPIAS.

Vehmas, S. (2008) Philosophy and science: the axes of evil in disability studies. *Journal of Medical Ethics*, 34: 21-23.

Vehmas, S. (2014) *Ad hominem is a fallacy, but not in disability studies?* [online]. Available: <http://nndr.no/ad-hominem-is-a-fallacy-but-not-in-disability-studies/> [5 September 2014].

Vehmas, S. and Watson, N. (2014) Moral wrongs, disadvantages, and disability: a critique of critical disability studies. *Disability & Society*, 29(4): 638-650.

Vernon, A. (1996) A stranger in many camps: the experience of disabled black and ethnic minority women. In: Morris, J (ed.) *Encounters with strangers: feminism and disability*. London: The Women's Press.

- Vernon, A. (1998) Multiple oppression and the people with disabilities's movement. In Shakespeare, T. (ed.) *The disability reader: social science perspectives*. London: Cassell.
- Vernon, A. (1999) The dialectics of multiple identities and the people with disabilities's movement. *Disability & Society*, 14(3): 385-398.
- Watson, N. (2012) Theorising the lives of disabled children: how can disability theory help? *Children & Society*, 26(3): 192-202.
- West, K., (2013). The grip of personalization in adult social care: Between managerial domination and fantasy. *Critical Social Policy*. 33 (4): 638-657.
- Williams, G. (1984) The genesis of chronic illness: narrative reconstruction. *Sociology of Health and Illness*, 6(2): 175-200.
- Williams, S.J. (1999) Is there anybody there? Critical realism, chronic illness and the disability debate. *Sociology of Health and Illness*, 12(6): 797-819.
- Williams-Findlay, R. (2011) *Lifting the lid on People with disabilities Against Cuts* [Online]. Available: <http://dpac.uk.net/2011/03/bob-williams-findlaylifting-the-lid-on-disabled-people-against-cuts/> [10 July 2014].
- Wolff, J. and De-Shalit, A. (2007) *Disadvantage*. Oxford: Oxford University Press.
- Wood, C. (2012) *Destination unknown: summer 2012* [Online]. Available: http://www.demos.co.uk/files/Destination_Unknown_Summer_2012_-_web.pdf?1340294386 [12 July 2014].
- Wood, C. and Grant, E. (2010) *Destination unknown* [Online]. Available: http://www.demos.co.uk/files/Destination_unknown_-_web.pdf?1286894260 [12 July 2014].
- Wood, C. and Grant, E. (2011a) *Destination unknown: spring 2011* [Online]. Available: http://www.demos.co.uk/files/Destination_unknown_Spring_2011_-_web.pdf?1305026600 [12 July 2014].
- Wood, C. and Grant, E. (2011b) *Destination unknown: autumn 2011* [Online]. Available: http://www.demos.co.uk/files/DestinationUnknownAutumn2011_-_web.pdf?1322826138 [12 July 2014].
- Wright Mills, C. (2000) *The sociological imagination*. Oxford: Oxford University Press (Original work published in 1959).
- Yates, S. and Roulstone, A. (2013) Policy and transitions to training and work for disabled young people in the UK: neo-liberalism for better and for worse? *Disability & Society*, 28(4): 456-470.
- Young, J (2014) Dignity and opportunity for all: securing the rights of people with disabilities in the austerity era [Online]. Available: http://just-fair.co.uk/uploads/Dignity_Opportunity_for_All_-_Full_report.pdf [12 July 2014].
- Zarb, G. (1992) On the road to Damascus: first steps towards changing the relations of research production. *Disability, Handicap & Society*, 7(2): 125-138.
- Zarb, G. (1997) Researching disabling barriers. In: Barnes, C. and Mercer, G. (ed.) *Doing disability research*, Leeds: The Disability Press.

Zarb, G. and Nadash, P. (1994) Cashing in on independence: Comparing the costs and benefits of cash and services for meeting people with disabilities's support needs. Derby: BCODP/PSI.