SIXTEEN PLUS, PEOPLE WITH DECLINING CAPACITY DUE TO PROGRESSIVE ILLNESS: A CRITIQUE BASED ON GOVERNMENTALITY.

By

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Abstract

This study aims to add to the governmentality-based critique of health and social care and bring to bear such analysis to the specific context of those who are sixteen and above and have declining capacity due to progressive illness.

The thesis is concerned with aspects of Foucault's work in regards to disciplinary and biopower. It adopts Michel Foucault's term 'governmentality' for analysis of the state's ability to manage its resources economically and efficiently, in a way that allows for regulation and the need to negotiate through a process of self-governing. Through problematising England's health and social care system, the thesis examines the governance of families via policy and legal framework centred on the Mental Capacity Act 2005, the Care Act 2014, and the Children and Families Act 2014. It suggests that the care and support assessment processes control individuals, the workforce, and the population.

The study observed how ageing is a problem at a global, national, and local level and examined England's present economic, political, and legal responses. The programme of enquiry examined whether or not the rights and interests of people with advanced or progressive illness under these Acts are interpreted and followed as parliament intended. This study observed individuals, family and friend carers as they engaged and experienced the formal assessment processes - bringing to the forefront the ways of obtaining new knowledge into everyday contemporary life.

The empirical study has made visible, comments within the carers' perspective and experiences. The impact of the conversational practices illustrate what Foucault termed the relationship of power and the possibility of resistance within the power/ knowledge nexus.[1] The carers' responses highlighted underlying tensions to the health and care system, and specifically the impact

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[1] James Bernauer and David Rasmussen (edn), *The Final Foucault* (J.D. Gauthier tr, The MIT Press 1988); see ch 2 of this thesis discussing discourse and Foucault's thoughts.

of being an unpaid carer. Furthermore, only one of the five had received their carers’ assessments as part of the whole family approach. This suggests that the wellbeing of family and friend carers remains expendable in today’s contemporary society.

However, the 2020 coronavirus pandemic has impacted on this study. During the pandemic, we observe the rapid shift in legislation (whether temporary or permanent), which indicates how forms of institutional power are based on the ability to maintain and change over periods of time, and are not necessarily based on specific laws and legislation in a fixed time.

This thesis, therefore, contributes to understanding the specific issue of health and social care governance of those 16 and over with declining capacity due to progressive illness, and the field of governance of health and social care. It combines these two aspects in the context of Foucault’s work.

Acknowledgements

Firstly, I would like to express my sincere thanks to my key academic supervisor Austen Garwood-Gowers, who has remained with me throughout my research exploration and has continued to support, encourage, inspire and offer friendship during this time.

I am also extremely grateful to my co-supervisor Dr Linda Gibson and my former co-supervisor, Mr John Tingle, who has provided me with valuable guidance and commented on this thesis and earlier documents submitted in partial fulfilment of the research degree.

I am greatly indebted to members of the Solihull Metropolitan Borough Council Special Needs and Disabilities Board, Solihull Carers Centre and Solihull Action through Advocacy, who provided advice and feedback on the information required for participants, and the design and suitability of questions within the questionnaires used between 2016 and 2017.

A big thank you goes to my daughter Annabelle Luce, who patiently taught me about website design, techniques for marketing website traffic, and with the help of my husband, Duncan Luce, her father, helped create my research website that published the participant surveys.

Particular thanks go to those who helped disseminate or participated in my research surveys, without whom this study would not have been possible.

Finally, I would like to thank all my family, friends and colleagues who have supported me in my academic endeavours, and particularly Sarah Luce for her careful proofreading.

A note on terminology

Throughout this study, the terminology is that of the legislative framework and supporting statutory and non-statutory guidance. The exception relates to the work of the French philosopher, Michel Foucault.[2] Michel Foucault's concepts used in this thesis are explained further in chapter 2. In addition, there are introductory texts published to guide new readers through his thoughts and concepts. This study utilised Tony Schirato and others, glossary.[3]

A note about translated texts

As stated in an earlier research report,[4] it is not the purpose of this study to examine or give a detailed account of Foucault's theories, influences, methods or influences, which are documented in books and lectures and have been extensively commented on and interpreted by other scholars and editors.[5] However, one of the texts translated into English which is relevant to medical discourse has recently come under particular academic scrutiny. This text is a well-known book, *Birth of the Clinic*. In 2010, David Olivier Gougelet, in "The World is One Great Hospital", stated that the editor A.M. Sheridan Smith translated and combined two editions of Foucault's work, with 'no mention or explanation as to which passage came from which edition', rendering the *Birth of the Clinic* translation, 'useless' and 'misleading'.[6] For this reason, this thesis

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[2] Born in 1948 and died on 25th June 1984; Didier Eribon *Michel Foucault*, (Betsy Wing tr, Harvard University Press 1992) provides a biography of Michel Foucault.

[3] Tony Schirato, Geoff Danaher and Jen Webb, *Understanding Foucault: A critical introduction* (2nd edn, Sage Publications 2012) xvii - xxviii.

[4] Rosemary Luce, 'The Voice of the Public: The Findings, Research Report 2, Is it working? A family approach to care and support' (Document Four is submitted in partial fulfilment of Nottingham Trent University for the Professional Doctorate Degree in Legal Practice, December 2019), 10.

[5] For example, Michel Foucault *On the Government of the Living*: *Lectures at the Collège de France, 1979 -1980* (Michel Senellart ed, Arnold I Davidson English ed, first published 2008, Palgrave Macmillan 2014); Michel Foucault, *The Birth of Biopolitics*: *Lectures at the Collège de France, 1978-79* (Michel Senellart ed, Davidson A English ed, Burchell G tr, Palgrave Macmillan 2008); John S. Ransom, *Foucault's Discipline: The Politics of Subjectivity* (Duke University Press 1997); Michel Foucault, *The history of sexuality: An introduction* (Penguin Allen Lane 1979); David Howarth, 'Power, discourse, and policy: Articulating a hegemony approach to critical policy studies' (2010) Critical Policy Studies 3:3-4, 309-335.

[6] Guillaume le Blanc, 'La pensée Foucault' (Paris Ellipses, 2006) 154, in Gougelet DO, 'The World is One Great Hospital' (2010) Journal of French and Francophone Philosophy – Revue de la philosophie française et de langue française Vol XVIII, 1 (2008-2010), 1.

treats the *Birth of the Clinic* with caution and relies on Gougelet's translation of the passages cited from *Naissance de la clinique*,[7] also the transcripts of interviews with Michel Foucault on 20 January 1984 in *The Final Foucault*.[8]

A note about earlier doctoral documents

In contrast to a Ph.D, a Professional Doctorate Degree requires submissions of earlier documents for marking. As such, and balancing the need to cite correctly to avoid allegations of self-plagiarism, this document makes brief references to earlier documents but also makes use of sections of earlier texts which are relevant and required for the final thesis.

A note about excluded material

Owing to the parameters of the research, this study excludes literature explicitly related to child and adult safeguarding or protection and the deprivation of liberty safeguards, and subsequent amendments made by the enactment of the Mental Capacity (Amendments) Act 2019 – Liberty Safeguards.

While the thesis refers to the emergence of reforms such as Care Act easements: guidance for local authorities as a response to the 2020 coronavirus pandemic, a critique of the more comprehensive emergency measures under the Coronavirus Act 2020 is excluded.[9]

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[7] Michel Foucault, *Naissance de la clinique* (Presses Universitaires de France, coll. Gallien 1972. Sheridan Smith A M, English (tr) *The Birth of the Clinic*: *An Archaeology of Medical Perception,* first published Tavistock Publications 1973, Routledge 1997).

[8] ibid (n 1).

[9] Enacted on the 25th March 2020 in the government response to the coronavirus epidemic.

Chapter 1: Introduction

This thesis examines the governance of families under three main Acts. The Mental Capacity Act 2005, the Care Act 2014, and the Children and Families Act 2014. The Care Act and the Children and Families Act are relatively new Acts that were meant to provide a family approach to supporting people with care and support needs and their family or friend carers. The Acts were supported by statutory guidance,[10] and also best practice guidance to make a whole-family approach a reality.[11] The thesis examines whether or not the rights and interests of people with advanced or progressive illness under the Children and Families Act 2014, Care Act 2014 and the Mental Capacity Act 2005 are interpreted and followed as parliament intended.

The thesis was originally conceived looking through a whole family-based lens to analyse the health and social care support system as it relates to those who are sixteen and above and have declining capacity due to progressive illness. This lens was particularly relevant to the empirical work I conducted as part of the doctoral programme.

This consisted of gaining personal knowledge about the family's direct involvement in the care and support processes; in other words, their lived experiences revealed by three surveys as the family navigated its way through care, treatment and support arrangements. The main aims of the surveys were to provide a benchmark and insight into people's experiences and to begin to investigate the impact that resources have had in raising public awareness following the House of Lords Select Committee on the *Mental Capacity Act 2005: Post Scrutiny Report*[12] and the recent implementation of the Care Act

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[10] Department of Health, *Care and Support Statutory Guidance*. Issued under the Care Act in October 2014; Department for Education and Department of Health and Social Care, *Statutory Guidance on the special educational needs and disability (SEND) system for children and young people aged 0-25*, issued under part 3 of the Children and Families Act.

[11] Department of Health, Local Government Association, Directors of Adult Social Services, The Children's Society and Carers Trust, *The Care Act and Whole-Family Approaches* (2015).

[12] Select Committee on the Mental Capacity Act 2005, *Mental Capacity Act 2005: Post-legislative Scrutiny* (HL 2013-14 TSO).

and Children and Families Act, including the provision of accessible information and advice, their experiences of the assessment process and meeting of needs. Taking a public perspective, as opposed to a professional one, key research questions were:

a. Why, what, where and how information and advice were sought and obtained. Specifically, the provision of accessible information and advice that describes the range of services available to people with care and support needs, those with special educational needs and disabilities and/ or to the carers who help them;
b. The extent to which assessments include a person's preference, wishes, beliefs and values regarding their future care;
c. the difference between making an advance decision to refuse a specific type of treatment and an advance statement;
d. knowing if lasting powers of attorney for health, welfare and finance were made.

It should be noted that the surveys were originally designed to test participants' knowledge of decision making, as well as legal powers in the context of diminished capacity. However, following Foucauldian views of power in context within the existing health and social care system, the study examines the way that discourses within those systems have contributed to and advanced the management of health and social bodies by expanding new ways of obtaining knowledge of everyday life via surveillance and disciplinary techniques.

We observe the controlling of individuals through a process of systematic regulated activity, and the normalisation of formal assessment processes in the health, social care and educational fields and the communities we live in - a form of hegemonic authority within the operation of law and policy governing the health and social care systems. 'Their coercive character is often disguised and masked by their normative involvement in the troubles and problems of individuals. They are coercive, normative and also voluntary'.[13]

The study's findings are therefore relevant to individuals, patients, carers and their families, as the research should evaluate how well health and social care professionals are involving people and their families in formulating their plans and goals. It will ensure intelligence gathered drives improvements for the patient, service users' experiences, and informs commissioning and service decisions, as well as strategic plans.

The research is also relevant throughout England to local and developing integrated care systems and 'place-based' commissioning in local areas. Interested parties include the NHS England and Improvement, Public Health England, clinical commissioning groups, local authorities, Health and Wellbeing Boards, multi-agency partnerships and practitioners, such as Special Needs and Disabilities Boards, local and neighbouring safeguarding children's partnerships or adult safeguarding boards.

Public sector partners and members of boards including health and social care commissioners and provider organisations have statutory obligations under the Care Act, Mental Capacity Act and Children and Families Act, including seeking assurance that crucial pieces of legislation are implemented and that practitioners have the knowledge, skills, competence and confidence to enable this to happen.

The account of this study forms the basis of part 2 of the thesis and is reflected on further below. Part 1 provides a broader critical context within which to view part 2. In **Chapter 2** we begin with certain manifestations of power that Foucault thought important in constituting history, including disciplinary and biopower, then moving on to exploring and defining the nature of Foucault's concept of governmentality. **Chapter 3** applies this lens and critiques the care and support system in England.

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[13] Deborah Lupton, 'Foucault and the medicalisation critique' in *Foucault, Health and Medicine* (Alan Petersen and Robin Bunton eds, Routledge 1997), citing Bryan S. Turner, Foreword in Foucault.

It analyses the health and social care support system and its specific application to people aged sixteen and above and have declining capacity due to progressive illness. The principal tool I have used for this critique is the Foucauldian concept of governmentality.[14]

Foucault used the term governmentality to refer to the state's ability to manage its resources economically and efficiently, in a way that allows for 'regulation' and the need to 'negotiate' through a process of 'self-governing'.[15]

In analysing that system, I was therefore concerned not just with the content and operation of relevant law – particularly Mental Capacity Act 2005, the Care Act 2014, and the Children and Families Act 2014 - but also governance more broadly – or what in Foucauldian terms is known as the art of governing, which is concerned with 'regulating and monitoring the outward and inward life of each and every citizen'.[16]

Research justification

Following theoretical reading inspired by Michel Foucault, examining the structure of the Acts that directly influence individuals' 'choice' and relationships, I point out that the health and social care system, being structured through policy and law, is 'destined to act upon the possibilities of actions of others'.[17] This thesis points out that present-day health and social care legislation frequently includes a statement of fundamental principles that inform decision-makers as to what to consider when a decision or action is to be taken under the specific legislation. Key examples related to this particular

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[14] Burchell G, Gordon C and Miller P (eds), *The Foucault Effect: Studies in Governmentality, With Two Lectures and an Interview with Michel Foucault* (University Press 1991), 102.

[15] ibid (n 3) xvii - xxviii.

[16] James Miller, 'The Distant Roar of Battle' in *The Passion of Michel Foucault* (Simon & Schuster, 1992) ch 9, 299.

[17] Michel Foucault, 'The Subject and Power' (1982) Critical Inquiry 8, 4, 777-795, 789.

research are the Mental Capacity Act (MCA) 2005 (best interests' principle), and the Care Act 2014 (wellbeing principle).[18]

The Care Act and the Children and Families Act are relatively new Acts which contain substantial legal duties guiding decision-makers, and the duties owed to people who use health and social care services. For example, the enforcement duties of carrying out assessments and involving relevant persons when undertaking several functions under the Care Act;[19] include:

1) Carrying out a needs assessment.[20]
2) Carrying out a carer's assessment.[21]
3) Preparing a care and support plan.[22]
4) Revising a care and support plan.[23]
5) Revising a support plan.[24]
6) Carrying out a child's needs assessment.[25]
7) Carrying out a child's carer's assessment.[26]
8) Carrying out a young carer's assessment.[27]

Section 12 (1) (a) provides a power to make regulations that require local authorities to have regard to the needs of the family of the person to whom an assessment relates. Section 12 (5) allows the assessment to be linked to other assessments and Section 65 allows local authorities to combine assessments if agreed by the parties involved. The intention is to enable practitioners to consider the effects of an individual's support needs on the rest of the family.

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[18] Care Act 2014, s 1 (2) (a) to (e). Examples in other jurisdictions are seen in The Adult Support and Protection (Scotland) Act 2007; Mental Health (Care Act and Treatment) (Scotland) Act 2003; Adults with Incapacity (Scotland) Act 2000. Aged Care Act 1997 (Australia); Family Law Act 1975 (Australia); Long-Term Care Act 2000 (Canada).

[19] Care Act 2014 s 67 (3) (a) to (i).

[20] ibid s 9 (5) and (b).

[21] ibid s 10 (7) (a).

[22] ibid s 25 (3) (a) and (b).

[23] ibid s 27 (2) (b) (i) and (ii).

[24] ibid s 27 (3) (b) (i) and (ii).

[25] ibid s 59 (2) (a) and (b).

[26] ibid s 61 (3) (a).

[27] Ibid s 64 (3) (a) and (b).

Another example is that of:

> [A] child who is under compulsory school age, and a clinical commissioning group, NHS trust or NHS foundation trust forms the opinion that the child has (or probably has) special educational need, or a disability. The group or trust must inform the child's parents of their opinion and their duty, and allow the child's parents to discuss their opinion with an officer of the group or trust. The health body must then bring their opinion to the attention of the appropriate local authority in England. Also, if the group or trust thinks a particular voluntary organisation is likely to be able to give the parent advice or assistance in connection with any special educational needs or disability the child may have, they must inform the parents of that.[28]

Nevertheless, during the passage of the Acts, the government resolved to undertake post-legislative scrutiny of the Care Act three and five years after Royal Assent. This has not happened,[29] whereas being disabled in Britain and having access to health care has received some scrutiny through the Equality and Human Rights Commission.[30]

In the MCA, there are five guiding principles designed not only to protect people who cannot make individual decisions but to maximise their ability to participate in decision-making, but also to guide others in their decision-making and actions. Section 1 reads as follows:

1. The following principles apply for the purpose of this Act.
2. A person must be assumed to have capacity unless it is otherwise established that he lacks capacity.
3. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

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[28] Children and Families Act 2014, s 23 <www.legislation.gov.uk/ukpga/2014/6/section/23/enacted > accessed 9th August 2020.

[29] Tim Spencer-Lane*, Care Act Manual* (3rd edn, Thomas Reuters (Professional) 2019), Preface, xx.

[30] Equality and Human Rights Commission, "Being Disabled in Britain: A journey less equal" (April 2017).

4. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
5. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity, must be done, or the decision is made, in his best interests.
6. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be effectively achieved in a way that is less restrictive of the person's rights and freedom of action.[31]

In May 2013, the House of Lords (HL) Committee began to scrutinise the way that the Mental Capacity Act (MCA) was working in practice.[32] In June 2004 the government had said that the MCA Bill would, 'empower, protect and support people who lack mental capacity' and that 'professionals, families and friends who care for people who lack capacity need to understand more fully and more clearly their legal rights and responsibilities'.[33] The government expected that "over time" the Bill would 'bring a quiet revolution in public attitudes and practice', (through providing liberty and requiring organisations and professionals to act in specific ways in order to implement the legislation as intended).[34] However, in recognition of the scale of change in culture and working practices,[35] resources featured a series of publications 'aimed at families, friends and unpaid carers, and professionals in health and social care, and included DVDs and monthly newsletters'.[36]

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[31] <www.legislation.gov.uk/ukpga/2005/9/section/1>accessed 2 August 2020.

[32] ibid (n 12).

[33] HC Deb 11 October 2004, col. 22; ibid (n 12) ch 2, Background to the Mental Capacity Act provides a useful summary to the government's intentions and resource allocations <https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13906.htm#n27> accessed 2 August 2020.

[34] HC Deb 18 June 2001, col 68 WS.

[35] The change of name from Mental Incapacity Bill to Mental Capacity Bill was recommendation 99 of the Joint Committee on the Draft Mental Incapacity Bill; *Joint Committee on the Draft Mental Incapacity Bill, Draft Mental Capacity Bill (First Report*) (2002 – 03, HL 189-1) <https://publications.parliament.uk/pa/jt200203/jtselect/jtdmi/189/18924.htm> accessed 2 August 2020.

[36] 'How did the Government set out to achieve it?' ch 2, para 27 <https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13906.htm#n27 > accessed 25 July 2020.

In 2013, as part of the post-legislative review, the House of Lords Committee was established to scrutinise the way that the MCA was working in practice. This report was published on 13th March 2014 (*Mental Capacity Act 2005: Post Scrutiny Report*), and Lord Hardie said of it:

> The Committee believes that the Act is good and it needs to be implemented. What we want to see is a change in attitudes and practice across the health and social care sector which reflects the empowering ethos of the Act. To achieve this, we recommend that overall responsibility for the Act be given to an independent body whose task will be to oversee, monitor and drive forward implementation…
>
> Our other key finding concerns the Deprivation of Liberty Safeguards. The intention of the safeguards is to provide legal protection for people who are being deprived of their liberty for their own safety. The evidence suggests that tens of thousands of people are being deprived of their liberty without the protection of the law, and without the protection that Parliament intended. The Government needs to go back to the drawing board to draft replacement provisions that are easy to understand and implement and are in keeping with the style and ethos of the Mental Capacity Act.[37]

Since then, a large quantity of resources was allocated via NHS England and other government departments to improve the awareness and implementation of the Act across professionals. At the same time, the Care Act 2014 was coming into force, requiring a similar fundamental cultural shift across agencies to meet the requirements under the Act. Given the relatively recent legislative developments, impetus and drive from the Minister of State for Justice, Lord Faulks QC,[38] this research focused on:

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[37] See, <www.parliament.uk/business/committees/committees-a-z/lords-select/mental-capacity-act-2005/news/mca-press-release---13-march-2014/> accessed 25 July 2020.

[38] See, Letter from Lord Faulks to all Peers (9 March 2015) <www.parliament.uk/mental-capacity-act-2005> accessed 25 July 2020.

- a ‘whole family approach’ to assessments;[39]
- vulnerable adults and young people in transition into adult services;[40]
- those who have care and support needs, and carers’ assessments;[41]
- those who are likely to have fluctuating capacity or to lack capacity in the future (applying MCA and 2005 MCA Code of Practice).

As mentioned above, the transition of children to adult care and support[42] includes children in receipt of an Education, Health and Care Plan under Part 3 of the Children and Families Act 2014.[43] The three Acts form a hybrid of different legislative approaches; these range from being non-specific, broad-ranging and generally outcome-focused,[44] to being specific and process-driven, for example, the case of *Marcin Antoniak v Westminister City Council*[45] - the enforceable duties of carrying out an individual assessment and of meeting needs.

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[39] Department of Health, *The Care Bill explained -including a response to the consultation and pre-legislative scrutiny on the draft Care and Support Bill*, para 122; Department of Health, *Care and Support Statutory Guidance under the Care Act 2014*, June 2014, amended by the Department of Health and Social Care, *Care and Support Statutory Guidance*, 2018, para 6.65 – 6.73 < www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance> accessed 25 July 2020.

[40] Care Act 2014, s 58; Children and Families Act 2014 under pt 3, Children and young people in England with special educational needs or disabilities < www.legislation.gov.uk/ukpga/2014/6/part/3/enacted> accessed 25 July 2020;

[41] ibid s 9 and 10; Children Act 1989, s 17ZA and 17ZB.

[42] ibid (n 40) s 58- 66 <www.legislation.gov.uk/ukpga/2014/23/part/1/crossheading/transition-for-children-to-adult-care-and-support-etc/enacted> accessed 9th August 2020.

[43] ibid (n 40) Children and young people in England with special educational needs or disabilities < www.legislation.gov.uk/ukpga/2014/6/contents/enacted> accessed 9th August 2020.

[44] See the wellbeing principle, s 1, Care Act 2014.

[45] [2019] EWHC 3465 (admin); An assessment carried out by a London borough did not constitute a discharge of its duties under the Care Act because the borough failed to include all the individual’s needs, whether currently being met, or not. The claimant was a national of Poland. He came to work in the UK in 2013 as a painter and decorator. He was unable to work since 2018 and he became homeless. He had acute psychotic episodes, apparently brought on by the stress of being homeless. In August 2018 he was involved in a serious road traffic accident. When discharged from the hospital he used a wheelchair. At the time of the needs assessment, the claimant’s needs were being met by accommodation and a charity. The case centered around the question of the meaning of the word ’needs’ in part 1 of the Care Act. There was no definition in the Act itself, and no case law has defined the meaning of ‘needs’. The High Court clarified the meaning of ‘needs’ in the context of a ‘needs’ assessment. ‘Needs’ does not exclude a need that is being, or is readily capable of being met. A ‘needs’ assessment of what an individual need is without regard to the existing help and support they are receiving.

In turn, the different legal approaches create a complex area of health and social policy involving chronic health problems, and are influenced by multiple factors, including improvements in medical science, ageing populations, economic disparities, educational attainment, lifestyle choices and behaviour.

By eliciting lived experiences from the public as they navigate their way through care, treatment and support arrangements, the study involves individuals, patients, carers, and their families, thus the research should evaluate how well health and social care professionals are involving people and their families in formulating their plans and goals. It will ensure intelligence gathered drives improvements for the patient, service user's experiences, and informs commissioning and service decisions, as well as strategic plans.

Returning to part 2 of the thesis, it is interesting to observe how well it dovetailed with the Foucauldian approach, not least because of the emphasis that Foucault, both generally and specifically in the area of health, placed on looking at people's 'lived experience'.[46] Part 2 starts with chapter 4, which focuses on the research design of the empirical programme. Tying in with the desire to take a whole family approach and understand lived experience, I developed the design in the wake of not just examining the relevant literature but also consulting with those at 'the coal face', including the Solihull Special Needs & Disabilities Board and engaging with parents and Experts by Experience (see further, **chapter 4**). The engagement process was explored more fully within an earlier research document, for example, exploring possible methods of generating data, including conducting interviews either as a gender mix and or via single gender-focused groups.[47]

I have discussed sampling and demographics, ethical considerations and the question of research bias in earlier documents, therefore only touch on them briefly in chapter 4. **Chapter 5** sets out the core findings of the empirical study

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[46] ibid (n 13) ch 5, 101.

[47] Rosemary Luce, 'Sixteen Plus: A Whole family approach to understanding and protecting the rights and interests of people with advanced or progressive illness under the Children and Families Act 2014, Care Act 2014 and the Mental Capacity Act 2005' (Document two was submitted in partial fulfilment of the requirements of Nottingham Trent University for the Professional Doctorate Degree in Legal Practice 2017), 26.

and examines the lived experiences of participants. The three surveys tested the rights and entitlements to assessments up to 13th July 2018, see:

- Fraser case study one;
- findings from the carers' surveys;
- making longer-term plans when one is unable to make specific decisions for oneself.

The remit of the thesis

Part 2 of this study focuses on the research design of the empirical programme. The programme of inquiry therefore sits within a longitudinal study,[48] using a mixed method approach (see **chapter 4** – Mixed Methods). A mixed method approach utilises 'the strengths of both qualitative and quantitative research'.[49] Mixed method design is 'a growing area of importance within health social sciences to understand health problems'.[50] Mixed method research was chosen because the population group involves various people (e.g. professional and unpaid workforce) and organisations (e.g. NHS, local authorities and charities) likely to be involved with the person with care and support needs or their carer. Accordingly, to support ethical approval, the study is required to be pre-planned and staged to be as inclusive as possible of the intended participants. See **chapter 4**, the involvement of others in the research design.

The empirical programme, the methods and sequences utilised to generate the data and the new knowledge include:

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[48] Stewart J Anderson, 'Longitudinal Study Designs' in Liamputtong P (ed), *Handbook of Research Methods in Health Social Sciences* ch 35, 603 <http://doi.org/10.1007/978-981-10-5251-4_70> accessed 16 May 2020.

[49] John W. Creswell, *Research Design, Qualitative, Quantitative, and Mixed Methods Approaches* (3rd edn, Sage Publications 2008) ch 10, 203.

[50] Kate A. McBride and others, 'The Use of Mixed Methods in Research' in Liamputtong P (ed) *Handbook of Research Methods in Health Social Sciences* ch 40, 697 <http://doi.org/10.1007/978-981-10-5251-4_97>accessed 16 May 2020.

1. Document analysis, accessing relevant grey literature and statistical data from both published and internal sources across law, health and social care and featured throughout this thesis.
2. Theoretical analysis. The problematisation and relativisation of what the health and social care system might mean to us in the present;
3. Results of Phase 1: Data transformation using the surveys (research strategy) integrating quantitative (telling us “If”) and qualitative (telling us “How or why”) data collection and analysis concurrently has been adopted. In conjunction with Experts by Experience and professional members of a Special Needs and Disability Board, three surveys were designed to study three different population groups of the general public;
4. The conclusion and recommendations, which led to further research, phase 2 and beyond.

As mentioned above, drawing upon the data gathered through the public surveys will ultimately lead to a conclusion about whether or not rights and interests of people with advanced or progressive illness under the Children and Families Act 2014, Care Act 2014 and the Mental Capacity Act 2005 are interpreted and followed as Parliament intended (see, chapter 5, the overall conclusion).

Generating new knowledge

By eliciting lived experiences from the public as they navigate their way through care, treatment and support arrangements, the study reveals participants’ first-hand experience of the care and support system for those people and family members with declining capacity. In addition, the study generates new knowledge, including broader public health, social care, and legal services about participants' experiences and tests what individuals aged sixteen and above knows about sharing wishes with family and close friends.

Drawing on Michel Foucault’s explanation of how institutional power operates, the thesis examines the governance of families under the provisions of three main Acts; the Mental Capacity Act 2005, the Care Act 2014, and the Children and Families Act 2014, and shows that the care and support assessment process is a means of controlling individuals, the workforce and populations.[51]

The thesis therefore contributes to understanding the specific issue of health and social care governance of those aged 16 and over with declining capacity due to progressive illness, the field of health and social care governance more broadly, and the application of Foucault’s philosophy.

Later in Phase two of a much longer-term study, Phase two will narrow down and focus on individuals aged sixteen to thirty who have a progressive illness. Progressive disease or illness is a term used to describe a condition or disease that worsens over time, resulting in a decline of health or function. The study will continue to discover how much knowledge people and their carers have in making, updating and cancelling advance decisions to refuse treatment. In addition, it will determine the extent to which professionals ascertain and follow the wishes and views expressed in advance decisions to refuse treatment and find out how well they are implementing care and support, choice and control, including making safeguarding personal.

However, before situating Foucault within the theory of power relations and governmentality, I shall locate myself within the study.

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[51] Please note that this research study has been modified following a number of challenges along the way; it does not go on to examine the connection between power and management or administration see, chapter 2 commentary.

Locating myself within the study

Professionally, I am an independent nurse lawyer researcher specialist, with over thirty-four years working as a qualified nurse. Employment and experience have spanned children's urgent care, cardiothoracic nursing; ward sister in a general hospital children's ward (Dudley); health visiting - public health specialist across all ages (Birmingham, Nottinghamshire and Leicestershire); therapeutic counsellor and Healthy Living Facilitator for age 16 and older (GP practice); Sister within nursing homes for older people; national charity and smaller charitable not-for-profit organisations, as well as working within the independent sector. Currently, I am an Assistant Director of Quality and Safeguarding, Regional Safeguarding Lead for NHS England and NHS Improvement.

After undertaking a Masters of Law in Claims and Risk Management in Healthcare, I developed a deep understanding of organisational governance, as well as practical experience in providing specialist advice and support to multi-agency professionals and members of the public. As a senior manager and specialist working within the NHS, I am not a stranger to living and working through NHS restructuring and change.

Organisational changes have impacted on my journey as a researcher and the modifications made within the design of the study itself. Significant changes within the NHS Clinical Commissioning Group (CCG), meant that the current CCG was no longer going to be a legal entity. In 2017 and 2018, the effect impacted on the sites of research, on Part C of the Integrated Research Application System (IRAS) and brought in additional Data Protection Act requirements: Part B, Section 8 – additional information to the Confidential Advisory Group (CAG).

As to the second change, I could no longer specify the work base and sites, employer, or even if employment was to continue within the NHS, following the organisational restructuring process as the three CCGs merged to form one body. As a result, the design and methodology of the thesis changed to adopt a lay perspective and a mixed methodology within which Phase one mentioned above was located.

Later, during 2019, NHS restructuring continued to take place, which was of course outside my control and which in turn, slowed down the progress and finalising of Phase one of this study.

Finally, in March 2020, the global coronavirus pandemic and the enactment of the Coronavirus Act 2020 and emergency plans have affected the completion of the research project. The primary aim of the study has had to be adapted accordingly.

My interest in conducting this professional doctoral study and focusing on people with care and support needs and their family carers arose from personal experiences of having been both a family and friend carer since 2006 and up to January 2016. The care and support needs related to three different older adults, all three requiring significant assistance and support from various agencies to remain living within our home or theirs. During this period, there were the challenges of accessing pupillage, maintaining work, undertaking caring responsibilities, balancing different family needs, as well as experiencing first-hand the relentless tiredness, frustrations and barriers carers face when supporting people.

Caring is multi-faceted in terms of conditions and disabilities, both as regards the person cared for and the carer; the residential area in which they or the person they care for lives, the impact upon income status and the wider support of family and community networks. My family carer's role brought us into contact with other people with care and support needs and their families, at times informally giving help and guidance as they too navigated both the health and social care system.

My experience commenced during the implementation period of the Mental Capacity Act 2005, and later during the dawning of the Care Act 2014 and the Children and Families Act 2014 – a new era that promised change and improvements to the lives and entitlements of people with care and support needs and their carers. The combination of both personal and professional life experiences was a strong motive in my undertaking this study and in acquiring a broader interest in the care system.

PART ONE

Chapter 2: The theory of governmentality

Introduction and setting the scene of Foucault's thoughts

This study examines the governance of families via the policy and legal framework provided by the Mental Capacity Act 2005, the Care Act 2014, and the Children and Families Act 2014. It has adopted Michel Foucault's term 'governmentality' for analysis of the state's ability to manage its resources economically and efficiently in a way that allows for regulation and the need to negotiate a process of self-government.

This chapter examines Foucault's thoughts concerning the body, health, knowledge, power, discourses and governmentality relevant to this thesis. I draw upon several of Foucault's books, which include *Madness and Civilization*,[52] *The Order of Things*,[53] *The Archaeology of Knowledge*,[54] *Discipline and Punish*,[55] *History of Sexuality,*[56] *Security, Territory, Population,*[57] *The Birth of Biopolitics*[58] *and On the Government of the Living.*[59] In addition, critical lectures translated by David Macey as *Society Must Be Defended* [60] in 2003 came between the publications of *Discipline and Punish* (1975) and *The History of Sexuality*, *Volume one* (1976).

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[52] *A History of Insanity in the Age of Reason* (R. Howard tr, Tavistock 1965).
[53] *An Archaeology of the Human Sciences* (Tavistock/ Routledge 1970).
[54] (A.M. Sheridan Smith tr, Routledge 2002).
[55] *The Birth of the Prison* (A. Sheridan tr, Penguin 1975).
[56] *Vol 1: The Will to Knowledge; Vol II: The Use of Pleasure; Vol III: The Care of the Self.*
[57] *Lectures at the Collège De France 1977-1978*, Michel Senellart, François Ewald and Alessandro Fontana, Arnold I. Davidson (eds) and Graham Burchell (tr) (Paperback edn Palgrave Macmillan 2010).
[58] *Lectures at the Collège De France 1978-1979*, Michel Senellart, François Ewald and Alessandro Fontana, Arnold I. Davidson (eds) and Graham Burchell (tr) (Paperback edn Palgrave Macmillan 2010).
[59] *Lectures at the Collège De France 1979-1980*, Michel Senellart, François Ewald and Alessandro Fontana, Arnold I. Davidson (eds) and Graham Burchell (tr) (Palgrave Macmillan 2014).
[60] *Lectures at the Collège De France 1975-76* (Mauro Bertani, Alessandro Fontana, François Ewald and Arnold I. Davidson (eds) and David Macey (tr) Penguin Books 2003).

Underpinning Foucault's writing, his discourse approach relates to individual acts of language, or language in action – the idea and statements that allow us to make sense of and ‘see’ things.[61] He adopted the term ‘discourse’ to produce knowledge and meaning, and what he called ‘practices that systematically form the objects of which they speak’.[62] In regards to institutions, power and the historical period in which the issue or problem arises, Foucault considered discourse from a structuralist point of view. The effects of power in a particular social order are established through rules and categories, which define the criteria of the particular knowledge and truth within the discursive order. However, the rules and categories are considered before the discourse.[63] As a result, discourse masks its construction and capacity to produce knowledge and meaning.[64] Furthermore, through reaffirmation in society, the rules of discourse fix the statements and texts to be conducive to the political rationality that underpins its production.[65] According to Foucault, the discursive process reduces other possible meanings of text, in order to eliminate or reduce challenges that could destabilise the meaning and power of the discourse:

> In every society, the production of discourse is at once controlled, selected, organised and redistributed by [several] procedures whose role is to ward off its powers and dangers, to gain mastery over its chance events, to evade its ponderous, formidable materiality.[66]

Through commentaries on the discourse, statements or texts can reaffirm the meanings enacted by the discourse, Foucault explains:

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[61] Schirato T and others (n 3), Glossary of theoretical terms, xix-xx.

[62] Michel Foucault, *Archaeology of Knowledge and the Discourse on Language* (1969) (AM Sheridan Smith tr, 1972), 54, 133-141. See also M Foucault ‘The Order of Discourse’ in R Young (ed) *Untying the Text: A Post-Structuralist Reader* (Routledge & Kegan Paul 1981).

[63] Michel Foucault, ibid (n 58) 54.

[64] ibid (n 58) 126-134.

[65] ibid 126-134.

[66] ibid 53.

> Commentary averts the chance elements of discourse by giving its due: it gives us the opportunity to say something other than the text itself, but on condition that it is the text itself which is uttered and, in some ways, finalised. The open multiplicity, the fortuitousness, is transferred, by the principle of commentary, from what is liable to be said to the number, the form, the mask and the circumstances of repetition. The novelty lies no longer in what was said but in its reappearance.[67]

Through reiteration, the 'uttering' of the commentary processes discourse normalises and homogenises, fuses, including upon the bodies and subjectivities of those it dominates. In *Madness and Civilisation*, Foucault demonstrated discursive practices of exclusion in the categories of reason and madness.[68] In *Discipline and Punish,* Foucault fixes the meaning and categories of reason by which statements are accepted, creates knowledge and a degree of validation (epistemic reality) which becomes a technique of control and discipline.[69]

Later, in *Society Must Be Defended,* Foucault further discussed discourse as a norm. He said:

> The discourse of disciplines is about a rule, not a judicial rule derived from sovereignty, but a discourse about…a norm. Disciplines will define not a code of law but a code of normalisation, and they will necessarily refer to a theoretical horizon that is not the edifice of law, but the field of the human sciences [with the jurisprudence of clinical knowledge].[70]

However, it was in his last published works with respect to sexuality and the discourse that Foucault provided a captivating description of the function of discourse analysis as a technique, Foucault wrote:

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[67] ibid, 221.

[68] ibid (n 32).

[69] ibid (n 55), 'The means of correct training', 170-194.

[70] Michel Foucault, *Il faut défender la société* (Seuil/Gallimard 1997. Macey D English tr, as *Society Must Be Defended*, New York: Picador 2003) 38.

> Why has sexuality been so widely discussed, and what has been said about it? What were the effects of power generated by what was said? […] The central issue, then, is […] to account for the fact that it is spoken about, to discover who does the speaking, the positions and viewpoints from which they speak, the institutions which prompt people to speak about it and which store and distribute the things that are said. What is at issue, briefly, is the over–all 'discursive fact', the way in which sex is 'put into discourse'.[71]

Foucault set out in broad terms the task of discourse analysis and problematisation. The method of problematisation and critique, is applied in chapter 3 in regard to England's care and support system.

Foucault

Whilst this thesis does not engage extensively with Foucault's biographical detail, eminent authors such as David Mace situate events in which Foucault lived in the context of work.[72] Michel Foucault (1926-1984) was a French philosopher associated with the structuralist and post-structuralist movement.[73] After World War II, Foucault believed that all notions of truth, subjectivity, knowledge and reason were influenced by historical forces. Foucault's work was mainly concerned with 'the body and its forces',[74] histories of the medical and social sciences, which focused on the impact of knowledge upon disadvantaged and marginalised groups, whereby whole categories of people were divided, made into subjects and objects on order to develop forms of knowledge. For example, exposing life in institutions, 'to see

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[71] Michel Foucault, *The History of Sexuality: Volume 1 The Will to Knowledge* (Robert Hurley tr, reprinted Penguin Classics 2020), 11.

[72] David Macey, *The Lives of Michel Foucault* (Verso 2019).

[73] Gary Gutting and Johanna Oksala, "Michel Foucault" in Edward N. Zalta (ed), *The Stanford Encyclopaedia of Philosophy* (Spring edn, 2019) <https://plato.stanford.edu/archives/spr2019/entries/foucault/> Stanford Encyclopaedia of Philosophy, first published Wed 2 April 2003, substantive revision Tuesday 22 May 2018 < https://plato.stanford.edu/entries/foucault/> accessed 8 November 2019.

[74] Michel Foucault, ibid (n 55).

into the prison, to know the prison, to hear from the prison, to know the prison'.[75]

Hearing the voice of the general public is a fundamental feature of the design of this study. Thus, Foucault's approach is appropriate in making heard the comments of the general public and the voice of people aged 16 and above who have care and support needs, or who care for people with a progressive illness and declining capacity.

Another feature of Foucault's work was identifying a problematic relation from the time he lived, such as the political turbulence of May 1968, hunger strikes in January 1971, prison reforms during the 1970s in France, and then tracing back the origins that shaped those problems.[76] Foucault believed that history is not conceived linearly but formed of multiple events and a struggle between opposing forces and forms of power. Of relevance to this study in its examination of health and social care institutions are also the concepts of 'government' 'governmentality' and the 'art of governing'.

Discipline and punish, the concept of disciplinary power

When discussing the body and the effect of disciplinary power, Foucault claims that the power is not possessed; instead, it is exercised:

> It invests them, is transmitted by them and through them; it exerts pressure upon them, just as they themselves, in their struggle against it, resist the grip it has on them.[77]

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[75] Perry Zurn and Andrew Dilts (ed), *Active Intolerance: Michel Foucault, the Prisons Information Group, and the Future of Abolition* (Palgrave Macmillan 2016).

[76] ibid 3.

[77] Michel Foucault, ibid (n 55), 26-27.

Disciplinary power, therefore, targets individuals, employs surveillance and normalizing techniques and is exercised on the punished, whether it be on those whom ‘one supervises, trains and corrects, over madmen, children at home and at school, the colonized, over those who are stuck at a machine and supervised’.[78]

The disciplinary normalisation process consisting of:

> Trying to get people, movements, and actions to conform to [a] model, the normal being precisely that which can conform to this norm, and the abnormal that which is incapable of conforming to the norm. [As a result], the division between the abnormal and normal emerges.[79]

Foucault also draws on the political aspects related to his field of study and in discussing acquiring knowledge and power relationships he claims:

> The body is also directly involved in a political field; power relations have an immediate hold upon it; they invest it, mark it, train it, torture it, force it to carry out tasks... perform ceremonies, to emit signs. This political investment of the body is bound up, in accordance with complex reciprocal relations, with its economic use; it is largely a force of production that the body is invested with relations of power and domination; but, on the other hand, its constitution as labour power is possible only if it is caught up in a system of subjection (in which need is also a political instrument meticulously prepared, calculated and used); the body becomes a useful force only if it is both a productive body and a subjected body. [80]

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[78] ibid 29.

[79] ibid (n 60), 25 January 1978, 57; ibid (n 77) 193.

[80] Michel Foucault, ibid (n 77) 25-26.

Foucault's early work relating to power was also criticised for being under-theorised, ‘and reducing subjectivity to the disciplining and ordering of docile bodies, leaving little or no space for human freedom and agency’.[81]

In the first volume of the *History of Sexuality*, Foucault redefined power, emphasising that it is not a substance or thing, and concluded that:

> Power is everywhere: not because it embraces everything, but because it comes from everywhere…. Power is not an institution; and not a structure; neither is it a certain strength we are endowed with; it is the name we give to a complex strategic situation in a particular society.[82]

Biopower

Foucault introduced the concept of biopower in the final chapter of the first volume of the *History of Sexuality*.[83] According to Morton and Bygrave, *Society Must be Defended* was seen ‘to form a bridge between Foucault’s work on the disciplinary power and biopolitics’. John Marks explained:

> [D]isciplinary power has as its target the individual, employing surveillance, normalizing techniques and a "panoptic" grid of institutions. Biopower, on the other hand, has as its target the population as a whole.[84]

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[81] David Howarth, ibid (n 5) 316.

[82] Michel Foucault, ibid (n 71) 93.

[83] ibid; biopolitics and biopower concepts were first introduced by Foucault but he did not distinguish them, see (n 57), Lecture of 11 January 1978, 22, with regard to Moheau. “who was no doubt the first great theorist of what we could call biopolitics, biopower”. Later in the Lecture 7 March 1979, 185, Foucault also intended to talk about biopolitics, instead “I have ended up talking at length, and maybe too long, about neoliberalism”. Foucault also meant to talk in his 1980s lectures about the government of the living, but the “government of the men by the truth” and therefore not the techniques of control of populations, see Michel Senellart, ibid (n 57) 327.

[84] Cited in *Foucault in an Age of Terror: Essays on biopolitics and the defence of Society*, Stephen Morton and Stephen Bygrave (eds), (Palgrave Macmillan UK 2008) 1, fn 1. Citing John Marks, ‘*Foucault, Franks, Gauls: Il faut défendre la société: The 1976 Lectures at the Collège de France’* (Theory, Culture & Society 2000) 17, 123.

According to Foucault, the West's political and economic mechanisms of power developed during the transition from the classical age to modern times.[85] The pre-modern power is characterised by a sovereign power, the right to seize things, times, bodies, life itself and so forth. In the modern era, biopower is characterised by the government taking an active interest in people's lives and seeing the population as objects; used to produce and manage a state’s human resources. Foucault defined governmentality as a complex form of ‘power that has the population as its target, political economy as its major form of knowledge and apparatuses of security as its essential technical instruments’.[86]

Security, Territory, Population and *The Birth of Biopolitics*

For Foucault, the notion of security had a broader meaning and explored how power forms create room for further growth and development. In contrast, disciplinary power exists to contain and limit power. *Security, Territory, Population* and *The Birth of Biopolitics Lectures* were published simultaneously. They continued from the introduction of ‘bio-power’ in the 1976 lectures *Society Must Be Defended,* which retraced the emergence of the ‘power of life’ and explored how power over life was organised in the West, with 8 March 1978 lecture exploring the ‘political government of men’.[87]

Originally Foucault’s research programme proposed to examine the mechanisms at the end of the nineteenth century that defended society, extending on ‘the slow formation of a knowledge and power of normalisation based on traditional juridical procedures and punishment’.[88] Foucault intended to theorise with social defence, but instead, these lectures “no longer dealt with social defence but with the war in historical discourse”.[89] Nevertheless, he did discuss epidemics in the mid-eighteenth century and the ‘prevention’

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[85] Michel Foucault, (ibid n 71), 136.

[86] Michel Foucault, (ibid n 57), 108.

[87] Lecture of 11 January 1978, 11; Lecture of 8th March 1978, 227- 248, 243.

[88] ibid (n 57), Lecture of 25 January 1978, 79.

[89] Michel Senellart, ibid 377.

strategy; the town, the home and ‘populations’ were linked to economic and political problems and new government techniques.[90] The following section expands on Foucault's method of governmentality, but the prevention strategy and techniques are later applied under the Impact of Covid-19 on this study.

Governmentality

Governmentality is a method of examining the State’s ability since the 18th century to manage its resources, economically and efficiently, including the population, in a way that increased the State’s intervention in the lives of citizens by regulation and the need to negotiate through a process of self-governing.[91]

Foucault’s ideas were derived from thinking through the ascendance and descendances of individuals, namely the various levels of governing individuals and their desire to become part of an undifferentiated group.[92] Governing oneself (linking to morality or the mentality of rule),[93] governing one’s family (linked to the economy), and governing the state. Forms of knowledge acquired by the state or institutions are applied to ‘act on the consciousness of people’, modifying their views and opinions, ‘and along with their opinions their way of doing things, their way of acting, their [behaviour] as economic subjects and political subjects’.[94]

Foucault’s claims that the role of the state is to create conditions for a form of personal autonomy and citizenship, which incorporates responsibility for oneself and one’s dependants through the adoption of those norms. I argue that the normalisation process is also present in the provisions of three main Acts; the Mental Capacity Act 2005, the Care Act 2014, and the Children and Families Act 2014, suggesting that the care and support assessment

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[90] ibid (n 87) 60-67.

[91] ibid (n 57), Lecture of 8 February 1978.

[92] ibid (n 55) 193.

[93] Peter Miller and Nikolas Rose, *Governing the Present: Administering Economic, Social and Personal Life* (Wiley 2008).

[94] Michel Foucault, ibid (n 57) 275.

processes are a means of controlling individuals, the workforce and the population.

Taking a Foucauldian approach to ‘government’, and specifically, to the organised practices by which we, in turn, are governed and through which we govern ourselves,[95] the way the state governs applies to a range of practices and activities that various organisations undertake, agencies and authorities to shape the conduct of citizens and subjects.[96] In chapter 3, I illustrate the process of normalisation in contemporary society through legislation and policy of the care and support system, as well as demonstrating how social isues today are problematised. Meanwhile, we turn back to Foucault’s influence after he died.

After Foucault

Following Foucault’s death critical theorists of ‘postmodern ideas’, philosophers and political theorists such as Giorgio Agamben, have engaged further with Foucault's thoughts on sovereign power, biopolitics, the economy and government, and the connection of power and management.[97] In contrast to Foucault, Agamben argues that economy, not politics, is the critical connection between power and management. However, whilst noting Agamben's thoughts, phase 1 of this study takes a public perspective and has not delved deeply into political theory or organisational management; [98] future investigations and writing may well do so.

Meanwhile, the concept of discourse in the social sciences, as well as later forms of discourse analysis, has been introduced. For example, the field of

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[95] Mitchell Dean, *Governmentality: Power and Rule in Modern Society* (Sage 1999) 18.

[96] ibid; Nikolas Rose, *Powers of Freedom: Reframing Political Thought* (University Press 1999); Nikolas Rose, ‘Government, authority and expertise in advanced liberalism’, (1993) Economy and Society 22 (3) 283-300.

[97] Giorgio Agamben, *The Kingdom and the Glory: For a theological genealogy of economy and government* (Lorenzo Chiesa and Matteo Mandarini (trs) Stanford University Press 2011)

[98] Michael Reed, ‘Organisations and Modernity: Continuity and Discontinuity in Organizational Theory’ (1993) 168 in John Hassard and Martin Parker (eds): ‘Postmodernism and Organizations’ (Sage 1993) 240; (1994) Organization Studies 15(6), 936–936 <https://doi.org/10.1177/017084069401500613 > accessed 19 December 2020.

policy and post-Marxist studies, a seemingly fast-growing study area since the 1980s, has advanced a programme of Critical Discourse Analysis (CDA),[99] a Discourse Historical approach,[100] and approaches to discursive psychology and psychoanalysis.[101] These approaches have yielded papers, particularly about the morality of informal caring and the discursive construction of informal care and the framework within which carers have to operate and which is difficult to resist.[102] However, papers and educational materials are also available regarding parenting and parenting caregiving roles.[103] Further studies focusing on carers have explored the impact or burden of caregiving, coping strategies, and relationships between carers and health care professionals. For example, the framing of dementia and cancer within a biomedical context presents wider challenges for carers. Family or carers were appearing to be:

> side-lined as superfluous to the healing process. At best, they can provide sociomedical information to inform a clinical approach, and at worst, they are deemed as untrustworthy historians whose input may

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[99] Norman Fairclough, *Critical discourse analysis: the critical study of language* (London: Longman 2010); Norman Fairclough and Ruth Wodak, *Critical Discourse Analysis* in Tuen. A van Dijk, ed. *Discourse as social interaction* (London: Sage), 258-284; Ruth Wodak*, Critical Discourse Analysis at the End of the 20th Century* (1999) Research on Language and Social Interaction 32 1-2, 185-193; Frank Fischer, *Reframing Public Policy: Discursive Politics and Deliberative Practices* (Oxford University Press 2003); Frank Fischer and John Forrester, *The argumentative turn in policy and planning* (Durham University Press 2003).

[100] Martin Reisigl, 'The Discourse Historical Approach', in John Flowerdew and John E Richardson eds, *The Routledge Handbook of Critical Discourse Studies* (Routledge handbook Online 18 July 2017) < www.routledgehandbooks.com/doi/10.4324/9781315739342> accessed 11 January 2020.

[101] Jacques Lacan, *The Seminar of Jacques Lacan Book XVII: The Other Side of Psychoanalysis* (Russell Grigg Tr, Duke University Press 2006); <https://en.wikipedia.org/wiki/Essex_School_of_discourse_analysis > accessed 11 January 2020.

[102] For example, Monika Bednarek and Helen Caple, *News Discourse* (Bloomsbury Classics in Linguistics 2018); Monika Bednarek, *Evaluation in media discourse: Analysis of a newspaper corpus* (London Continuum 2006); Philip Clarke, 'Understanding Aging and Disability Perspectives on Home Care: Uncovering Facts and Values in Public-Policy Narratives and Discourse' (2007) Canadian Journal on Aging/ La Revue Canadienne Du Vieillissement 26 (S1), 47-62.

[103] For example, Jeni Harden, '"Unchartered waters": The experience of parents of young people with mental health problems' (2005) Qualitative Health Research 15 (2), 207-223 <https://doi.org/10.1177/1049732304269677>accessed 11 January 2020.

> be perceived as unreliable, irrelevant, and a hindrance to the discourse of medical care.[104]

However, I argue that the provision of socio-medical information is not only a discourse of medical care but also of social care, and ultimately is a product of governing an ageing population. The economy, the workforce (paid and unpaid) are players in a system of power dynamics and relations to sustain power.[105] In his later work, his focus has since been upon the protection of the population itself,[106] and the welfare of the state and its citizens.

Further, and with reference to my position within the health and social system as described in chapter 1, this study is mainly interested in aspects of care, the operation of institutional power hidden through the ongoing restructuring of the health and social care system, shift in terminology and the legislative framework that presents individuals with health, social, educational and economic choices promoting their health and wellbeing, including their families, friends, and the communities where they live.

Whilst the legislative framework supports the restructuring, acquisition and sharing of information and knowledge about individuals to allow better care and support plans, it is also suggested that the state, via the social and health institutions are, according to Foucault, players within the operating power relations, and as mentioned above in this chapter, form part of the process to 'act on the consciousness of people', modifying their views, opinions and choice.

Conclusion

This chapter has provided commentaries on the work of Michel Foucault as he developed his concept of governmentality. Rethinking his earlier work about

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[104] For example, Gary Witham and others, 'Carer Experience Supporting Someone with Dementia and Cancer: A Narrative Approach' (2018) Qualitative Health Research 28 (5) 813-823 <https://doi.org/10.1177/1049732317736285>accessed 23 January 2020.

[105] Derina R. Holtzhausen, 'Towards a postmodern research agenda for public relations' (2002) Public Relations Review 28 (3) 251-264, 257.

[106] David Howarth, ibid (n 5) 316.

the relationship between domination, power and discourse, he began to explore how the state governs. The next chapter uses the Foucauldian governmentality lens to critique the health and social care system as a whole, but specifically, its application to people aged 16 plus with care and support needs and who have declining capacity owing to progressive illness.

Chapter 3 – A Foucauldian critique of the care and support system

Introduction

Michel Foucault is one of the influential thinkers of our time. Studies of his work have extended beyond academia but also influenced attitudes of practice, individuals, practitioners, and society as a whole. Foucault was interested in the way that social issues become 'problematised' and the circumstances that support the issue as a problem at a particular time.[107]

This chapter evaluates the health and social care support system critically within the conceptual apparatus of Foucault's use of the term governmentality. Adopting his term governmentality for analysis of the state's ability to manage its resources economically and efficiently in a way that allows for regulation and the need to negotiate through a process of self-governing, I argue that this framework is;

- a product of governing an ageing population, the economy, and the (paid and unpaid) workforce in contemporary society, and
- that the care and support assessment process maintained under it is an element of the moral control of individuals, the workforce and the population;
- a mechanism of diffused 'power', to create forms of discipline and normalisation, including via individuals undergoing a process of self-governing through the provision of accessible information and advice, and the formal assessment procedure, which is presented as a consensual process, respecting autonomy, independence and individualism.

In effect, they normalise the processes into current practice, modifying views, opinions, and choices. We now continue to sketch in critical policy solutions

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[107] ibid (n 71) 11.

that operate both at a national and local government level (the strategic perspective of governmentality), and at an individual level, where more constrictive forms of discipline, surveillance and normalisation techniques are observed. Thus, the study continues to investigate the way that discourses on the care and support system have contributed to and advanced the management of health and social bodies by expanding new ways of obtaining knowledge into everyday life via surveillance and disciplinary techniques.

Earlier, research document 2 provided a substantial chapter on concepts and terminology used, including legal and policy changes towards children and adults.[108] Of relevance 'vulnerability' is now a concept commonly used by policy makers, researchers, practitioners and social science literatures, but it is not a term used without criticism:

> Mackenzie and Walker explored concepts and distinguished vulnerability between inherent, situational sources of vulnerability and pathogenic vulnerability.[109] Inherent vulnerability arises from intrinsic specific characteristics such as mental illness and incapacity.
>
> Situational vulnerability refers to vulnerability that arises from personal, social, political and/ or environmental circumstances of a person or social group, whereas, in Rogers, Mackenzie and Dodds' view, pathogenic vulnerability arises from 'conditions that are unjust in various ways, or when social policy interventions that aim to ameliorate inherent or situational vulnerability have the paradoxical effect of increasing vulnerability, [that is said to] 'exacerbate the sense of powerlessness engendered by vulnerability'.[110] Mackenzie and Walkers' article also reflected the statutory definition of 'vulnerable adult,' but this was repealed by the Protection of Freedoms Act 2012.[111]

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[108] ibid (n 47) 4-11.

[109] Catriona Mackenzie and Wendy Rogers, 'Autonomy, vulnerability and capacity: A philosophical appraisal of the Mental Capacity Act' (2013) International Journal of Law in Context 9(1), 37-52, 40.

[110] Wendy Rogers, Catriona Mackenzie and Susan Dodds, 'Why Bioethics Needs a Concept of Vulnerability (2012) International Journal of Feminist Approaches to Bioethics 5 (2), 11-38.

[111] ibid (n 109) 37-52, 40, 41; s 59, Safeguarding Vulnerable Groups Act 2006 repealed (10.9.2012 immediately after the coming into force of the Safeguarding Vulnerable Groups (Miscellaneous

Recalling chapter 2, over the past few decades, the construction of the 'vulnerable' adult or child is another critical example of institutional discourse. It emerged that vulnerability is another form of normalisation. Both adults and children are individually and collectively positioned in policy as vulnerable consumers who must have information, choice and control, and at the same time, protection; this necessitates government intervention.

This chapter is concerned with the shaping of the contents and operation of law, but also with governance more broadly. We begin by studying the strategic perspective relating to health and social care policy and construct the problem, applying the concept of governmentality to the issue of restructuring the health and social care system to support an ageing population with growing complex health and social needs.

The strategic perspective – constructing the problem

> The world is on [the] brink of a demographic milestone. The world is facing a situation without precedent: We soon will have more older people than children and more people at extreme age than ever before.[112]

Foucault's interests examined how social issues become problematised. For example, ageing is a global, national, and local problem. The number of people aged sixty-five and over is set to grow from approximately 526,688 million in 2010 to 10,587,774 million in 2050, with most of the increase in developing countries.[113]Currently, and in 2020, the estimated total world population is 7,794,799, with 727,606 sixty-five and above and 21,387 over ninety.

Amendments) Order 2012 (SI 2012/ 2157) by the Protection of Freedoms Act 2012 (c.9), s 65 (1), 120, Sch. 10 Pt. 5 (with s.97); SI 2012/ 2234, at. 2 (b) (bb); ibid (n 47) 10.

[112] World Health Organisation, 'Global Health and Aging' (2011), 1-2.

[113] United Nations, Department of Economic and Social Affairs, Population Division (2019) *World Population Prospects 2019: Methodology of the United Nations population estimates and projections* <https://population.un.org/wpp/Download/Standard/Interpolated/ >accessed 14 January 2020; Note, the Global Health and Aging, World Health Organisation, (2011) at page 1 cites estimated 1.5 billion for 2050 but at the time of writing, it is unclear as to the source and accuracy of this prediction.

Since the twentieth century, improvements in medicine have yielded advances in life expectancy, ranging from the curing of infectious and parasitic diseases that used to kill younger lives to chronic non-communicable diseases. Chronic and longer-term conditions include heart disease, cancer, diabetes and dementia. Dementia, in particular, is described by the World Health Organisation (WHO), as a 'burden' and the projected costs for caring are described as 'daunting'.[114] The estimated worldwide cost of dementia exceeded US$600 billion in 2010, including informal care provided by family and others, social care provided by community care professionals, and the direct costs of medical care.[115]

In summary, the increase of chronic non-communicable disease seen in today's developing countries:

> reflects changes in lifestyle and diet, as well as ageing. The potential economic and societal costs of non-communicable diseases of this type rise sharply with age and have the ability to affect economic growth.[116]

Further, globally each year, 'around 20 million people need end of life care, including 6% that are children'.[117] In England, owing to improvements in medical science, children with complex needs and life-limiting conditions are also now living into adulthood.[118] In January 2019, 1.3 million pupils in England were identified as having special educational needs and disabilities (SEND), costing the Department for Education an estimated £9.4 billion in 2018-19 to support pupils[119] with SEND.[120]

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[114] ibid (n 112) 'The burden of dementia', 14-15.

[115] Ibid 14.

[116] ibid (n 112) 2, 9-13.

[117] World Health Organisation, *Global Atlas of Palliative Care at the End of Life* (Geneva: WHO 2014) <https://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf >accessed 11 September 2019

[118] Department of Health 'Our Commitment to you for end of life care' (July 2016) <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf >accessed 11 September 2019.

[119] Pupil numbers exclude those in nursery schools.

[120] Comptroller and Auditor General, *Support for pupils with special educational needs and disabilities in England* (HC 2636, 2017-2019 11 September 2019) < https://www.nao.org.uk/report/support-for-pupils-with-special-educational-needs-and-disabilities/ > accessed 11 September 2019.

As a result, an ageing population affects health, social security, education, socio-cultural activities, family life and the workforce.[121] Over the past few decades around the globe, particularly in developed countries, the decline in female fertility,[122] improved early childhood survival, extended longevity, and ultimately the rapid growth of the population, have in turn generated both academic and governmental interest and 'expert' writings that conclude that we have entered 'the phenomenon of the so-called Third Demographic Transition'.[123]

The transition to an aged society continues to bring problems of finding the money to pay for retirement income and rising health and social costs, with some academics raising questions such as 'to what extent should public money be spent to save the life of the few, mostly elderly?'[124]

Changing family structures

In developed countries, changing family patterns and structures and the decline in fertility rates and delayed childrearing have resulted in the new expression, a 'beanpole family', meaning 'a vertical extension of family structure characterised by more but smaller generations...consequently, more children will know their grandparents and even their great-grandparents, especially their great grandmothers'.[125] However, while people are surviving longer, today's families are more likely to live separately, changing the shape of the family and access to family support.[126]

; Department for Education, *National Statistics, Special educational needs in England (January 2019,* Pub 4 July 2019), < https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2019 > accessed 11 September 2019.

[121] Meltem Ince Yenilmez, 'Economic and Social Consequences of Population Aging the Dilemmas and Opportunities in the Twenty-First Century' (2015) Applied Research Quality Life 10, 735–752.

[122] ibid (n 112) 4.

[123] Seiritsu Ogura and Mihajolo M Jakovljevic edn, 'Global Population Aging-Health Care, Socio and Economic Consequences' (2018) Frontiers in Public Health (6), 335.

[124] ibid 1.

[125] ibid (n 112) 22.

[126] ibid (n112) 22.

In terms of caring, smaller numbers of siblings imply that future cohorts of potential caregivers will be smaller than current ones.[127] Likewise, the changing characteristics of carers and workforce patterns which increase the participation of women and older people in the labour market mean that shortly there will be fewer people to provide informal care or even volunteers to support needs in local communities.

Meanwhile, the prediction of gender balance for informal carers is likely to continue. The majority of informal carers are female, at least seventy-five per cent in the USA and an estimated fifty-five to sixty per cent in Europe. However, Pickard and King noted that men are less engaged in informal care at working age.[128] Even as young pensioners, they engage less in care provision than women in most countries, but in some countries, ‘a greater share of men act as informal carers, in particular for their spouses’.[129]

Societies continue to rely heavily ‘on the unpaid labour of informal carers who cover an estimated seventy to ninety-five per cent of all care needs.[130] Informal care saves public spending on formal care services, but reliance on informal care has hidden costs to the carers, mainly if not adequately supported. This causes them to face negative impacts on their health and wellbeing and forces them to reduce or quit employment – putting themselves at risk of poverty and social exclusion.[131]

Globally, nationally and locally, policy strategies and measures to support informal carers remain ongoing. The United Nations Economic Commission for Europe Nations (UNECE) Working Group on Ageing continues to be engaged in developing the guidelines and policy recommendations to address the challenges of an ageing population across member states. Nations are

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[127] UNECE, ‘The challenging roles of informal carers’ (UNECE Policy Brief on Ageing No. 22, September 2019), 5.

[128] Luke Pickard and Derek King ‘Informal care supply and demand in Europe ’ENEPRI Research Report (Joanna Geerts, Peter Willemé and Esther Mots (eds), ANCIEN Brussels, Belgium 2012), 116.

[129] ibid (n 127) 5.

[130] ibid.

[131] ibid 1.

required to provide a clear definition of informal care and the status of informal carers at the national level, an important step towards acknowledging;

> the unpaid contribution by informal carers..forms the basis of formal entitlements relating to financial support, employment regulations and respite services. Informal care provision and the situation of unpaid carers need to be better understood to provide the support needed. Research, awareness-raising and education on informal care among the general public and health and social care professionals can contribute to a greater acknowledgement of informal carers as co-producers of social services[132] (and health services).

Moving from the global perspective to nations, the sections below focus on England's political understanding of the health and social care support system pre Covid-19, related population pressures, then subsequent government policy responses to an ageing population in England, with demands on services and funding pressures.

England's demographics

In England between 2006 and 2016 the population of people aged sixty-five had risen by 23 percent, and the numbers of those aged 85, rising by 28 percent, compared with 8% for all age groups.[133] Further projections of people aged sixty-five indicate an increase of 19 percent between 2016 and 2026 and a 90 percent increase between 2016 and 2036.[134] Also, 'young adults with learning or physical disabilities are living longer, with increasingly complex

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[132] ibid (n 127) 9.

[133] Office for National Statistics, *Annual Mid-year Population Estimates: 2016 Statistical Bulletin* (June 2017) in the National Audit Office Report, *The health and social care interface* (2017-19, 2018 HC 950) 11.

[134] Office for National Statistics, *National Populations Projections: 2016 – based Statistical Bulleting* (October 2017), ibid 11.

conditions'.[135] Demands for health and social care services continue to increase for both systems.[136]

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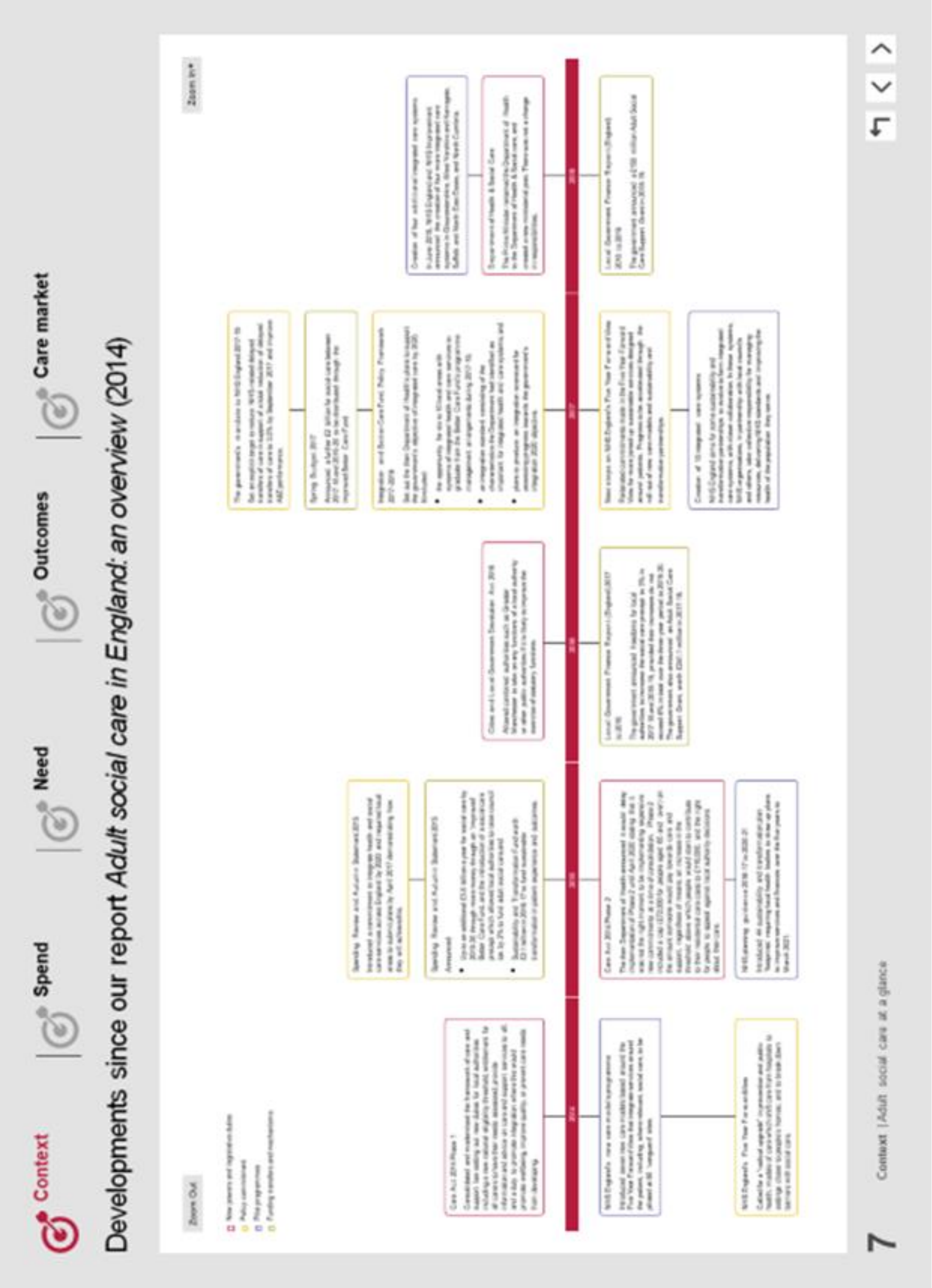
[135] Comptroller and Auditor General, *Adult Social Care in England: Overview (HC 2013-14*, 1102) (National Audit Office March 2014) <www.nao.org.uk/report/adult-social-care-england-overview-2/> accessed 7 October 2019; Comptroller and Auditor General, *Pressures on children's social care* (HC 2017-2019, 1868) (National Audit Office, 23 January 2019).

[136] Comptroller and Auditor General, *Financial sustainability of local authorities 2018* (HC 2017-2019, 834) (National Audit Office March 2018) <www.nao.org.uk/report/financial-sustainability-of-local-authorities-2018/> accessed 7 October 2019.

England’s policy responses

Introduction



Context | Spend | Need | Outcomes | Care market

Developments since our report *Adult social care in England: an overview* (2014)

7 Context | Adult social care at a glance

Diagram 1: Developments since the Care Act 2014.[137]

Diagram 1 shows developments since the Care Act 2014, and the National Audits Office 2014 reports.[138] Previous doctoral documents explored the context that led to the enactment of the Care Act 2014 and the Children and Families Act 2014 (as the Act relates to children with special educational needs and disabilities), developments following scrutiny of the Mental Capacity Act 2005, which led in turn to Part 2 of this thesis- the methodology and findings of this research project at an individual level of the public experience.

Nevertheless, the topic of children with special educational needs and disabilities has long been an area of political debate within educational and political arenas, notably in respect of equity of services and inconsistencies in practice. Following successive government interventions, in September 2019 the National Audit Office[139]stated that 'significant concerns' remained, also that many school pupils are still not being supported adequately, and that pupils with SEND who do not have EHC plans are particularly exposed. Despite the good intentions of reforms introduced by the Children and Families Act, this confirmed that the '*shocking failure of the SEND system'* remained.[140]

The next section continues to explore the strategic perspective of the health and social care system in England, in particular articulating governing at various levels within the health and care system, and in the words of Howarth, identifying the political and ideological construction of the health and care system in England.[141]Taking account of population needs, I begin by looking at the financial problems of funding the health and social care system and

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[137] National Audit Office, *Adult Social Care at a glance*, <www.nao.org.uk/report/adult-social-care-at-a-glance/> accessed 8 January 2020.

[138] ibid.

[139] ibid (n 120).

[140] See, Kathryn Snowdon, 'Shocking failure of SEND system' <Https://schoolsweek.co.uk/national-audit-office-send-system-report-shocking>accessed 12 September 2019.

[141] ibid (n 5).

move towards integrated systems in managing the population's demand for services.

Accountability for the care and support system

The National Audit Office ‘helps’ Parliament to hold the government to account for the way it spends public funds[142], including working towards transforming health and social care services.[143]The Department for Education is accountable to Parliament for the system of support and for securing value for money from the funding it provides to schools in England to support pupils with special educational needs and disabilities, as well as children’s social services. The Department of Health and Social Care is now one department and accountable to Parliament as well.[144]

UK health spending has grown by 1.6 % a year over the last four years (2015/ 2019). The strategy for the NHS Long Term Plan requires an average funding growth of 3.3 % a year, starting in 2019,[145] but excludes workforce education and training, public health and capital, and does not have either a plan or long-term funding.[146] Investment in modernising as set out in the NHS Long-term Plan requires a further 4.1% a year, approximately four billion pounds, in addition to the £3bn increase in order to maintain the current standard of care.[147] [148]

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[142] National Audit Office, *NHS Financial Sustainability* (2017-2019, HC 1867) <www.nao.org.uk/report/nhs-financial-sustainability/> accessed 22 January 2020;

[143] See <www.nao.org.uk/search/pi_area/transforming-public-services/type/report/> accessed 21 January 2020.

[144] See Mickey Smith, "Jeremy Hunt has got a new job in Theresa May's Cabinet reshuffle after an hour inside Number 10" Daily Mirror (8 January 2018) <www.mirror.co.uk/news/politics/jeremy-hunt-new-job-theresa-11818996> accessed 10 January 2018.

[145] Ben Gershilk and others, ‘Health and social care funding. Priorities for the next government’ Health Foundation 23 November 2019 1-22, 3.

[146] ibid 3.

[147] Ibid.

[148] The Covid-19 pandemic has had a significant effect on the economy and as a result, initial projections have been recalibrated; see Stephen Rocks and others, ‘REAL Centre Projections. Health and social care funding projections 2021, Report’, The Health Foundation, October 2021. The analysis however was prepared ahead of the government announcements for health and social care funding on 6 and 7 September 2021.

While there are significant challenges within the health care system, the greatest ones relate to adult and children's social care. For adults, funding has not kept pace with demand, and local authorities are on the 'edge of collapse',[149] with a prediction of £12.2bn needed for councils to restore access to 2010/11 levels of service.[150] The Health Foundation reports[151] indicate that there are two key areas for future investment:

1. Investment in the wider health care system outside NHS England, moving away from the traditional 'pots for NHS England' and wider NHS spending, such as workforce, education and training, to setting out funding for the entire department of health and social care budget;
2. Stabilisation, improvement and reform of social care, firstly by boosting staff pay to aid recruitment and retention problems, and secondly to improve access to publicly funded care; a future funding system to be fairer and to provide government protection against social care costs.

Local authorities spent £8.8bn on children's services in 2017-18, with 91 percent overspending on children's social care services. The main stages of the children's social care system are shown below in diagram 2.

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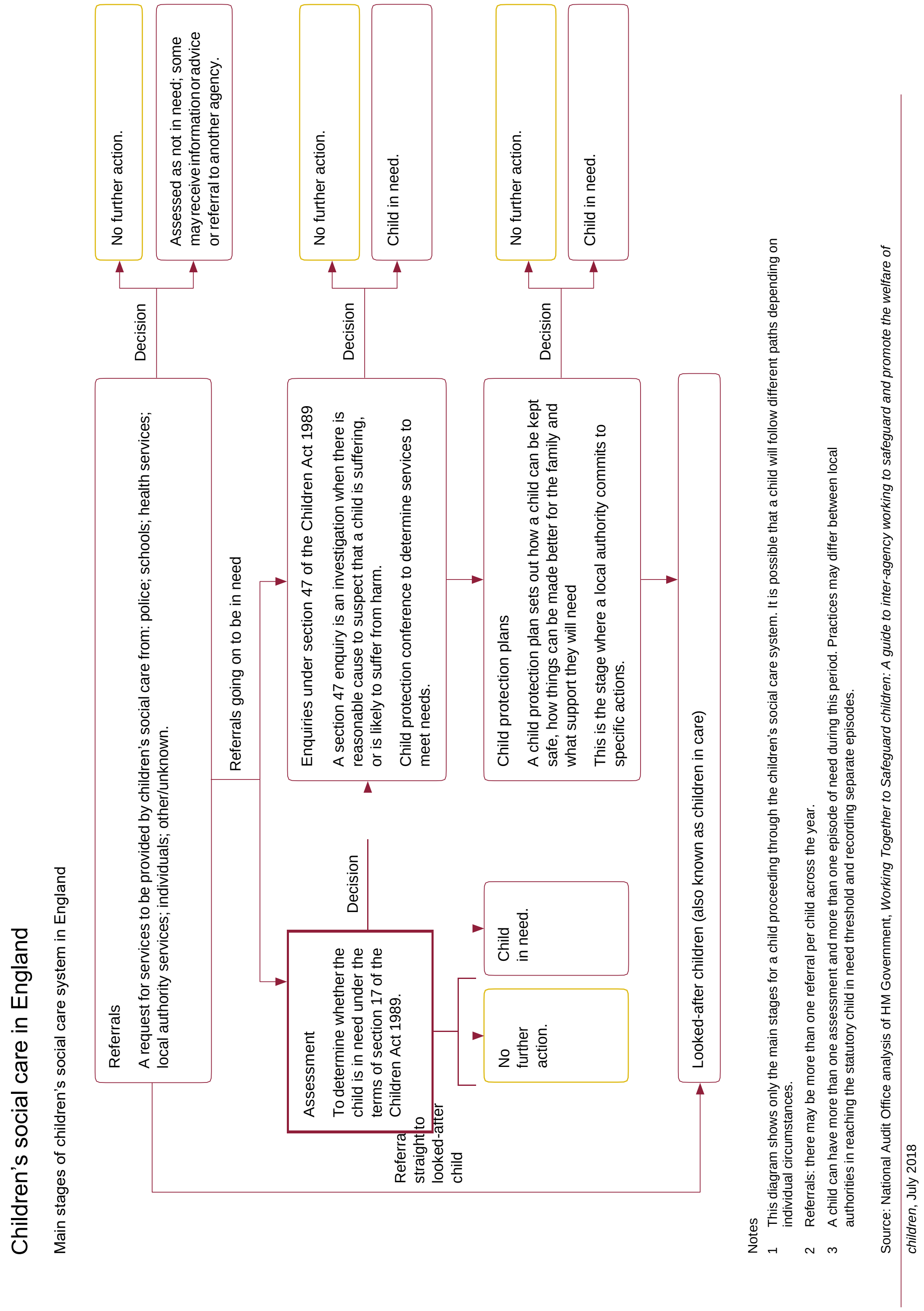
[149] ibid (n 145) 19.

[150] ibid (n 145) 3.

[151] ibid (n 145) 19.



Notes

1 This diagram shows only the main stages for a child proceeding through the children's social care system. It is possible that a child will follow different paths depending on individual circumstances.

2 Referrals: there may be more than one referral per child across the year.

3 A child can have more than one assessment and more than one episode of need during this period. Practices may differ between local authorities in reaching the statutory child in need threshold and recording separate episodes.

Source: National Audit Office analysis of HM Government, *Working Together to Safeguard children: A guide to inter-agency working to safeguard and promote the welfare of children*, July 2018

Diagram 2: Main stages in children's social care system[152]

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[152] ibid (n 135), cited in Report by the Comptroller and Auditors General, *Pressures on children's social care*, 5.

As with adult social care, there is an increase in demand, but at this stage, and owing to the National Audit Office ‘*not seeing*’ children’s social care as a central part of its responsibility to understand drivers in demand for child care across all authorities, it had made little qualified analysis of the drivers of demand or reasons for variations between authorities. Further, there appears to be no link between spending per child in need and the quality of services as assessed by Ofsted. As a result, the National Audit Office is unclear as to what is causing increases in demand and activity.[153]

Currently, funding for social care is means-tested. Where the Department of Health and Social Care currently spends its money, is shown in diagram 3.

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[153] ibid (n 135) 9.

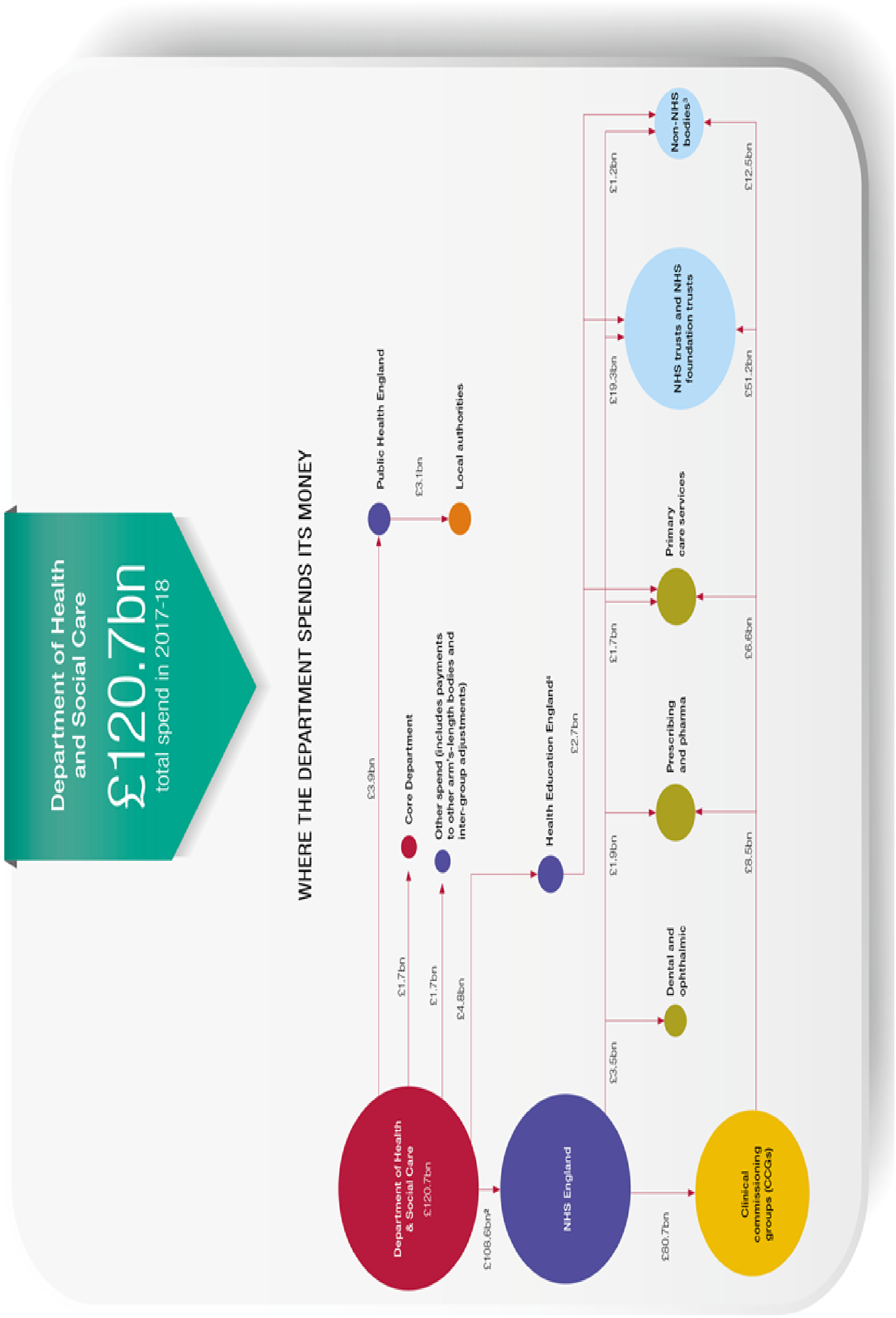

Diagram 3: 2017 – 18 Department of Health and Social Care spending[154]

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[154] National Audit Office, Department of Health and Social care, *Department Overview* (*October 2018)* <www.nao.org.uk/report/departmental-overview-department-of-health-and-social-care-2017-18/> accessed 8 January 2020.

Furthermore, the *Health and Social Care Interface Report* is helpful in setting the scene for the population's health and social care needs. The Report places emphasis on the need to plan care services around the needs of the individual. 'With the passing of the Care Act 2014 that enshrines the wellbeing of the individual as a key goal' and a greater focus on the need to reduce inefficiencies, such as tackling around a third of people who are 'stuck in hospital' when medically fit to leave, but are waiting for social care services to be put in place.[155]

The accountability for the adult social care system is shown in diagram 4.

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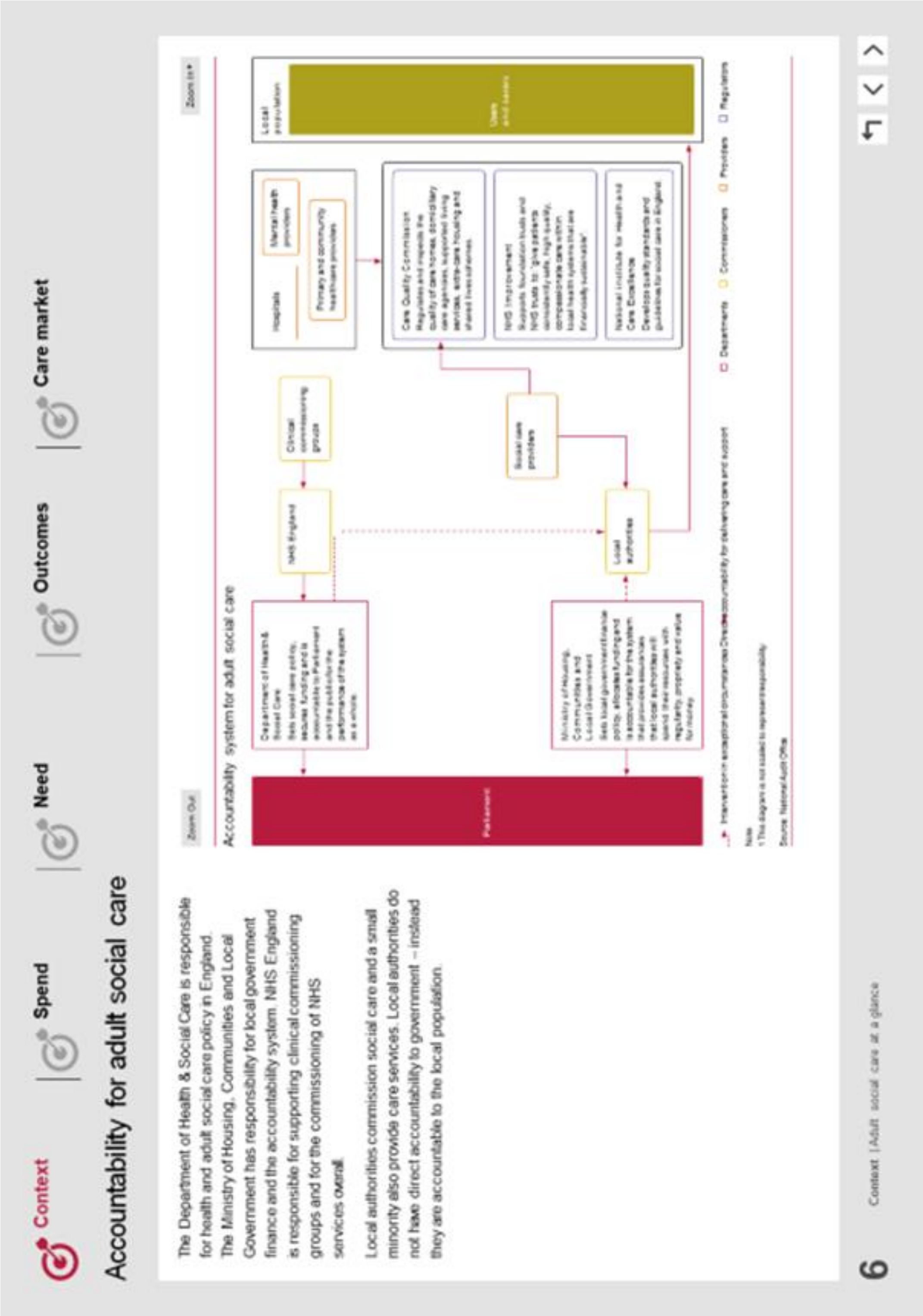
[155] ibid (n 133) 6.



Accountability for adult social care

The Department of Health & Social Care is responsible for health and adult social care policy in England. The Ministry of Housing, Communities and Local Government has responsibility for local government finance and the accountability system. NHS England is responsible for supporting clinical commissioning groups and for the commissioning of NHS services overall.

Local authorities commission social care and a small minority also provide care services. Local authorities do not have direct accountability to government – instead they are accountable to the local population.

Accountability system for adult social care

Department of Health & Social Care
Sets social care policy, secures funding and is accountable to Parliament and the public for the performance of the system as a whole.

Ministry of Housing, Communities and Local Government
Sets local government finance policy, allocates funding and is accountable for the system that provides assurances that local authorities will spend their resources with regularity, propriety and value for money.

Care Quality Commission
Regulates and inspects the quality of care homes, domiciliary care agencies, supported living services, extra-care housing and shared lives schemes.

NHS Improvement
Supports foundation trusts and NHS trusts to: 'give patients consistently safe, high quality, compassionate care within local health systems that are financially sustainable'.

National Institute for Health and Care Excellence
Develops quality standards and guidelines for social care in England.

Intervention in exceptional circumstances Direct accountability for delivering care and support

Note
1 This diagram is not scaled to represent responsibility.

Source: National Audit Office

6 Context | Adult social care at a glance

Diagram 4: Accountability for adult social care[156]

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[156] ibid; copyright permission <www.nao.org.uk/copyright-statement/> accessed 22 January 2020.

Accountability for local system delivery

The Health and Social Care Act 2012 amended the National Health Services Act 2006 and is an extensive piece of legislation that created new duties and powers for government departments and organisations such as the National Health Service Commissioning Board, clinical commissioning groups and NHS England. The Act also abolished other former organisations such as Primary Care Trusts and the Patient Safety Agency.[157]

The Act provided for duties and powers and established local health and wellbeing boards[158]in each local area to encourage the integrated commissioning of health and social care services. Essentially, duties require NHS England and Clinical Commissioning Groups to promote integration where this would improve quality or reduce inequalities, whereas NHS Improvement, as a sector regulator, has the function of removing any barriers and considering how to enable the integrated provision of care services in the interests of patients within the local authority area. During 2019/2020, both NHS Improvement and NHS England have been undergoing a significant organisational change in order to function as one body, to "improve collaboration" across the health service.[159]

Since 1st April 2013, and as part of the central government's decision to give more power to councils and the NHS system, local organisations now decide how to spend hundreds of billions of pounds each year within their local area.

In addition, central government continues to be responsible for protecting the public; when services fail, there are systems in place to seek redress, for example, via the Local Government and Social Care[160] and the Parliamentary

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[157] See, <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted >accessed 23 January 2020.

[158] ibid, ch 2 Local Authorities, pt 5 – Public Involvement in local government.

[159] Sharon Brennan, 'NHS England and NHS Improvement seek full merger', Health Service Journal (28 February 2019) <www.hsj.co.uk/policy-and-regulation/nhs-england-and-improvement-seek-full-merger/7024536.article> accessed 20 March 2019.

[160] See, <www.lgo.org.uk/> accessed 23 January 2020.

and Health Ombudsmen.[161] Beginning in 2018, for children with special educational and disability needs, there is a two-year national trial reviewing decision issued by the First-tier Tribunal Special Educational Needs and Disability.[162]

However, while central government continues to set the aims and objectives for local expenditure, local organisations decide how to spend the funding based on local needs and priorities[163], local bodies must inform the public how the funds are allocated and spent, and through monitoring and performance reporting via the establishment of Health & Wellbeing Boards and Scrutiny Boards[164], assure the local electorates that funds are spent well and that they can question decisions.[165]

In effect, and as argued above in chapter 1 and 2, the strategies adopted have created an extensive apparatus for monitoring and surveillance of the nation's population and assuring accountability of local systems delivery, leading to a body of knowledge related to spending public funds, and the nation's wellbeing, as well as ensuring the regulation of a competitive market for health and social care provision.

Monitoring, surveillance and negotiation

We now turn to the operation of power and relations in the context of the health and social care assessment processes. Foucault would suggest that the role of the state is to create conditions which promote personal autonomy and

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[161] See, <www.ombudsman.org.uk/> accessed 23 January 2020.

[162] See, Department for Education, *SEND Tribunal: Single route of redress national trial, Guidance for Local authorities, health commissioners, parents and young people* (8 March 2018) <www.gov.uk/government/publications/extended-powers-send-tribunal-national-trial> accessed 22 January 2020.

[163] Health and Social Care Act 2012 pt 5, ch 2, s 192-193, Establishment of Joint Strategic Needs Assessment.

[164] ibid s 190-191, Scrutiny functions of local authorities.

[165] ibid s 194- 196, Establishment, duties and functions of the Health and Wellbeing Boards; National Audit Office, *Accountability in local service delivery* <www.nao.org.uk/search/pi_area/accountability-in-local-service-delivery/type/report/> accessed 8 January 2020.

citizenship, incorporating responsibility for oneself and dependants through the adoption of those norms. I have argued that the normalisation process is under the provisions of three main Acts: the Mental Capacity Act 2005, the Care Act 2014 and the Children and Families Act 2014, suggesting that the care and support assessment process is a means of controlling individuals, the workforce and the population.

In reality, at some point in their lives, individuals become unwell for a variety of reasons and may require some form of help with day-to-day life and/or with their care and treatment arrangements. Through legal and policy changes, children and adults with care and support needs are both individually and collectively positioned in policy as vulnerable consumers who must have information, choice and control, and at the same time, protection.

The fundamental principles within the Acts and statutory and non-statutory guidance inform decision-makers what to consider when a decision or action is taken under the relevant legislation—linking the governing of the state to governing one’s family and governing oneself. For example, the general duty, section 1 of the Care Act, is to promote an individual’s well-being in so far as it relates to any of the following:

a. personal dignity, including respect,
b. physical and mental health and emotional well-being,
c. protection from abuse and neglect,
d. control by the individual over day-to-day life,
e. participation in work, education, training or recreation,
f. social and economic well-being,
g. domestic, family and personal relationships,
h. suitability of living conditions, and
i. the individual’s contribution to society.

The breadth and scope should be noted within which the area’s professionals will be gathering information and intelligence about individuals lives when carrying out a needs assessment,[166] carrying out a carer's assessment,[167]preparing a care and support plan,[168] revising a care and support plan,[169] revising a support plan,[170] carrying out a child's needs assessment,[171] carrying out a child's carer's assessment;[172] and carrying out a young carer's assessment.[173] This information will be stored in electronic health and social care data and later accessed through NHS Digital - adding, as Foucault would suggest, to the body of knowledge about individuals as regards health and social care. [174]

Similarly, since 2003, the then Department for Children, Schools and Families (DCSF), launching the Every Child Matters: Change for Children Programme, 'taking forward the Government's vision of radical reforms for children, young people and families',[175] aimed to remove barriers to achievement, including children and young adults up to the age of 19, or 24 for those with disabilities.[176] Every child shall be: Safe, healthy, enjoy and achieve, make a positive contribution and achieve economic well-being.

The principle aim was to maximise opportunities and minimise risks for all children and young people, focusing services more effectively on the needs of children, young people and families.[177] The Children Act 2004 in 'providing the

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[166] s 9 (5) and (b).
[167] s 10 (7) (a).
[168] s 25 (3) (a) and (b).
[169] s 27 (2) (b) (i) and (ii).
[170] s 27 (3) (b) (i) and (ii).
[171] s 59 (2) (a) and (b).
[172] s 61 (3) (a).
[173] s 64 (3) (a) and (b).
[174] Nick Carding, 'Ministers seek greater powers over NHS patients' data' Health Service Journal (22 June 2021) < www.hsj.co.uk/technology-and-innovation/ministers-seek-greater-powers-over-nhs-patient-data/7030352.article > accessed 28 November 2021
[175] Department for Children, Schools and Families, <https://webarchive.nationalarchives.gov.uk/20101220152656/http://www.dcsf.gov.uk/everychildmatters/> accessed 28 April 2020.
[176] Department for Children, Schools and Families, <https://webarchive.nationalarchives.gov.uk/20101220155629/http://www.dcsf.gov.uk/everychildmatters/earlyyears/sendisability/sendisability/ > accessed 28 April 2020.
[177] Explanatory Notes to Children Act 2004, para 3; Jennifer Beecham and Ian Sinclair, *Costs and Outcomes in Children's Social Care: Messages from research (Costs & Effectiveness of Services Children in Need)* (Jessica Kingsley Publishers 2007) have attempted to calculate costs of care

legislative spine for developing more effective services focused [on] the needs of children, young people and families'.[178] This Act created clear accountability for children's services, to enable better joint working with statutory partners[179], and to secure a better focus on safeguarding children.[180] The intention of Parliament was 'to concentrate on outcomes that children and young people themselves have said are important, rather than prescribing organisational change'.[181]

Arrangements under the Children Act 2004 were made to improve the well-being of children in the authority's area, including their physical and mental health and emotional well-being, protection from harm and neglect, education, training and recreation, the contribution made by them to society, and their social and economic well-being.[182] In England, organisations were to have regard to the importance of parents and other persons caring for children in improving the well-being of children when providing services and undertaking assessments.[183]

Individuals, therefore, undergo a process of self-government through those formal assessment processes, which are presented as a consensual process, respecting autonomy, independence and individualism. On the one hand this can be seen as a positive benefit as individuals are provided with choice and access to information, in order to maintain independence. On the other hand,

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packages that cross services and agency boundaries. This was to inform the planning and commissioning process.

[178] DCSF, <https://webarchive.nationalarchives.gov.uk/20101220155519/http://www.dcsf.gov.uk/everychildmatters/about/background/background/ > accessed 28 April 2020.

[179] s 10, co-operation to improve well-being, and s 11 arrangements to safeguard and promote welfare.

[180] Explanatory Notes to Children Act 2004, para 4 < http://www.legislation.gov.uk/ukpga/2004/31/notes/division/1/1> accessed 28 April 2018.

[181] ibid.

[182] s 10 (2) (a) to (e).

[183] ibid, s 10 (3); For critical dialogue on young carers see, Jo Aldridge, 'Where are we now? Twenty-five years of research, policy and practice on young carer' (2018) Critical Social Policy, 38 (1), 155-165 <https://doi.org/10.1177/0261018317724525>accessed 22 January 2020.

gathering knowledge about people’s lives, as findings from the carers’ survey show, can be seen as quite intrusive.

I shall return to examining the interplay of conversational health and social care practices in Part 2, Empirical Study, Chapter 5, as I examine the core findings from the three surveys which focused on lived experiences during the assessment processes.

Conclusion

Chapter 3 adopted Foucault’s approach to problematising the health and social care system in the twenty-first century. I have sketched in critical policy solutions that operate both at a national and local government level and at an individual level.

I have argued that the government governs families through the legal frameworks centred on the Mental Capacity Act 2005, the Care Act 2014 and the Children and Families Act 2014 and informs decision-makers what to consider when a decision or action is taken under the relevant legislation.

As individuals engage in the process of assessments, whether or not they are the subject of the assessments or are the assessors, the assessment process becomes normalised. As workers within the health and social care system, we, including myself in my professional role, are players within the system of managed care—a system funded through governmental initiatives. We promote and encourage individuals to make choices within their communities and to be responsible for their own health and wellbeing, care and support needs. This is extended through their greater participation in their local communities, so as to spend funds efficiently and effectively.

Conversely, and as indicated above, through legal and policy changes, children and adults with care and support needs are both individually and collectively positioned in policy as vulnerable consumers who must have information, choice and control, and at the same time, protection. This necessitates government intervention. In Part 2 of this thesis, COVID- 19 appears as a stark example of immediate government intervention, including a definition of ‘vulnerable’ that arose on account of the Covid pandemic.

PART TWO – EMPIRICAL STUDY

Chapter 4: The design of this study – Mixed methods

As previously mentioned in Part 1, this thesis examines the governance of families under three main Acts: Mental Capacity Act 2005, the Care Act 2014, and the Children and Families Act 2014. The three Acts create a complex area of health and social care policy that is multifaceted, and the programme of enquiry examines whether or not the rights and interests of people with advanced or progressive illness under these Acts are interpreted and followed as parliament intended.

A whole family approach was central to analysing the health and social care support system as it relates to those who are sixteen and above and have declining capacity due to progressive illness. Mixed methods research has been chosen because the population group involves various people and organisations likely to be involved with the person with care and support needs, or their carer. In doing so, I am mindful of people's sensitivities as we discern and uncover their understanding and experiences via the three surveys. The surveys focused on the provision of accessible information and advice, the assessments process and meeting of needs. From a public perspective key research questions were:

a) Why, what, where and how information and advice were sought and obtained. Specifically, the provision of accessible information and advice that describes the range of services available to people with care and support needs, to those with special educational needs and disabilities and/ or to the carers who help them;
b) The extent to which assessments include a person's preferences, wishes, beliefs and values regarding their future care;
c) the difference between making an advance decision to refuse a specific type of treatment and an advance statement;
d) Knowing if lasting powers of attorney for health, welfare and finance were made.

Mixed methods have been defined as “research in which the investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or a program of inquiry”. [184] Whilst debate exists around the emergence of mixed methods and can be dated back to the early twentieth century, pragmatism is regarded as the “philosophical partner for mixed methods approach”[185] as mixed methods engage the practice of building, refining, improving and adapting to the successes and challenges along the way.[186]

Mixed methods design is also recognised as ‘a growing area of importance within health and social sciences to understand health problems’.[187] To support ethical approval, the study is required to be pre-planned and staged to be as inclusive as possible of the intended cohorts.[188] Involving others in the design is therefore set out further below.

Document analysis and the epistemology documented in earlier research documents informed the research strategy. The use of surveys combined both the data transformation integrating quantitative (telling us “if”) and qualitative (telling us “how or why”) collection and analysis concurrently.

The longitudinal study design allows for time trajectories for cohorts and to track the experiences of individuals by following up people with care and support needs as they age and travel through the health and social care system. This study is sequential and is in phase one and informs phase two, leading on to a later longitudinal study.[189]

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[184] Abbas Tashakkori and John Creswell JW, ‘Editorial: the new era of mixed methods’ (2007) Journal of Mixed Methods Research 1(1) 4.

[185] Martyn Denscombe, ‘Communities of practice: a research paradigm for the mixed method approach’ (2008) Journal of Mixed Methods Research 2 (3), 273.

[186] Document 6 provides a professional journal of reflection and reflexivity and is not repeated here.

[187] Kate A. McBride and others, ibid (n 50) 697.

[188] ibid, ch 40.

[189] ibid, 703.

We now turn back to the very beginning of this study programme, the steps taken for involving others and subsequent ethical considerations, the evolution of the methods as a result of feedback, and recruitment, sampling and addressing research bias in the design, later examining the data acquisition via the webpage before reconnecting with the surveys, findings and ongoing approach for further analysis.

Involvement of others in the research design

The research journey began in late 2014 in preparation for the doctoral programme, and I continued to involve people with care and support needs, parent and family carers and practitioners in the development of the proposal. Informal discussions had taken place with:

- Solihull Action for Advocacy Service, Head of Service;
- Carers UK via brief discussions at Solihull Safeguarding Adult Board membership meetings;
- two members of the Birmingham and Solihull Muslim and Hindu faith communities;
- Solihull Metropolitan Borough Council, Assistant Director of Adult Services;
- Solihull Special Needs & Disabilities Board with the parents' forum leads and Experts by Experience as members of the board.

The research proposal (Document 1 of the doctoral programme) was officially endorsed at the Board meeting on 22nd May 2015 and later approved in December 2015.

Ethical considerations

Research participants are open to adverse effects such as pain, distress, feelings of intrusion, and inconvenience. As such, the research design and ethical approval process requires the researcher to identify risks or burdens resulting from participation in the study and explain how the researcher intends to mitigate potential harm.

Risks to the researcher

As an autonomous nurse lawyer and in respect of personal safety, I did not envisage any additional risks that were not already part of professional practice and lone working. As regards indemnity for an independent project, the Royal College of Nursing Indemnity covered the necessary project.

Phase 1: Risks, burdens and benefits

Modifications of the research design and methodology in 2017 changed direct contact to indirect contact with potential participants, significantly reducing burdens on participants, their families, the organisation and myself. In March 2017, I was required to provide a statement on ethical issues that arose from the ethics questionnaire, given that:

- the project aimed at recruiting young people aged 16 to 17 years;
- people participating might be over the age of 65 years and might or might not be perceived as vulnerable;
- pregnant women might choose to participate;
- people with mental health illness might choose to participate, as well as
- others perceived as vulnerable groups.

Although the overall study took a mixed method approach; the ethics application was made for Phase 1 of the project, which involved indirect contact and adopted surveys as a research strategy, integrating quantitative and qualitative data collection and analysis. Dissemination, sampling and population size, demographics and class bias, language bias, information for participants and the consent process, had been built into the survey design. These would be obtained as part of the entry into the surveys.

I ensured that respondents must answer the consent question before they could continue with the survey. Some questions used skip logic to take the respondents more smoothly on to relevant questions.

The quick public survey included making long term plans to cover a time when decisions could not be made personally. Those aged 16 to 17 could reply. Under 18s, however, could be filtered out of specific comparisons of advance decisions about refusal of medical treatment.[190]

Under the MCA 2005, the main provisions apply to adults, which includes young people aged 16 years or over. Those aged 16-17 are assumed to have capacity concerning surgical, dental or medical treatment.[191] The MCA does not apply if it can be established that a young person lacks the maturity to understand what is involved (i.e. they lack 'Gillick competence'),[192] or they feel unable to make the decision for themselves. (With complicated or risky treatment, they could be overwhelmed by the implications of the decision).[193]

There was also an assumption that those who accessed and proceeded to complete the survey did so of their own free will. The information for all participants aged 16 and above was integral to the surveys. I enabled this functionality in order to ensure that respondents answered the consent questions before they continued with the survey.

Testing the survey, the researcher received feedback from an Expert by Experience, a parent carer. Over all this was positive. Feedback was shared with supervisors. Amendments were made, for example increasing the use of skip logic, thus participants only needed to answer the questions relevant to themselves, improving the functionality so that it was easier for them to find

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[190] Mental Capacity Act 2005, s 25.

[191] Family Law Reform Act 1969, s 8 (1).

[192] The principle was established in *Gillick* v *West Norfolk and Wisbech Area Health Authority* [1986].

[193] Department for Constitutional Affairs, *Mental Capacity Act 2005: Code of Practice* (TSO 2007), para 12.13.

where they had left off. However, after further discussions, changing the order of questions was not compatible with the skip logic feature.

Confidentiality, anonymity and security of research data

I identified a potential risk relating to compliance with data collection, storage and processing. Because of these requirements, I had therefore chosen Smart Survey, which was compatible with the former Data Protection Act 1998 and continues to be compliant with the General Data Protection Regulation (GDPR) 2017, together with the new Data Protection Act 2018. In 2015 and into 2016. Initially I looked at other survey tools such as Survey Monkey, but these at the particular time stored their data outside the UK in the United States of America.

The laptop computer used was and remains encrypted and is password protected. Only I have access to the laptop and data storage contained in the laptop. Contact details of organisations were kept within the restricted access of the Doctorate Research folder. If respondents wanted a copy of their returns, they would need to provide their email address in order to obtain a pdf copy. Contact details will be destroyed on the completion of the research programme. Data storage and retention are continually reviewed. Data within Smart Survey were exported into excel for doctoral supervision.

The data drawn from the surveys are analysed in the next chapter, **Chapter 5**, Lived experiences – findings and analysis.

For those patients, carers, public and professionals that take part in the surveys, published materials will be anonymous, and any quotes used will not contain the real name if the participant has mentioned an individual by name within their response.

Ownership and copyright

At this point, ownership and copyright rest with me as an individual researcher undertaking the Professional Doctorate in Legal Practice. However, ownership may be shared or amended following further programme developments and successful future funding applications.

From an ethical perspective, I believe and declare that I have taken all steps available to ensure as far as reasonably practicable safe practice and conduct in regards to survey design and recruitment of respondents.

Changes made to the study design as a result of service engagement

These followed discussions at the Solihull Special Needs & Disabilities Board, hereafter known as the ‘Board’; members included parents and Experts by Experience, as well as multiple agencies involved in children's and adult services). Following comments from the parent carers at the Board, the research had been broadened to include young people age 16 in transition from children's services into adult services (originally the age was 17 and only focused on advance decisions).

Recruitment, sampling and addressing research bias in the design

Recruitment process

In terms of maximising the potential population, surveys are well known to generate a poor return, but by targeting interested groups, this could generate a better return as people may have a personal interest in contributing. Time was deliberately built into the study to enable word of mouth dissemination, family and friends cascading via their networks, and notifying organisations through their respective newsletters that this study was taking place, with links showing how to participate. I developed briefings for local radio, and for organisations which published e-newsletters and/or used audio libraries. This allowed such organisations to promote and disseminate the research to allow maximum opportunities of choosing to participate, using a preferred method. By July 2018 there had been 43 downloads. On reflection and although draft news briefs had been submitted as part of the ethical approval process, following initial feedback from one UK Carers organisation in March 2016, news briefs were described as too wordy and had to be simplified (see **Appendix 1:** the amended marketing and news brief). Further, when reflecting on the research question of accessible information, that is specifically:

> The provision of accessible information and advice that describes the range of services for people with care and support needs, to those with special educational needs and disability and/or for the carers who help them.

On reflection, I could also have completed a podcast or developed a U-Tube video to be more accessible. Unfortunately, at the time, it was not considered by myself nor through feedback during the design phase. However, one of the advantages with mixed methods is that the future design of Phase 2 of the longitudinal study would enable refining and improvements following the weakness identified in the first phase.

Sampling and addressing demographics bias

I designed the dissemination process to encourage maximum participation using the voluntary and charitable sectors, and by using existing charitable and carers' networks across Nottinghamshire (place of residence and study) and the West Midlands (Birmingham and Solihull area of work). Disseminating via known networks had the disadvantage of creating a demographic **bias** towards the West Midlands, Nottinghamshire and the middle class. To reduce demographic bias, I attempted to host a researcher's website and initially targeted the key local authorities in Birmingham, Solihull, Nottingham and Nottinghamshire statistical neighbours. Targeting statistical neighbours could generate public participation across a possible 33 local authorities. Unfortunately, at the time the surveys were initially launched, purdah was announced, which in turn potentially reduced the numbers of responses and opportunities for dissemination via the local authority route. [Purdah is a commonly used term to describe the period running up to an election when normal behaviour and protocols in Councils are restricted. In the context of this study, restrictions related to publicity and communications by Councils and their Members and Officers].

In contrast, findings suggest that using the media and email dissemination via potentially interested parties resulted in rluceresearcher.com having **371** different people looking at the content on the website between **29th March 2017 to 13th July 2018.**

Of the 371 viewers, **350 (95%)** were new users and **19 (5%)** returning. **Table 1** below lists the number of users; the sessions show how many times these people came back to look at the website. The comments section indicates what I was doing around peak times that resulted in the outcome that followed a particular activity that prompted a user to view the website.

Table 1: Number of users

Month	Users	Sessions	Comments
Mar-17	6	6	Launch.
Apr-17	25	30	Cascade of emails and newsletter briefings.
May-17	80	98	31st May – Bolton FM radio broadcast.
Jun-17	55	61	
Jul-17	12	16	
Aug-17	13	14	
Sep-17	4	5	
Oct-17	9	9	
Nov-17	4	4	
Dec-17	7	8	
Jan-18	23	23	Supervision advised re-opening surveys to obtain more returns.
Feb-18	109	109	Email - relaunched via networks, but this time used a shorter brief linking to the website only.
Mar-18	13	15	
Apr-18	5	5	
May-18	2	2	
Jun-18	3	3	
Jul-18	1	1	Closed Surveys.

TOTAL	371	409

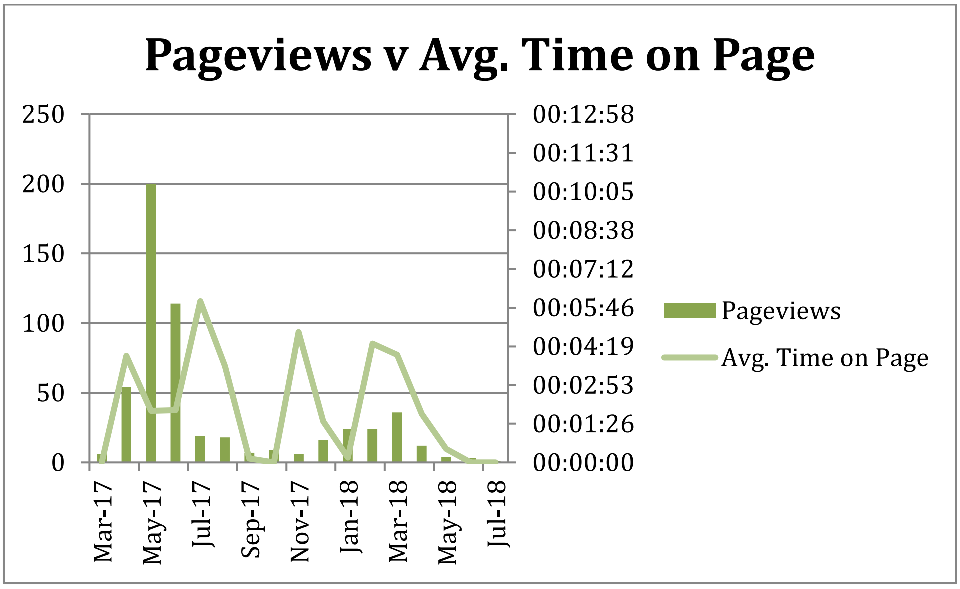
Pageviews v Average time spent on a web page

Table 2: Pageviews show how many times the users looked at different pages showing how long they generally looked at each page.

Table 2: Pageviews v Average time spent on a web page

Month	**Pageviews**	**Avg. Time on Page**
Mar-17	6	00:00:00
Apr-17	54	00:03:58
May-17	200	00:01:55
Jun-17	114	00:01:57
Jul-17	19	00:06:00
Aug-17	18	00:03:35
Sep-17	7	00:00:09
Oct-17	9	00:00:00
Nov-17	6	00:04:51
Dec-17	16	00:01:32
Jan-18	24	00:00:11
Feb-18	24	00:04:25
Mar-18	36	00:04:00
Apr-18	12	00:01:48
May-18	4	00:00:30
Jun-18	3	00:00:00
Jul-18	1	00:00:00

Graph 1: Pageviews v average time on a page

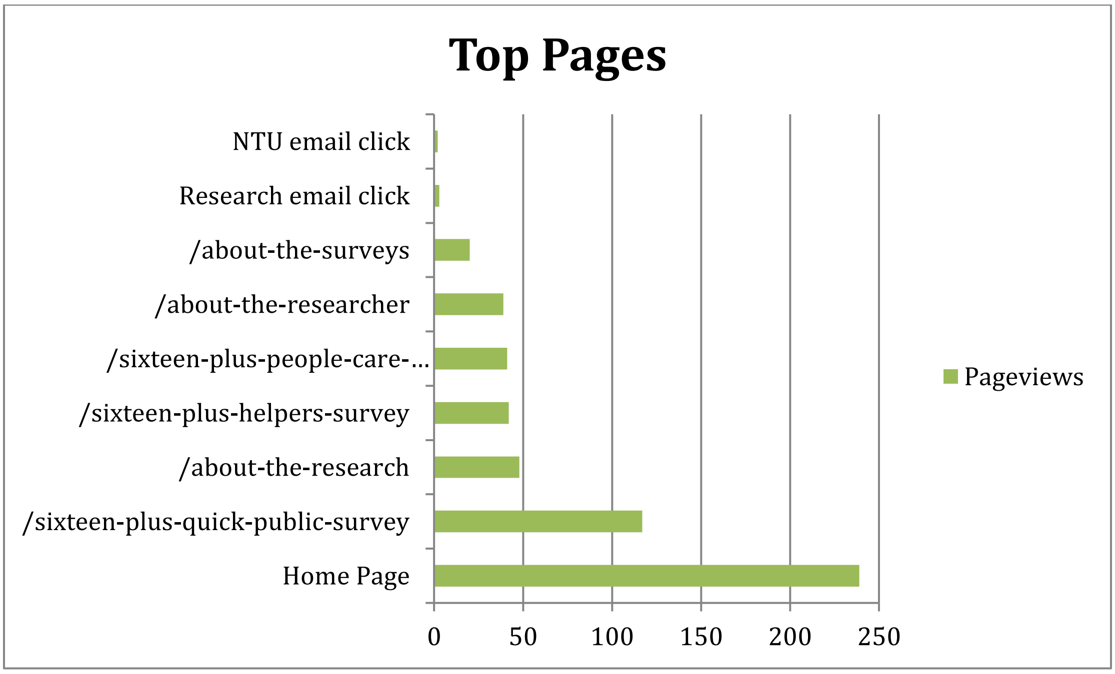


The top-performing pages tell us what users liked to look at most; see **Table 3** and **graph 2**.

Table 3: Pageviews

Page	Pageviews
Home Page	239
/Sixteen-plus-quick-public-survey	117
/About-the-research	48
/Sixteen-plus-helpers-survey	42
/Sixteen-plus-people-care-support-needs	41
/About-the-researcher	39
/About-the-surveys	20
Research email click	3
Nottingham Trent University (NTU) email click	2
TOTAL	553

Graph 2: Pageviews



Acquisitions

Table 4: Acquisitions tell us how the researcher's website was found. Referrals – link from another site (by the looks of the data this was mainly spam sites).

Direct – using the URL (rluceresearcher.com).

Organic Search – using a service like Google.

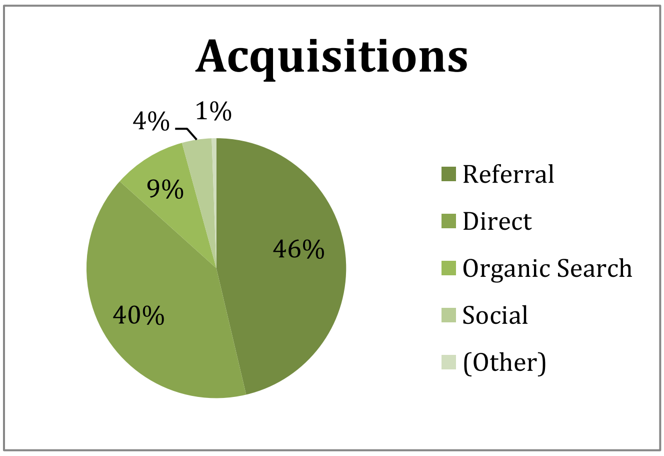
Social – from links on social media (Facebook for the researcher only – this was posted via a family member's Facebook profile and Bolton FMs).

Table 4 - Acquisitions

Default Channel Grouping	Users
Referral	163
Direct	142
Organic Search	32

Social	13
(Other)	2

Graph 3: Acquisitions



Language and communication bias

The primary language of the data collection methods of the surveys is English, but to obtain a diverse multi-cultural perspective, there are other language options that I explored. Unfortunately, to have the full surveys translated in order to include, for example, both quantitative and qualitative data, the cost would be in excess of £15,000.00. For the purposes of the doctoral programme, a full translation was not affordable, therefore this particular study accepted a weakness in respect of obtaining views from a diverse multi-cultural perspective and highlighted this within the ethics approval process.

Language and location demonstrate a global reach, which although small in numbers in terms of validating the research, was surprising; see **Table 5**: Language, **graph 4** Language and **graph 6**: Global Locations. I had not expected people outside the country to be interested in the website.

Table 5: Language

Language	**Users**
(Not set)	131
English -GB	126
English -US	65

Brazilian Portuguese	14
Computer robots	5
Portuguese	3
Italian	2
Dutch	1
Spanish	1
Mexican Spanish	1

Graph 4: Language

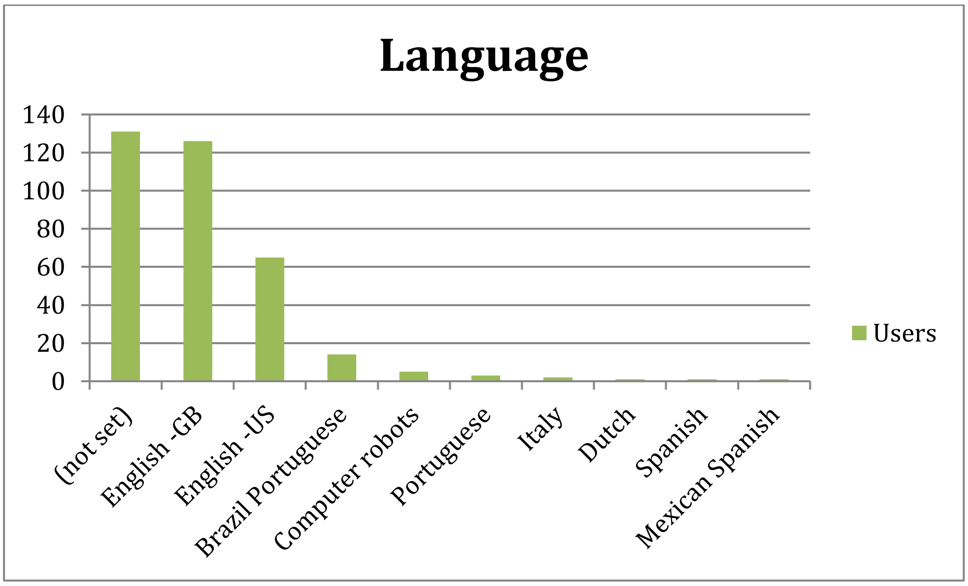
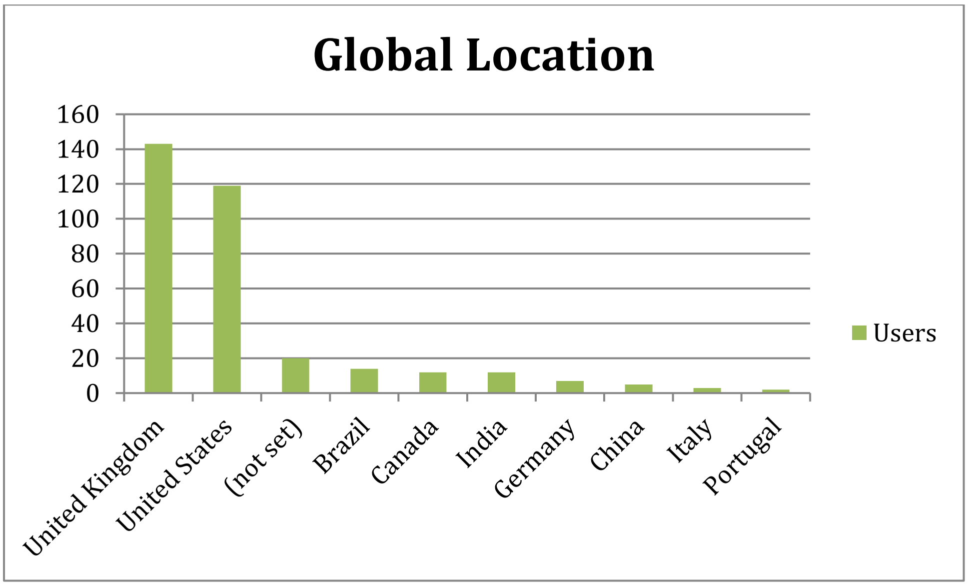


Table 6 Global Location



Conclusion

The surveys focused on the provision of accessible information and advice, the assessments process and meeting of needs. The design of the surveys took account of the legal, policy and assessment frameworks that were in operation during 2016. The main aims of the surveys were to provide a benchmark and insight into people’s lives as the three Acts continued to be implemented in England. The next chapter provides those findings.

However, before I move on, it is to be noted that later in 2019 my thesis became concerned with aspects of Foucault’s work in regards to discipline and biopower. As described in chapter 2, Foucault set out in broad terms the task of discourse analysis and problematisation.[194] Chapter 5 reveals comments within the carers’ perspective and experiences, in particular the impact of the conversational practices, and discovering who does the speaking, the institutions which prompt people to speak, and where the organisations may store and distribute things that are said.

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[194] See ch 2 of this thesis discussing discourse, 31.

Chapter 5: Lived experiences - findings and analysis

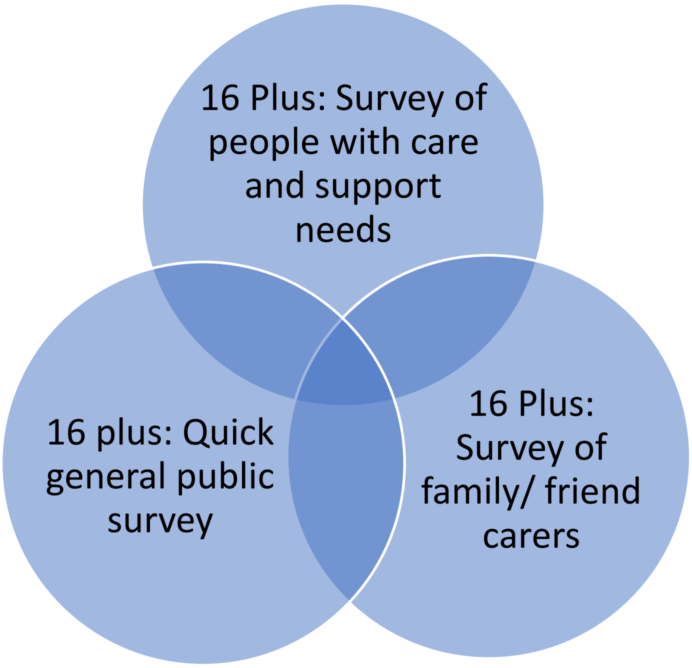

Diagram 5: Overview of the three public surveys

Introduction

This chapter reveals comments within the carers' perspective and experiences. The three surveys designed took account of the legal, policy and guidance and assessment frameworks which were operational during 2016. As highlighted in Research report 1 (document 3), which covered the survey design and ethical approval process, any member of the public aged 16 and over, service user or family/friend carer in England could take part. I was particularly interested in people's experiences from January 2016 onwards, following the 39 recommendations made by the Select Committee on the Mental Capacity Act,[195] and during the Care Act, 2014 and the Children and Families Act implementation phase.

Experts by Experience shaped all three surveys; care and advocacy services and professionals who were members of the Solihull Metropolitan Borough

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[195] ibid (n 32).

Council Special Educational Needs and Disabilities Board during 2015 and 2016 contributed.

Ethical approval was received on 13th April 2017, and numerous news briefs were issued via interested charity groups and radio broadcasts. The first publication of the surveys closed on 31st July 2017, but owing to low returns was relaunched in 2018, finally closing on 31st May 2018. The relaunch was promoted both verbally through contacted leads established within the Nottinghamshire and West Midlands area, as well as via email correspondence through the Mental Capacity Act Sub Group of the National Safeguarding Team.

Research Report 1 mentioned the bespoke researcher’s website, which was developed to host the surveys and to provide information to the general public, and was essential to recruit participants. The website had three hundred and seventy-one views. The first report analysed the methodology, ethics and data collection tool, whereas this report continues to analyse the responses received.

Of the three hundred and seventy-one views, only forty-five went on to complete a full Quick Survey (see further below -Testing Public Awareness). Five completed the survey for people who help others (see, Findings from the carers’ surveys) and only one completed the survey for people *with* care and support needs (see, Fraser – a case study).

The main aims of the surveys were to provide a benchmark and insight into people's experiences and to begin to investigate critically the impact that resources have had in raising public awareness. However, in regards to the survey: 16 Plus with care and support needs, only one adult male responded. Statistically speaking, a single response would not be considered as representative of a whole population group, but his view and experience would provide valuable insight into whether or not his assessments included a whole family approach. His story is now set out below as a case study.

Fraser, who had care and support needs, case study one – anonymised

Fraser was aged between 61 and 70. He lived within the Nottingham area and had a white British background. Fraser had a stroke[196] in 2015 and received a care and support plan undertaken by the local authority in January 2015 (during the very early phase of the implementation of the Care Act). Fraser said: *'I required considerable support for at least 12 months after my stroke but [I] do not have any needs at the moment'.*

Fraser indicated that the statement: *'A personalised approach – made me feel in control, gave me choices about my care, I felt respected. My views and wishes were asked,'* was very accurate. He was also asked about what he wanted to achieve in his day-to-day life. His wishes and views were followed '*perfectly*'. When Fraser's interests were asked about, he answered:

> *I wanted to get back to the sporting life I had before my stroke. I had an NHS physio for 12 months, and I now play golf one-handed, I umpire at cricket (but [do] not play, unfortunately), and walk regularly.*

Fraser was told about someone else being able to make a decision for him and what steps [he] needed to take if in the future, [he] could not decide for himself; he responded: *"I have taken the necessary steps to sign a legal document for my family to [make] decisions for me in case I become ill again"*. [Research question (d): making lasting powers of attorney for health, welfare and finance].

Fraser indicated that he was asked about support within the community, but in answer to the question that identified other professionals involved in his care and support needs, the only professional he indicated from the multiple-choice

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[196] At the time of Fraser's stroke, the 'Stroke and transient ischaemic attack in over 16s', NICE guideline (CG68), July 2008 was in place. Replaced in May 2019, by NICE Guideline (NG128); 'The NICE Quality Standard, Strokes in Adults' (first published in June 2010, April 2016) <www.nice.org.uk/guidance/ng128>accessed on 17th October 2019.

answers was the physiotherapist. Later in the survey he mentioned that his wife had '*considerable support from NHS staff and local authority workers*'.

Fraser was asked about what it was like living with his illness, condition or disability, about where he would seek support in the community, and about his faith and his culture and how they influenced his day-to-day life and his choices. He said that '*in the first few weeks in [the] hospital, [he and his partner] had spoken to several members of staff who ascertained [his] culture etc*'. [Research question (b), recording person's preferences, wishes, beliefs and values regarding their future care].

In his response to being asked about the best way to communicate with him to help others understand his care and support needs and what might be happening to him; Fraser said this '*was done on a one-to-one basis with my physio*', adding that he did not have difficulty understanding what was being offered to him in respect of health, care and support, as this '*was explained very clearly*'.

In response to accessing information and advice about the range of services available to people with care and support needs, Fraser, '*sought [the] information [about] support [he required], when [he] returned home*'. He found it '*very difficult to find'*, but when he did [find it], he indicated that the advice and guidance received was easy to use and to understand. [Research question (a): Why, what, where and how information and advice were sought: Specifically, the provision of accessible information and advice that describes the range of services available to people with care and support needs, including to those with special educational needs and disabilities and/ or, to the carers who help them].

Overall, Fraser indicated that he was very satisfied with the advice and guidance he received in the area in which he lived, and in respect of the final question, 'Is there anything else you want to tell me?' His response was, '*the treatment I received from the NHS was first class, and everything possible was done to meet my needs*'.

Family and friend carers

The following reflects Fraser’s perspective and experiences and is not necessarily that of those who assisted him in meeting his needs. In the Care Act 2014 section 9 and 10, there is a distinction made between the carers who have need of ‘support’[197] and people who are cared for, who have need of ‘care and support’.[198]

In terms of Fraser's family, he was asked about who lived in the house and whether there were children in the family, also who was important to him, who had helped him and what they were doing for him; as well, what impact his needs had on other family members who were also helping him with his needs. Initially, Fraser indicated that the person who helped him was his wife; however, the response to the age range of his carers at this point is uncertain, as Fraser indicated that this person was aged between 19 and 25. No other relationship or friendship group was identified in addition to the ‘wife’ response. However, a question later in the survey (a cross-check question), asked if more than one person supported the respondent. The answer here was: ‘*My two daughters provide support*’. The response to the age range of the carers leaves uncertainty, as the answer may be correct or could also be a mistake. In any event, the family were supporting him with his needs.

Whomever he had in mind, he thought that the carer (s) did not need help to support them and also, in response to whether or not they had been asked if they needed help in their role, he chose the ‘not applicable’ answer.

The following question asked if a carers’ assessment was offered, but Fraser responded: ‘*Yes, but they did not want one*’. He further added: ‘*My wife took the lead, with considerable support from NHS staff and local authority care workers*’.

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[197] s 9.

[198] s 10.

The survey also enquired whether or not a combined or joint assessment had been received. The answer was a clear ‘no’, as opposed to ‘no-one asked us’, which was an option in responding to the question.

Three questions followed which asked Fraser if the person who helped him had a health problem, disability or special educational needs; all of those were answered in the negative.

In conclusion, it was a positive response with respect to Fraser’s own care and support experiences, a helpful insight that suggests that a ‘whole family approach’ to care and support and assessments had been adopted in this case.[199]

Fraser received an assessment of need which specifically covered the outcome requirements set out by section 9 (4) (a) of the Care Act 2014, in particular the assessment of the impact of the adult’s needs on their well-being (see further below), an assessment of the outcomes that the adult wishes to achieve in a day-to-day life (s.9 (4) (b)), assessment of whether, and if so to what extent, the provision of care and support could contribute to the achievements of the person’s outcomes (s.9 (4) (c)). According to Fraser, his wishes and views were incorporated into his assessment and care plan, and the process appeared to involve him and his family carers.

Findings suggest that the general duty of the local authority under section 1 of promoting an individual's well-being was also incorporated into Fraser's experiences. As mentioned above, well-being’ means 'that individual's well-being in so far as relating to any of the following:

a) Personal dignity, including respect,
b) Physical and mental health and emotional well-being,
c) Protection from abuse and neglect,
d) Control by the individual over day-to-day life,

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[199] ibid (n 39) para 122.

e) Participation in work, education, training or recreation,
f) Social and economic well-being,
g) Domestic, family and personal relationships,
h) Suitability of living conditions,
i) The individual's contribution to society.[200]

In conclusion, Fraser's case study suggests that he and his family received an assessment that incorporated all of the elements of the application and implementation of the Mental Capacity Act 2005 and the Care Act 2014.

Findings from the carers' surveys

There were five respondents, all over eighteen years of age — three from Birmingham, one from Wolverhampton and one other who specified 'Nottinghamshire'. Counties identified were three from West Midlands, one from Nottinghamshire and one from Shropshire.

The age range of the respondents: Two were aged between 26-50, two were 51-60, and one was aged between 61 and 70. Four were of white British origin, one Irish.

Research question (a) - accessibility of information and advice

Section 4 of the Care Act 2014 requires local authorities to establish and maintain a service for providing people in the local area with information and advice relating to care and support for adults and support for carers. During the Joint Committee stages, 'information' is data that are left to the individual to interpret, whereas 'advice' includes what should sensibly be done in the personal circumstances. [201] Furthermore, in the House of Commons, effective

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[200] ibid (n 18) Care Act 2014, s 1 (2) (a) to (e).

[201] Joint Committee on the Draft Care and Support Bill, *Draft Care and Support Bill Report* (2012-13 HL 143 HC 822), para 85 <https://publications.parliament.uk/pa/jt201213/jtselect/jtcare/143/143.pdf> accessed 24 October 2019.

information can ‘only’ be provided ‘by the local authority working together with health organisations’, and the duty to promote the integration of health with care and support services is pertinent to information and advice services under section 4.[202]Chapter 3 of the Statutory Guidance for Care and Support provides further details about section 4 of the Care Act 2014 and covers:

- the duty placed on local authorities to establish and maintain information and advice services relating to care and support for all people in its area,
- the broad audience for the information and advice service,
- the local authority role concerning financial information and advice,
- the accessibility and proportionality of information and advice,
- the development of plans/strategies to meet local needs. [203]

It is to be noted that:

> Information and advice [are] fundamental to enabling people, carers and families to take control of, and make well-informed choices about, their care and support and how they fund it. Not only do information and advice help to promote people's wellbeing by increasing their ability to exercise choice and control, [but] it is also a vital component of preventing or delaying people's need for care and support.[204]

The surveys were therefore designed to test why, what, where and how information and advice were sought and obtained. All five carers had tried to find information and advice, but for different reasons, and included both health services and care and support services (**Table 7** below). Two of the respondents found it very difficult to locate further information, two found it moderately difficult, and one person found it very easy. Once obtained, the

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[202] PCB Deb (PM) 9 January 2014, col.65 (Norman Lamb MP) <https://services.parliament.uk/bills/2012-13/enterpriseandregulatoryreform/committees/houseofcommonspublicbillcommitteeontheenterpriseandregulatoryreformbill201213.html> accessed 24 October 2019.

[203] Chapter 3, Information and advice <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#general-responsibilities-and-universal-services> accessed 24 October 2019.

[204] ibid, para 3.1.

usage and ease of understanding the advice or guidance, varied as well (**Table 8** below).

Supported accommodation, then later residential care.
In the beginning, we were looking for social groups/activities as a social outlet; then it was a benefit/financial check-up, then it was support in caring for my mother-in-law.
Access to CHC for assessments.
Disability Living allowance.
Support services for local residents.

Table 7 – Reasons for searching for information.

How accessible was the advice or guidance for you?								
Answer Choice **Scale Very easy to poor**		**Very Easy**				**Poor**		**Response Total**
1	Easy to obtain	0	1	2	0	2		5
2	Easy to use	1	0	3	0	1		5
3	Easily understood	1	0	1	1	2		5
Answered								**5**
Skipped								**0**

Table 8– accessibility of the advice and guidance

The local authorities must take:

> An active and critical role in the provision of information and advice, … a local authority is likely to need to go further than providing information and advice directly (though direct provision will be important) by working to ensure the coherence, sufficiency, availability and accessibility of information and advice relating to care and support across the local authority area.[205]

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[205] ibid

In terms of population groups, I now turn to establishing the extent to which advice and support have been available within the assessment processes.[206]

Research question (b) - Experiences of formal assessments – carers' perspectives

Regarding the relationship to the person with care and support needs, three were mothers, one a husband, one a mother-in-law and one was a 'resident'. Out of the five responses, two indicated that they had received 'care plans only' (for the person they cared for), and a further two had a 'care and support plan'. Two also indicated 'none of the below' (total of six responses), but none indicated that they had had a carer's assessment.

The duration of being a family or friend carer also varied, ranging from one to three years (one (20%)), two (40%) indicating that they had been a carer for eight to eleven years, and a further two (40%) for thirty-one to forty years. During these periods, only one (20%) indicated that they had been asked if they needed help in their role, and this was within the last few months. The respondent indicated that a health and social care professional had asked them, and that they had been asked three times. In response to, 'What happened and what was the outcome', the answer was '*Patchy and unreliable support*'.

Four (80%) had not been asked and therefore automatically skipped those questions.

Carers' perspectives on access to assessments and the assessment process

Of the five respondents, and in response to the question as to whether they had been offered a carer's assessment, one (20%) indicated they had but were waiting for the assessment. One (20%) had a support plan; it had been

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[206] ibid, para 3.3.

reviewed. Three (60%) had not been offered a carer's assessment. However, one carer made a further comment about their experiences and said:

> *I found the assessment intrusive and semi-exploitative. It really didn't achieve much, and I felt it was more of a tick box exercise than [a] genuine attempt to assist me*.

In considering the process of self-governing and the degree to which individuals as carers are provided with 'choice' through the conversations as required by accessing the health and social care system, this participant's experiences suggest at best that the process of decision making and choice of support remains questionable. At worst, the input from carers might be perceived as irrelevant and a hindrance to the discourse of health and social care, as suggested by Gary Witham and advanced in this thesis.[207]

The method used to undertake the assessments: one (20%) was face to face, one (20%) was phone and face to face, and three didn't respond, but commented that the assessment '*was not undertaken*', '*no assessment made*' and, *'[I] haven't had an assessment'*.

Only one (20%) was informed of the possibility that care and support and the carer's support plan could be combined. Four (80%) did not know this.

Question 21 of the survey begins to identify satisfaction in respect of support plans via asking the respondents to rate their satisfaction. One (20%) was 'very dissatisfied'. One was 'dissatisfied', and three stayed 'neutral' — possibly the three who had not been offered an assessment.

However, the comments made by one of the carers about their experiences were as follows:

> *It was a disaster of epic proportions; social worker reduced 'P' [person with care and support needs] to tears within minutes by assuring her that she (SW) would find ['P'] a "lovely" home for her when we went on holidays. We hadn't mentioned holidays; we had none booked, it wasn't*

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[207] ibid (n 104).

> *an issue. This resulted in [P] refusing to leave the house for weeks in case we were going to bring her to a home and leave her there.*

Foucault discussed the relationship that exits between power and knowledge in terms of the response they have to social, political and health reality.[208] The comments within the carers' perspective and experiences, in particular the impact of the conversational practices indicated the person cared for accepted the social workers authority and gave far more weight to the perceived 'holiday', as opposed to the reassurances provided by those who were close to 'P'. In this space of the assessment process, power is shown to be exercised through the social worker, exerting pressure on 'P' (and the carers), but both appear to reject the notion of a perceived need for a holiday.

The role of caring – the impact on the carers' life

Regarding the ethics of care and the impact on carers and their relationship to those cared for, the literature is full of examples of the impact on carers' well-being and welfare, and the vulnerabilities that become a feature of the interdependence within the relationship.[209] For decades there have been political arguments that:

> Care is not a parochial concern of women, a type of secondary moral question, or the work of the least well off in society. Care is a central concern of human life. It is time we began to change our political and social institutions to reflect this truth.[210]

As mentioned above, the role, impact and involvement of carers are incorporated into our domestic law. However, it remains to be seen through critical dialogue to what extent the health and social care professionals are

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[208] See, ch 2, 32-35.

[209] Eva Feder Kittay, *Love's Labor: Essays on Women, Equality and Dependency* (New York, Routledge 1999) xii; Fiona Williams, F, *'The Presence of Feminism in the future of welfare'* (2002) Economy and Society 502, 503; Jonathon Herring, *Vulnerable Adults and the Law* (Oxford University Press 2016).

[210] Joan B Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (Abingdon, Routledge 1993), 180.

taking into account the impact of the carer’s role, given that only one of the five respondents had received a carer’s assessment.

Nevertheless, all five described the way the role of the carer impacts on their life. **Table 9** outlines the answers given:

It’s sometimes hard to balance my role as a parent with my role as a carer, especially because I work full time and my mum doesn't live close by.
I found it very financially limiting. The carer's allowance of £62 is nearly insulting, it's so paltry. It's also very socially limiting as [person with care and support needs) could not be left on her own. Due to the nature of [Person with care and support needs] illness and her changing behaviour, lots of regular callers stopped calling at the house and that only increased the sense of isolation. [Person with care and support needs] living with us also had a huge impact on my husband (her son) and our three children, who were aged 15.5 and 17.5 when we moved house, in itself a big undertaking, and all three were facing state exams: [one young person - male] A levels and [other siblings – male and female] GCSEs.
Negative impact on finances and need to organise support from agencies that don't see our case as a priority.
Challenging, as I work and constantly worry about my husband and his memory issues at home.
My role can interrupt my daily life at any time, yet the clients expect and deserve the same response regardless of how busy I am. I enjoy it that I am able to fill a gap for clients, but there is stress when the client wants more than we can provide and statutory services are not able to provide what the client wants/needs.

Table 9: Impact of caring on the carers’ lives

The last response indicated that the person was not a family/ friend carer, but later on information demonstrated that the respondent was acting in an unpaid, voluntary capacity. Two of the five respondents appeared to be parents, and one family (second respondent in the table) moved house to accommodate the change in circumstances to care for her husband’s father within the 'whole family'. Four of the five respondents commented on the economic impact either directly or indirectly; two respondents made comments about the negative impact on their finances.

Access to support from within the local community

Where else do the carers who responded get their support within the community? One (20%) said, ‘No-one’. One (20%) said, ‘*A team of volunteers*’, one (20%) said they ‘*paid for a part-time carer(s) to help with meds and feeding/cleaning*’, one (20%) family and friends, with another response including a ‘*wide circle of friends and fellow parishioners at the Roman Catholic Church*’ (20%).

Analysis

This thesis is interested in the operation of hidden context and invisible power relations, the transformation of health, social, educational and economic choices to individuals, families and friends and local communities where we live. The economic impact was directly commented on by two of the respondents, and indirectly by a further two. The responses support the proposition advanced in this thesis, that forms of knowledge acquired by the state have in varying degrees acted on the consciousness of people, in particular, to modify their behaviour as economic and political subjects.

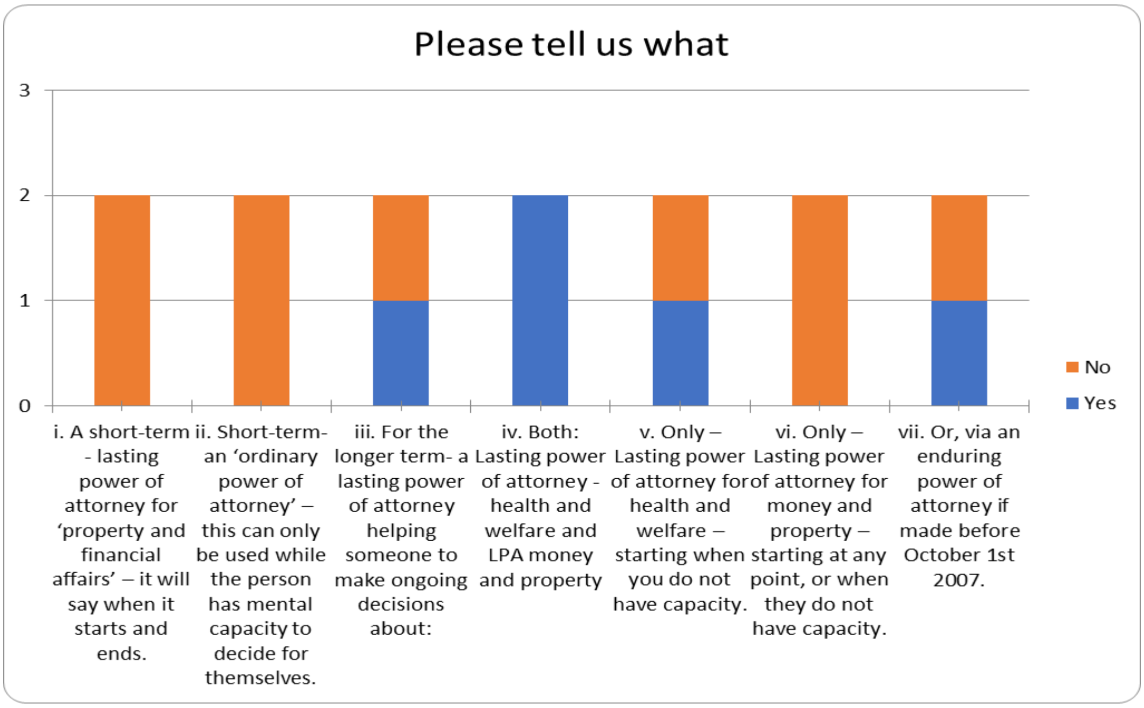
Local authorities need to take into account the impact of an individual’s need on those who support them and take steps to help others access information or support. At the time of writing, as only one carer had received an assessment, findings can be seen as inconclusive, but provide helpful insight into the embedding of a whole family approach, which requires seeing the person with care needs in ‘the context of their families and support networks’. Initial findings suggest that there is still a long way to go for health and social care professionals in achieving a balance ‘between the individual’s wellbeing and that of any friends or relatives who are involved in caring for the individual'.[211]

Involvement of carers when a person lacks the capacity to make decisions for themselves.

All five answered this question; one (20%) indicated that the person they cared for lacked capacity and a social worker and various health professionals were involved in their care—four (80%), saying '*No*'. The subsequent comments 'not applicable; my mum doesn't lack capacity', indicated on reflection that I should have added another option, 'not applicable'.

However, the final two questions of the survey went on to ask what type of power they held. Only two (40%) of the respondents held powers of attorney for the person they cared for. Three (60%) indicated 'none' and automatically skipped the final question. **Graph 5** indicated the types of powers the carer holds.

Graph 5 – Type of power of attorney held



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[211] ibid (n 39), Promoting well-being, para 1.14 (f).

> Good, person-centred care planning is particularly important for people with the most complex needs. Many people receiving care and support have mental impairments, such as dementia or learning disabilities, mental health needs or brain injuries. The principles of the Care Act apply equally to them, in addition to the principles and requirements of the Mental Capacity Act 2005 (MCA) if the person lacks capacity.[212]

Out of the five respondents, four had some form of power. The enduring power of attorney (EPA) was in place for property, money and financial affairs and provided it was signed and witnessed before October 2007, it is still valid. However, it could be replaced by a Lasting Power of Attorney (LPA), financial only, or both financial and welfare.[213]

The question prompted one of the respondents to find out what they should do with their 'EPA'.

Analysis

My research set out to examine the interplay between the three Acts and a whole family approach in the assessment, planning and review process – as well as the connection with the policy and legal framework of the children's legislation that underpins a whole family approach.[214] In this thesis, I adopted a governmentality-based critique to analyse the health and social care support system and its specific application to those who are sixteen and above and have declining capacity due to progressive illness. However, the responses have engaged the Care Act and Mental Capacity Act. The rationale for asking about the involvement of carers when the person they look after lacks capacity is partly to examine the impact the financial resources have had on raising public awareness with regards to making lasting powers of attorney for health, welfare and/or finances. The surveys were subsequently constructed to

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[212] ibid (n 39), Planning for people who lack capacity, para 10.9.

[213] See UK. Gov website, 'Use it or cancel it' <www.gov.uk/use-or-cancel-an-enduring-power-of-attorney> accessed 24 October 2019.

[214] ibid (n 39), Combining plans, para 10.73; Local Government Association, *The Care Act and the whole family approach* (22 December 2014).

examine the impact of public awareness campaigns following the Select Committee report [215] research question area (c) & (d) further below.

The survey responses did not yield any data from young carers or young people aged between sixteen and twenty-one with care and support needs. A further area of research is recommended as part of this longitudinal study programme. [**Recommendation 1**]

For adults, the whole family approach is beginning to be taken into account. This study provides a positive case study. In contrast, and for the carer's experiences, only one of the five respondents had received their carer’s assessment, as part of the whole family approach. More collaborative working within local communities and more accessible information is needed to achieve a better balance ‘between the individual’s wellbeing and that of any friends or relatives who are involved in caring for the individual’.[216]

Research question (c) & (d) - Making longer-term plans when you are unable to make specific decisions for yourself

This section is concerned with examining the impact that financial resources have had on raising public awareness in regards to:

a) understanding the difference between making an advance decision to refuse a specific type of treatment and an advance statement;

b) making lasting powers of attorney for health, welfare and/or finance.

The data collection tools were designed to be quick and easy to use and utilised skip logic. The time it took a respondent to complete the survey varied; it ranged from two minutes, forty-eight seconds to seventeen minutes and fifty-one seconds, the average being eight minutes and nineteen seconds.

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[215] ibid (n 12); ibid (n 36).

[216] ibid (n 39), Promoting well-being, para 1.14 (f).

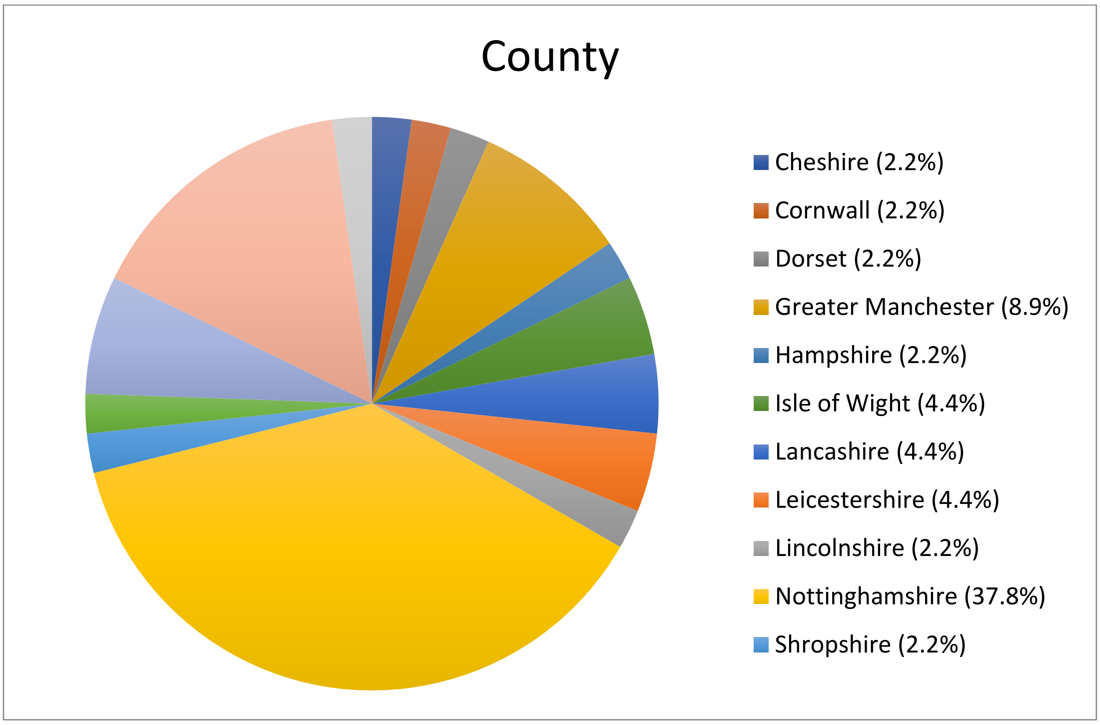
Geographical Location

Out of the 371 viewers of the research website, forty-six people (12.39%) responded to the Quick Survey. However, one participant was disqualified as they had accessed the survey during the ethical approval process and before the official launch. Of the forty-five remaining (12.13%), **Table 10** provides the locations and **graph 6**, the counties.

Please tell us the city or county where you live? City:			
Answer Choice		**Response Percent**	**Response Total**
1	Bath	2.2	1
2	Birmingham	17.8	8
9	Chester	2.2	1
11	Coventry	4.4	2
19	Lancaster	2.2	1
21	Leicester	2.2	1
23	Lincoln	2.2	1
26	Manchester	11.1	5
29	Nottingham	40.0	18
33	Portsmouth	6.7	3
39	Southampton	2.2	1
43	Truro	2.2	1
48	Wolverhampton	2.2	1
49	Worcester	2.2	1
		Total	45

Table 10: Quick Public Survey Responders locations.

Counties reflected by respondents



Graph 6 Quick Public Survey - Counties reflected by respondents.

In summary, there were not enough returns to make a comparative analysis of the local authority areas covered, but a broad geographical coverage was achieved. Areas of the country such as the South East and Cambridgeshire, Yorkshire, Derbyshire and Cumbria and the South West area around Bristol, produced no responses.

Age ranges

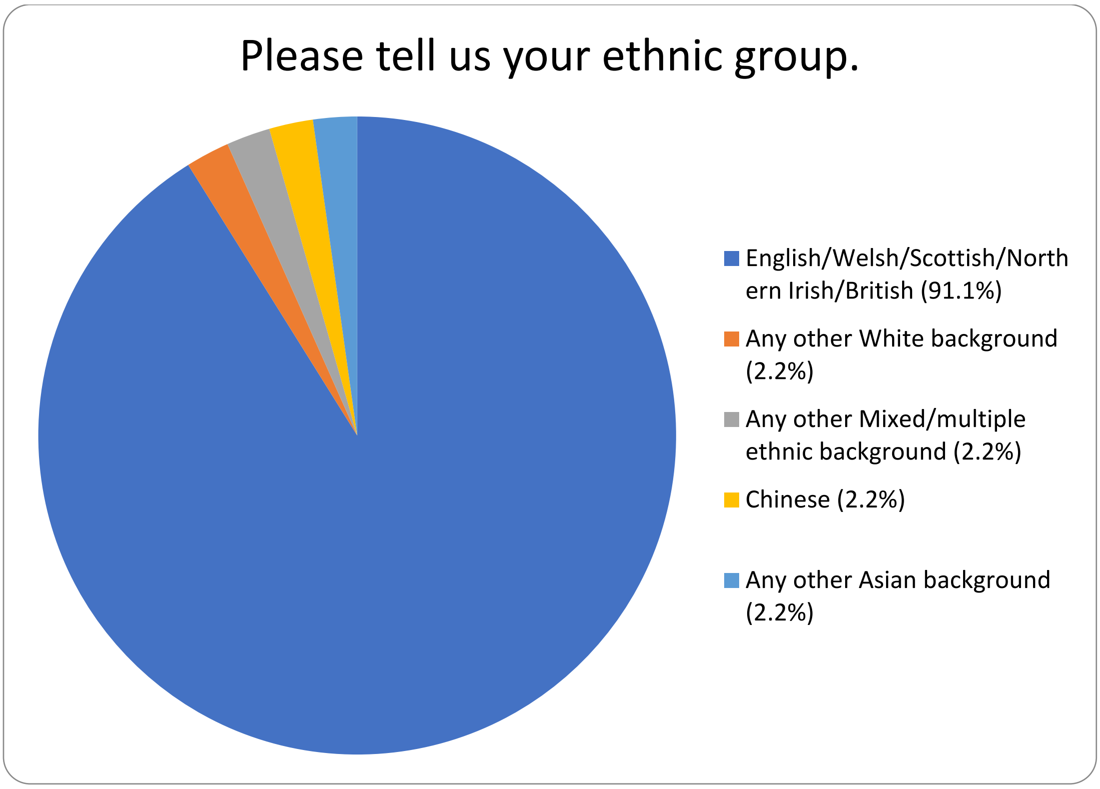
Of the forty-five, the highest number of respondents at 46.7% (21) were aged between 41 and 60, followed by 20% (9) aged between 26 and 40. **Table 11** further illustrates the age ranges.

Please tell us your age range?			
Answer Choice		Response Percent	Response Total
1	16 – 17	0.0%	0
2	18- 20	0.0%	0
3	21-25	15.6	7
4	26 – 40	20.0	9
5	41-60	46.7	21
6	61-70	13.3	6
7	71 – 80	2.2	1
8	81-90	2.2	1
9	90+	0.0%	0
			45

Table 11: Quick Public Survey – responders age range

Ethnic origin

Graph 7 illustrates the ethnic origin, noting that 91.1% (41) were of English/ Welsh/ Scottish/ Northern Irish/ British origin; 2.2% (1) from a multiple ethnic background and 2.2% (1) from an Asian background, but neither elaborated further.



Graph 7 Quick Public Survey- ethnic origin.

Knowing when one can make a decision for someone else

Academics have widely researched autonomy, liberty, competence and medical decision-making for a number of years,[217] including the relationship between autonomy and the Mental Capacity Act,[218] identity, personhood and the law, [219] as well as the compatibility with Convention rights[220] and the

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[217] Gerald Dworkin, *The Theory and Practice of Autonomy* (Cambridge University Press 1988, Online publication date June 2012); John Coggon, 'Varied and Principled Understanding of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?' (2007) Health Care Anal, Springer Science and Business Media 15, 235-255; John Coggon and José Miola, 'Autonomy, liberty, and Medical Decision-Making' (2011) Cambridge Law Journal 70 (3) 523-547.

[218] Paul Skowron, 'The Relationship between Autonomy and Adult Mental Capacity in the Law of England and Wales' (2019) Medical Law Review 27 (1) 32.

[219] Charles Foster and Jonathan Herring, 'Identity, personhood and the law: a response to Ashcroft and McGee' (2018) Journal of Medical Ethics 44,73-74

[220] Eliza Varney, 'Redefining contractual capacity? The UN Convention on the Rights of Persons with Disabilities and the incapacity defence in English Contract Law' (2017) Legal Studies, 37 3, 493-519.

controversy around the age of adolescent healthcare decision-making.[221] These are just a few examples of the subjects of academic writings.

The relationship between autonomy and self-determination is also well established and determinative in UK law. Munby J (as he was then) in *Burke*[222] examined this and affirmed that the adult is the judge of his or her own best interests; the court has no basis or jurisdiction to investigate a competent adult's best interest. In the same case, *Burke* also confirmed that in respect of advance decisions to refuse treatment, these would not apply to requests *for* treatment. [Emphasis added]. That could be explained because, if a treatment is refused, no one else apart from the patient is harmed, whereas if treatment is insisted upon, it could affect others and may affect the availability of resources for others. It is therefore essential to note that there are limits on autonomy. Firstly, autonomy is primarily a negative concept and the right to refuse treatment is strongly protected in law.[223] Less so is the right to demand or request treatment.[224]

Secondly, another limitation on autonomy is that the principle only protects those people who are deemed competent; for example, those with parental responsibility for children can make decisions on their behalf.[225] Similarly, a person who lacks capacity will be treated under the Mental Capacity Act and according to their best interests.

Before the Mental Capacity Act 2005 was passed, advance decisions played a significant part in applications relating to health care. No particular form was needed. To have legal effect, an advance refusal of medical treatment was required to be given if, and only if:

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[221] Vic Larcher and others, 'This House believes that we have gone too far in granting young people the responsibility for making decisions about their own healthcare: A record of a debate held in the Ethics and Law Session of the RCPCH Annual Meeting, York 2009' (2011) Arch Dis Child 96 (2) 123-126.

[222] *R (Burke) v GMC and Others* [2005] QB 424; *S v St George's NHS Trust* [1998] 3 ALL ER 673.

[223] ibid *S v St George's NHS Trust* [1998].

[224] ibid (n 222) *R (Burke) v GMC and Others* [2005] QB 424.

[225] Heather Montgomery and Marc Cornock, 'Children's bodies: The battleground for their rights?' (2013) Journal of Commonwealth Law and Legal Education 9 (1) 19-34; Jo Aldridge, ibid (n 180).

1. it was made at the time when the adult had [the] capacity to make a decision of such a nature;
2. it was intended to apply when that person was incapable;
3. it related to the circumstances that had arisen;
4. the maker understood the nature and consequence of his or her decisions; and
5. there was no undue influence or coercion by a third party. [226]

Documents setting out wishes regarding medical treatment were initially described as ‘living wills’. However, a refusal could be revoked (even when signed by the maker) by a subsequent verbal expression of contrary wishes or in relevant circumstances. The courts had to be satisfied that the advanced refusal change remained valid and applicable to the particular circumstances; if there was doubt, that doubt was resolved in favour of the preservation of life and the best interest test was applied.[227]

Ashton and others, in 2012 demonstrated that the drafting of advance directives in a particular form developed in practice, but challenges and inconsistencies arose around the interpretation of the application of the facts and the circumstances which had arisen.[228] Other terms used interchangeably within literature when searching under making advance decisions are ‘advance directives’, sometimes meaning ‘living wills’ or ‘statements made in advance’ or ‘advanced care planning’. However, these refer to someone's wishes and views and are not binding in UK law. In contrast, advance decisions to refuse treatment made by a capable adult are legally binding if valid and applicable when the adult becomes incapable. [229] These provisions under the MCA only apply to advance refusals of specified treatments. Under the MCA, an ‘advance decision’ means a decision made by a person, after [he/she] has reached 18 and when he has [the] capacity to do so’.[230]

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[226] Gordon R Ashton G and others, *Welfare and Health Care, Advanced Decisions and Research, in Mental Capacity Law and Practice* (2nd edn, Jordan Publishing 2012) 268.
[227] ibid.
[228] ibid, 266.
[229] Mental Capacity Act s 24 to 26.
[230] ibid s 24.

The advance decision comes into force when the person lacks capacity. This research study is focused on advance refusals of treatment, and the public's awareness and understanding of the distinction when a person is making longer-term plans for when they are unable to make specific decisions for themselves at a time in the future when they lack capacity. The following responses provide a position in time dating between 2017 and 2018.

Knowing when one can decide for someone else

Of the forty-five responses, 57.8% (26) said yes, they knew when one could make a decision for someone else, 13.3% (6) said no, and the remaining 28.9% (13) said they were not sure. Out of the forty-five, 53.33% (24) provided explanations. Many circumstances were included within the explanations, and therefore the explanations have now been grouped into themes, see **Table 12.**

Themed response	Response Percentage	Response Total
'Power of attorney/ lasting power of attorney in place.' [However, only two were more specific e.g., one of the fourteen specified *'If deemed to lack capacity, if a power of attorney in place'*, and another*, 'if you have a lasting power of attorney for health and wellbeing'].*	58.33%	14
'If I am a legal guardian'.	4.16%	1
'Next of kin if someone can't speak for themselves?'	4.16%	1
'When they do not have mental capacity to make the decision themselves' and '*when the person has lost capacity to make their own decision'.*	8.33%	2
'When you have formal preagreed authority to do so" and "with written specification to do so'.	8.33%	2
'Best Interest: If they lack mental capacity and it is in their best interests, and another specified*, 'We have a two-step mental capacity assessment at work for emergency situations (I work as a Paramedic)'.*	7.14%	2
'When significant risk to themselves or others.	4.16%	1
'Minors - As a parent of an under 18'.	12.5%	3

Table 12 – Themed responses as to when one can make a decision for someone else.

One of the respondents specified, '*if I am a legal guardian*'. It was not clear if they meant a Special Guardianship Order, introduced through the Children and Adoption Act 2002[231], which amended the Children Act 1989,[232] or, through the appointment of deputies by the Court of Protection to decide on their behalf if the person being cared for lacks the capacity to do so.[233]

Nevertheless, over half of the respondents said they were aware that if one had a Lasting Power of Attorney (and assuming the power applied in the circumstances), one could decide for someone else. One person thought that a next of kin could decide if someone could not speak for themselves; this may be so for an incompetent child, but in cases where a person has reached the age of 18, unless there is legal authority to do so by virtue of a specified power, no next of kin can consent on their behalf. If a person lacks capacity, then a healthcare professional can provide treatment if it is in their best interest.

With regard to the general public's knowledge about deciding for someone else, 41.3% said they did not know or were not sure when one could decide for someone else. Of the remainder who said that they did, the circumstances when this could occur also varied, with less clarity as to the age range of the person deciding. Perhaps this is not surprising. 'Children's rights to consent or to refuse medical treatment, including who has the right to control children's bodies," is seen as "one of the most significant battlegrounds for debate'.[234]

Who told the respondents about the way someone can choose a person to make and carry out certain decisions on their behalf?

46.7% (21) indicated that someone had informed them how to make and carry out decisions on behalf of someone else. 53.3% (24) had not been informed.

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[231] s 115.

[232] s 14.

[233] s 19 <www.legislation.gov.uk/ukpga/2005/9/section/19> accessed 5 November 2019; *MCA Code of Practice*, 'What is the role of the Court of Protection and court-appointed deputies?' ch 8, 137 -157; See, <www.gov.uk/become-deputy> accessed 5 November 2019.

[234] ibid (n 220).

Of the 46.7% (21) respondents, 47.85% (9) were informed by family members (mothers, wife, partner, parents); one by a friend at work, 4.76% (1) by a family friend. 4.76% (1) had researched online. 4.76% (1) stated that they had learned '*about Power of Attorney and /or finances in a training course some years back but [did not] think [their] knowledge was completely up to date'*. 23.8% (5) learned from solicitors or lawyers, one adding, '*when organising power of attorney for my mother*.' 4.76% (1), said the '*MCA*'.

Eighteen respondents stated where they would seek additional information. There were multiple responses, which are grouped in **Table 13.**

Themed response	Response Percentage	Response Total
Mental Capacity Act	5.2%	1
Internet search – general	36.84%	7
Internet search – Government website/ Office of the Public Guardian	21.0%	4
Citizen's advice	15.7%	3
Solicitor/ Lawyer	15.7%	3
Advocacy organisation	5.2%	1
Newspaper	5.2%	1
As part of [the] employed activity, in the care or nursing home, reading the forms or care plans	5.2%	1
Training	5.2%	1

Table 13: Places where respondents would seek information

Types of powers of attorney

All Forty-five responded as to whether or not they had made a power of attorney of some form. The type of power of attorney is contained in **Table 14.**

Type of Power	Yes Response Percentage	No Response Percentage	Response Total
A short-term - lasting power of attorney for 'property and financial affairs' – it will say when it starts and ends.	2.2% (1)	97.8% (44)	45
Short-term- an 'ordinary power of attorney' – this can only be used while you have mental capacity.	6.7% (3)	93.3% (43)	45
For the longer term- a lasting power of attorney helping someone to make ongoing decisions about both health and welfare and money and property.	6.7% (3)	93.3% (43)	45
For the longer-term- lasting power of attorney only – Health and Welfare – starting when you do not have capacity.	6.7% (3)	93.3% (43)	45
For the longer-term- lasting power of attorney only – Money and Property– starting at any point, or when they do not have the capacity.	6.7% (3)	93.3% (43)	45
Via an enduring power of attorney if made before October 1st 2007?	6.7% (3)	93.3% (43)	45
Total	35.55% (16)	64.45% (29)	100% (45)

Table 14 – Types of powers of attorney

Of the seven responses, the relationship to the respondents were mainly direct relatives (spouse, wife, parent, daughter, child and mother), with one being a '*friend business colleague'*.

Advance decisions

Earlier within the survey (question 7), and before it explored respondents' knowledge of advance decisions to refuse treatment (questions 13 to 17), the question asked at what age in England can one make a decision now to refuse a specified type of treatment at a time in the future? The 45 responses were as follows:

- aged 10 – 2.2% (1)
- aged 12 - 2.2% (1)
- aged 13 - 2.2% (1)
- aged 14 - 2.2% (1)
- aged 16 – 42.2% (19)
- aged 18 – 48.9% (22)

In contrast, and acknowledging that Question 13 was asked after the section on the powers of attorney, thus it could be seen as a leading question, Question 13 specifically asked: Did you know that if a person aged 18 and over, while still capable, may say in advance that they want to refuse treatment if they lose capacity in the future?

60% (27) said they knew this, whereas 40% (18) said they did not know—an increase of 11.11% (5).

Of the 27, twenty-four (88.8%) went on to explain how they knew. The comments varied:

- 37.5% (9) stated that they had '*guessed*', '*assumed*', '*heard through conversation*', or had '*general knowledge'*.
- 33.33% (8) said via the media, including internet, reading articles, news, television, leaflets (1 person mentioned leaflets) being the most common source of information.
- 16.66% (4) said at work, including research and training in the Mental Capacity Act and 'living' wills. Two of the respondents also indicated that they were working in the healthcare sector.
- 8.33% (2) said their mother had informed them, with one adding, '*She's a nurse'*.
- Interestingly, 8.33% (2) had specified '*lasting power of attorney*', including one particular response, '*I have financial and medical [power of attorney] for my mother*'.
- 4.16% (1) indicated through a solicitor.

Of the total of forty-five respondents, only 2.2% (1) had made an advance decision about their care and treatment. The respondent added that it was '*written and registered*'. This person was within the age range of 81-90 years. However, usually the Lasting Powers of Attorney (LPA) are registered with the Office of the Public Guardian. In contrast, the advance decision or advance statements can be written (see further below), and people who make them are advised to discuss with their doctor or health professionals involved with their care (as well as with their own family). Decisions should be entered in their health records.[235] It is therefore a possibility that the respondent has made an LPA, and perhaps made an advance decision at the same time, but only 'registered' the LPAs.

Out of the forty-five respondents, 28.9% (13) knew another person who had made an advance decision, whereas 40 % (18) said no; 31.1% (14) did not know.

If yes, and as far as the respondent was aware, assuming the decision made in advance was valid and applicable to the current circumstances, the respondents were asked if it was followed up by healthcare professionals. 8.9% (4) said, yes. 17.8% (8), said no. 73.3% (33) said that they did not know.

Of the eight that said no, two respondents added, '*it hasn't needed to be applied yet*' and '*the decision is made but the scenario has yet to occur*'.

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[235] See <www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/> accessed 11 January 2020; ibid (n 176) *Mental Capacity Act 2005, Code of Practice*, para 9.19 provides a list of information to follow and include in a written advance decision.

Where respondents would go to find further information about deciding for someone else

All 45 respondents answered this question, albeit 4.4% (2) said they did not know or it was not applicable. The remainder is set out in **Table 15.**

Themed response	Response Percentage	Response Total
Internet search – general	37.77%	17
Solicitor/ Lawyer	31.11%	14
Internet search – Government website/ Direct gov/ Office of the Public Guardian / NHS website	26.66%	12
Citizens' advice	15.55%	7
Family and friends	11.11%	5
Doctor and GP	8.88%	4
Health professional	2.22%	1
Social services	2.22%	1
Age UK	2.22%	1
Bank	2.22%	1
Through Mental Capacity Act Training	2.22%	1

Table 15 –Making a decision for someone else – general public sources

Distinguishing between an advance decision and an advance statement

Apart from advance decisions that apply to life-threatening treatment, the Mental Capacity Act 2005 (section 25) does not specify any procedures or formalities that must be followed for an advance decision to be made. It can be verbal or written and can be supported by a visual recording by the person making an advance decision.[236] The primary purpose of an advance decision (also referred to as 'living wills' and 'advance directives'), is to enable the person to refuse specified treatment when that person loses capacity to give

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[236] ibid (n 193) 'What does the Act say about advanced decisions to refuse treatment?' ch 9, 158-176.

or refuse consent to that treatment. Health professionals and the Court of Protection are bound by the advance decision (section 26),[237] and a clinician who follows a valid and applicable advance decision, 'is acting on the instructions of a capacitated individual', as opposed to the best interest principle,[238] which guides actions done 'for or on behalf of a person who lacks capacity'.[239]

> It follows that the best interest principle does not apply to such decisions and healthcare professionals must comply with a valid and applicable advance decision, even though they do not consider that it would be in the patient's best interest to do so.[240]

Unlike an advance decision, an advance statement is not legally binding. It identifies a person's views and preferences on a broad range of issues, not just medical or physical ones. [241]

Did the general public understand the difference between making an advance decision to refuse a specific type of treatment and an advance statement? 11.11% (5) people indicated that they knew the difference between an 'advance decision' and an 'advance statement'. 88.89% (40). However, on reflection, I had not added a follow-up question to test the respondent's knowledge about the difference per se. Instead, the next question was, 'Have you anything additional to say?'

Impact of the quick public survey

Of the respondents who had completed the survey, at least three of them were motivated into further action. A further two commented about information being

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[237] Effect of an advanced decision.

[238] s 4 – Best interests.

[239] ibid s1 (5) <www.legislation.gov.uk/ukpga/2005/9/section/1> accessed 4 November 2019.

[240] Richard Jones and Eve Piffaretti, *Mental Capacity Act Manual* (8th Ed, Published, Sweet and Maxwell 2018), 19, discussing the application of the best interest principle. section 1 (5).

[241] Gareth S Owen and others, 'Advanced decision making in mental health – suggestions for legal reform for England and Wales' (2019) International Journal of Law and Psychiatry 162-177; Tim Exworthy, 'Psychiatric advanced decisions – an opportunity missed' (September 2004) Journal of Mental Health Law 129, 132.

available and a need for promoting awareness- '*as people leave it too late, and then it creates real difficulties*' (see **Table 16** below).

Others commented on the design, i.e., a) not being able to identify the towns, (the survey used cities and counties as a drop-down.) and b) *'a rather complex survey and not easy to understand unless the readers have had prior knowledge of it*'. At this point, and given that the survey design and questions had input from Experts by Experience, I am not sure what could have been done to make the subject matter more accessible. If the surveys were to be repeated as part of the longitudinal study, identifiers such as gender would also be included to assist with seeking comparisons.

Final comments by the respondents

Intention to revise their will as soon as possible and to make 'my decision clear to my next of kin'. *'This has really made me think. I am not ill but could have an accident which puts people you love in a difficult place when they are feeling vulnerable'.*
'I think that there is a complete lack of awareness of the procedures to follow to appoint or be appointed with a power of attorney and there is a real need for awareness to be raised in this area - as people leave it until it is too late and then it creates real difficulties.
'I thought the age at which you can make a decision was not fixed, but dependent upon individuals' circumstances and understanding of the situation'.
'I have the forms to give my children LPA for us but haven't filled them in yet!'
'I have power of attorney over both parents and in the process for mother-in-law'.
'Do not know if need new powers of attorney if have [an] older version in place. Keep meaning to seek advice'.
'I've never publicly seen any information regarding any of the above circumstances.
'Doesn't feel like I need this at the moment, and if I did, I would ask the questions to find out more'.
'The first page of the survey isn't accurate. It asks for town or county, but you have to fill in both. My town isn't represented, only my county (Warwickshire), so I had to select a spurious town!'

'This is a rather complex survey and not easy to understand unless the readers have had prior knowledge of it'.

Table 16 – Quick Public Survey - Final comments by the respondents

Conclusion

The three-survey design took account of the content of the relevant law in operation during 2016. The principal objectives were to elicit experiences as they navigated their way through care, treatment and support arrangements.

The research was particularly interested in people's experiences from January 2016 and, as mentioned in the introduction to this chapter, following the findings of the Select Committee on the Mental Capacity Act,[242] and during the Care Act and the Children and Families Act implementation phase. The three surveys have tested the rights and entitlements to assessments up to July 2018. Overall, Fraser's case study suggested a positive experience, which was consensual, respecting autonomy, independence and his individualism.

In contrast, the carers' responses illustrated underlying tensions to the health and care system, and specifically the impact of being an unpaid carer. Furthermore, only one of the five had received their carers' assessments as part of the whole family approach. Of more concern this suggested that the wellbeing of family and friend carers remains expendable in today's contemporary society.

Applying a Foucauldian lens, I also observe the relationship of power and compliance of individuals as they engage with health and social care practitioners. The structure of the Acts and of these surveys has illustrated the provisions of accessible information and advice, range of promotional activities and encouragement for individuals to make choices for themselves, and negotiate with their families and communities to meet their own needs, at the

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[242] ibid (n 32).

same time, ensuring information is gathered to obtain knowledge of everyday life.

Finally, undertaking the public survey, modified some of the respondents behaviours to rethink and clarify their decisions for their next of kin.

Overall thesis conclusion

Adopting a governmentality approach worked well for this study. Its aims were to add to governmentality-based critiques of health and social care in general and more specifically to apply such critiques with particular reference to those who are sixteen and above and have declining capacity due to progressive illness.

The study took a governmentality-based critique and scrutinised the way the government governs families through the legal framework of the Acts, the Mental Capacity Act 2005, Care Act 2014, and the Children and Families Act 2014 - suggesting that the care and support assessment processes control individuals, the workforce, and the population.

We observed how ageing is a problem at a global, national and local level and examined the present economic, political and legal responses in England. The empirical aspect of this work sought to elicit lived experiences by conducting three surveys of people aged 16 and above and their families or friend carers who were likely to engage in the assessment process. Results have provided a platform for the public to say what has happened to them.

In keeping with a Foucauldian focus on the subject, we have tested what individuals aged sixteen and above knew about sharing wishes with family and friends. Also, through the operation of the communication exchanges, we observed the voluntary control of individuals and the workforce as they engaged and experienced the normalisation of formal assessment processes - bringing to the forefront ways of obtaining new knowledge in contemporary life.

2020 - Impact of the Coronavirus (COVID-19) on this research programme of enquiry

The impact of the coronavirus epidemic on the workings of the three Acts has revealed deep inequalities by the local area and socioeconomic deprivation across England.

A limitation to a Foucauldian approach and this study was how to address the impact of structural inequalities arising from multi-diverse communities, exploring the different types of knowledge and discourse among different social groups, including the way knowledge is made accessible and how people are excluded from it whilst being defined according to its categories.

Nevertheless, despite the challenges during the journey of this research, during the pandemic we observed the rapid shift in legislation (whether temporary or permanent) and this was indicative of how forms of institutional power are based on the ability to maintain and change over periods of time, and are not necessarily based on specific laws and legislation in a fixed time. We will return to the legislative changes during the pandemic in due course.

Impact on this research programme

In terms of completing this thesis and the long-term study, it was intended to adopt a follow-up study, which sought to recruit participants. At the same time, they had to have the mental capacity to consent to the research. One fundamental problem associated with longitudinal studies is that participants may change their mind and withdraw from the study before an event has happened. Other problems are likely to occur at any time due to the nature of the progressive and life-limiting illness. For this study, while an event might be death, which may occur at any age, an unprecedented event has occurred in 2020, the COVID-19 global pandemic. To put into context before the coronavirus (COVID-19) pandemic, globally each year ‘around 20 million people needed end of life care, including 6% that were children'[243] and children with complex needs and life-limiting conditions who were living into adulthood.[244]

Age, gender and other health and social issues all increase the risk of becoming seriously ill.[245] These figures are likely to increase dramatically during and following the pandemic. COVID-19 infections occur across all ages, although proportionally less in children under fifteen.[246] Children and adults with underlying or complex health conditions are at exceptionally high risk of contracting pneumonia and acute respiratory distress syndrome, leading on to death. At the time of writing this thesis (during the height of the pandemic), we do not know how coronavirus will affect health in the long term; acute respiratory distress syndrome develops in patients when the immune system goes into overdrive, causing damage to the lungs.[247]

Although adults over the age of sixty are at higher risk from complications, in rare cases, as shown by the recent death of a five-year-old in the United Kingdom and a twelve-year-old in Belgium, the disease can be fatal for children.[248]

Some measures of public health and clinical interventions have started to lead to a decline in new cases within communities. In the UK for example, the transmission control period enabled via the initial legislative response to the pandemic in England under the Health Protection (Coronavirus) Regulations

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[243] ibid (n 112).
[244] ibid (n 113).
[245] The World Health Organisation, *Europe, Statement – Where do we stand today on COVID-19, and what have we learned?* (8 April 2020) Statement to the press by Dr Hans Henri P. Kluge, WHO Regional Director for Europe <www.euro.who.int/en/media-centre/sections/statements/2020/statement-where-do-we-stand-today-on-COVID-19,-and-what-have-we-learned>accessed 18 April 2020.
[246] ibid.
[247] James Gallagher, 'Coronavirus: How long does it take to recover?' BBC News, Health and Science correspondent <www.bbc.co.uk/news/health-52301633> accessed 18 April 2020.
[248] ibid (n 112).

2020, SI No. 129, at 6.50 am on 10 February 2020, came in to force on the same day (10 February 2020).

Nevertheless, the government response is not a new reaction to national or global threats to health.[249] Disease outbreaks have sometimes changed the course of history and have dated back to circa 3000 B.C.[250] The historical measures taken in the plague towns and the quarantine enforced in large ports are two examples of collective control. Other measures include containment, the reduction of the spread of infection domestically, reducing the numbers within the population contracting the disease and dying, sustaining the infrastructure and mitigating the impact on the economy and functioning of society.[251]

In terms of Foucault, it is also very relevant when considering the impact of the Coronavirus epidemic on this study today. The 25 January 1978 lectures also discussed the normalisation process and how one might normalise a 'town,' and 'doctors, administrators, those responsible for the medical police and finally for the people themselves'. As mentioned earlier, Foucault used examples of epidemics, particularly smallpox, a disease in the eighteenth century of 'intense epidemic outbursts' and 'inoculation or variolization'.[252]

Foucault also illustrated the division between the normal and abnormal and prevention. In smallpox normalisation, Foucault observed the distribution of cases in a population in a particular time and space, integrating the individual and the collective phenomena and building a 'case': identifing risks of 'catching it', 'of dying from it or being cured'. The disease becomes accessible within groups and individuals; 'their age, where they live, and for each group, town

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[249] Michel Foucault, 'The politics of health in the eighteenth century', in Colin Gordon (ed) *Power/Knowledge. Selected Interviews and Other Writings* (Pantheon Books 1972-1977), 176.
[250] Owen Jones, '20 of the worst epidemics and pandemics in history' Live Science, <www.livescience.com/worst-epidemics-and-pandemics-in-history.html> accessed 18 April 2020.
[251] Center for Disease Control and Prevention, 'CDC 24/7: Saving Lives, Protecting people' <www.cdc.gov/flu/pandemic-resources/national-strategy/index.html> accessed 18 April 2020.
[252] ibid (n 87), 57-58.

or profession, will determine the risk of morbidity and mortality.[253] 'Case, risk, danger and crisis[..] are new notions'.[254]Then through the 'normal distribution' of cases and deaths due to smallpox, techniques are used to try and reduce the most unfavourable deviations and align them with the average level of morbidity and mortality.[255] The smallpox technique and analysis aimed to reduce the number of infant deaths; with Covid-19, the aim is to reduce the number of older people and other clinical vulnerable groups dying from the disease and to reduce the number of NHS hospital admission. The prevention system is opposed to discipline norm:

> In discipline one started from a norm, and it was in relation to the training carried out with reference to the norm that the normal could be distinguished from the abnormal. Here, instead, we have a plotting of the normal and the abnormal, of different curves of normality, and from the operation of normalisation consists in establishing an interplay between these different distributions of normality and [in] acting to bring the most unfavourable in line with the favourable.[256]

Similar to the mid-eighteenth century, the town and home saw the emergence of new and specific economic and political problems of government technique. In 2020, we also observed government responses and techniques of addressing the impact of the Covid-19 pandemic, including the magnitude of the impact on the economy, the extent of which at the time of writing was not known.

Impact of the Coronavirus (COVID-19) on the three Acts under study

Since late March 2020, there has been a tsunami of policies and legal restrictions of our ordinary civil liberties and further amendments to existing

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[253] ibid (n 87), 60 -63.

[254] ibid 61.

[255] ibid 62.

[256] ibid 63.

Acts, such as the *Care Act easements: Guidance for local authorities*.[257] The easements took legal effect on 31 March 2020:

> …but should only be exercised by Local Authorities where this is essential in order to maintain the highest possible level of services. They should comply with the pre-amendment Care Act provisions and related Care and Support Statutory Guidance for as long and as far as possible.
>
> They are temporary. The Secretary of State will keep them under review and terminate them, on expert clinical and social care advice, as soon as possible. All assessments and reviews that are delayed or not completed will be followed up and completed in full once the easements are terminated.

Similarly, on 1st April 2020, the Department of Health and Social Care published *Coronavirus (COVID-19): Guidance on vulnerable children and young people*.[258] The definition of 'vulnerable' children includes those who have a social worker and those children and young people up to 25 with education, health and care (EHC) plans.

Those who have a social worker include children who have a child protection plan and those who are looked after by the local authority. A child may also 'be deemed to be vulnerable' if they have been assessed as being in need or otherwise meet the definition in section 17 of the Children Act 1989.[259]

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[257] Department of Health & Social Care, *Care Act easements: Guidance for local authorities*, (first published 31 March 2020, updated 1 September 2020). <www.gov.uk/government/publications/coronavirus-covid-19-changes-to-the-care-act-2014/care-act-easements-guidance-for-local-authorities> accessed 30 October 2020.

[258] Department for Education, <www.gov.uk/government/publications/coronavirus-COVID-19-guidance-on-vulnerable-children-and-young-people/coronavirus-COVID-19-guidance-on-vulnerable-children-and-young-people#children-with-education-health-and-care-ehc-plans> accessed 1 April 2020

[259] ibid, para 1.

Likewise:

> The Coronavirus Act 2020 allows the Secretary of State, where appropriate, to temporarily lift the statutory duty on local authorities to maintain the precise provision in EHC plans; with local authorities needing instead to apply 'reasonable endeavours' to support these children and their families. As such, where the Secretary of State has issued a temporary notice, and a local authority is unable to secure the full range of provision stated in a plan, as long as they use their 'reasonable endeavours' to do this, they will not be penalised for failing to meet the existing duty in section 42 of the Children and Families Act 2014. [260]

The Mental Capacity Act 2005, and during the outbreak, the principles of the Mental Capacity Act 2005 (MCA) and the Deprivation of Liberty Safeguards (DoLS) still apply. However, emergency guidance for health and social care staff in England and Wales who are caring for, or treating, a person who lacks the relevant mental capacity during the coronavirus outbreak is also issued.[261] The guidance ensures that those decision-makers are clear about the steps they need to take during the outbreak period. It focuses on new scenarios and potential 'deprivations of liberty' created by the outbreak. [262]

Regrettably, depending on the longer-term duration and impact upon assessments, Phase two semi-structured interviews may not be possible as initially envisaged, that is, without significantly modifying the research design to take account of the impact of the COVID-19 pandemic. For example, addressing weaknesses within Foucault's concepts, there has not been a detailed discussion about how people have responded to the external discourses and strategies that have attempted to discipline them during the

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[260] ibid, para 21.

[261] Department of Health and Social Care, *Coronavirus (COVID-19): Looking after people who lack mental capacity* (9 April 2020) <www.gov.uk/government/publications/coronavirus-COVID-19-looking-after-people-who-lack-mental-capacity> accessed 10 Aril 2020.

[262] ibid.

lived experience of the pandemic,[263] coming to grips with the question of those affected by the pandemic and the effect of knowledge on society.[264]

In contrast, repeating the surveys of Phase one in a later stage is likely to encounter future validity problems for comparative analysis, because of the changes made to policy and guidance following the COVID-19 outbreak.

Digital literacy and poverty were also key factors in my current study and future studies. Access to knowledge is often limited for those without access to computers and the internet or who lack confidence in using online services. Furthermore, the potential recommendations related to improving access to making lasting powers of attorney in 2018, for example, moving to digitalise from paper-based service, which can take weeks, has been expedited by COVID-19. On 21st March 2020, the Public Guardian (OPG) Office published a response, including short-term options for health, welfare, and financial decisions.[265]

In July 2020, the OPG unveiled the new digital 'Use a lasting power of attorney' tool.[266] The new system allows those acting as an attorney to provide a secure code, which, when submitted via an online portal, confirms their status as an attorney and the power they hold, authorising them to take actions on behalf of the person. The existence of the performance of the service is now also published and available to the public.[267]

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[263] Chris Shilling, 'Educating the body: Physical capital and the production of social inequalities' (1991) Sociology 25, 664. <https://doi.org/10.1177/0038038591025004006> accessed 19 April 2020.

[264] Ibid, 664.

[265] (17 April 2020) see, <www.gov.uk/guidance/short-term-options-for-health-welfare-and-financial-decisions> accessed 18 April 2020.

[266] See, <https://publicguardian.blog.gov.uk/2020/07/17/weve-launched-the-new-use-a-lasting-power-of-attorney-service/> accessed 20 July 2020.

[267] Gov.UK, 'Dashboard, Lasting Power of Attorney registrations', <www.gov.uk/performance/lasting-power-of-attorney>accessed 28 August 2020.

There are now over 4 million registered lasting powers of attorney; in December 2016, there were over 2 million.[268] While there is a significant rise in applications, this depends on locality because:

> People living in less affluent areas of England and Wales are much less likely to create a [lasting power of attorney]. This is either because they don't know about the option to create one, or maybe they feel it's just not relevant to them.[269]

Knowing about the lasting power of attorney is arguably more difficult if English or Welsh is not the person's first language. Unfortunately, neither the OPG website nor the government website provides platforms in other languages. Since the advent of the coronavirus pandemic, material that is easily read, including in other languages, has been produced by charities[270] but is not available on the OPG website or the new digital platform mentioned above.

The recruitment, sampling and addressing research bias in design, language and communication was explored earlier. Obtaining views from a multicultural perspective by complete translation was not affordable for an independent study, but if there is a government will, it is affordable for the government.

As mentioned above, it is too early to analyse the long-term impact of COVID-19. It is, however, evident that it has exposed deep inequalities, the stark differences in life expectancy, following the publication of deaths involving COVID-19 by the local area and socioeconomic deprivation.[271] Verena Raleigh, commenting:

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[268] Chris Jones, 'Planning for the future, meeting the needs of our ageing population', (Office of the Public Guardian 17 January 2017) < https://publicguardian.blog.gov.uk/2017/01/17/planning-for-the-future-meeting-the-needs-of-our-ageing-population/ > accessed 28 August 2020.

[269] See, <https://publicguardian.blog.gov.uk/2017/01/17/planning-for-the-future-meeting-the-needs-of-our-ageing-population/> accessed 28 August 2020.

[270] Doctors of the World, <www.doctorsoftheworld.org.uk/coronavirus-information/#> accessed 18 April 2020.

[271] Office for National Statistics Report, *Deaths involving COVID-19 by local area and socioeconomic deprivation: Deaths occurring between 1 March 2020 and 31 May 2020*. <www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/de

> Covid-19 continues to follow the fault lines of inequality, with people in the poorest neighbourhoods more than twice as likely to be killed by the virus as those in the richest areas. Preventable conditions, including cardiovascular disease and type 2 diabetes, are major risk factors for dying from Covid-19, and these disproportionately affect people living in disadvantaged areas and from ethnic minority backgrounds. The virus has underlined the deep inequalities and stark differences in life expectancy that exist between different population groups and areas of the country. [272]

Although this study has started to analyse the pandemic, it remains for future academics, commentators, and researchers to continue the critical dialogue and examine the extent of the impact of COVID-19 both in the UK and following the mapping and analysis of different countries' data through the COVID-19 Health System Response Monitor. [273]

Regarding this study and the next phase, recommendation 2 from this study is that future research into lived experiences should target diverse, multicultural perspectives.

Recommendations

1. The survey responses did not yield any data from young carers or young people aged between sixteen and twenty-one with care and support needs. This other area of research is recommended as part of a longitudinal study programme.

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athsinvolvingcovid19bylocalareasanddeprivation/deathsoccurringbetween1marchand31may2020 > accessed 12 June 2020.

[272] Verena Raleigh, Kings Fund Press Release (12 June 2020) <www.kingsfund.org.uk/press/press-releases/covid-19-stark-differences-life-expectancy> accessed 28 August 2020.

[273] World Health Organisation – Europe, *Health System Response Monitor: New tool to analyse COVID-19 response measures across European countries launched* (2 April 2020) <www.euro.who.int/en/media-centre/sections/press-releases/2020/health-system-response-monitor-new-tool-to-analyse-covid-19-response-measures-across-european-countries-launched>accessed 18 April 2020.

2. Future research into lived experiences should target diverse multicultural perspectives.
3. A critique of the impact on individuals with care and support needs and their families following the temporary lift of statutory duties to undertake and maintain assessments during the COVID-19 pandemic should be carried out.

Finally, **Document 6** provides further reflection in the course of this professional doctorate research and changes made to the research design. Nevertheless, inherent in my daily work, exchanges of knowledge opportunities occur naturally through informal and formal conversations, meetings and virtual training opportunities with national, regional and local multi-agency partnerships, and as appropriate, legal services. Strategically, "*cultivating communities of practice*" is, therefore, "*a practical way to manage knowledge as an asset*,"[274] and to facilitate more in-depth knowledge and expertise in the care and support sector on an on-going basis.

Research is for all who are working in health and social care as it drives improvements. In some sectors, such as the medical workforce, research is well established and part of the job plan. For nurses however, and as my research journey has evidenced, the research community is not easy to navigate, nor is it embedded in the majority of nurses' job plans. Research is therefore often undertaken in one's own time. Nevertheless, my study and learning remain ongoing and I am committed to influence and advocate for nurse-led research within wider areas of nursing, including public health nursing and safeguarding communities.

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[274] Etienne Wenger, Richard McDermont and William M Snyder, *A Guide to Managing Knowledge, Cultivating Communities of Practice* (Harvard Business Review Press 2002) 6.

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Appendix 1: Email brief

If you are over 16 years of age, whether or not you're in your twenties, middle years or older, I am seeking views from a range of people.

My name is Rosemary (Rosie) Luce and I am currently undertaking a legal practice research doctorate at Nottingham Trent University. My research is seeking views from the general public, people with care and support needs and family/ friend carers. I am seeking to find out the extent and impact that policy and legislative changes have made to your lives.

Have your say

- On what you know about how to make long term plans to cover you when you are not able to make specific decisions about yourself. For the Sixteen Plus Quick Public Survey, click here
- For the Survey for people aged Sixteen **Plus**: People with care and support needs, click here
- For the Survey for people who help others – family and friend carers, click here.

The surveys close on **31^{st} July 2017**.

Will the study help me? Possibly, especially if the information contained within the surveys, is new information. However, the information you give us might help improve provision of services and the experiences for others. The information may help to shape new ways of working and/or providing services within our area.

For charities, communities, carers, faith-based organisations and other networks, I've put a newsletter brief together and the attachment can be located via https://rluceresearcher.com/about-the-research .It's at the bottom of the webpage. Please amend to reflect your organisation's needs.

For more information. Please see http://rluceresearcher.com/

Any queries, please contact rosemary.luce2014@my.ntu.ac.uk or

Thank you in anticipation,

Rosie Luce

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Word count 35,396 including textboxes, footnotes, end notes.