ECO-SYSTEMIC FACTORS THAT STRENGTHEN THE EDUCATIONAL INCLUSION OF YOUNG CARERS WITH ADDITIONAL NEEDS

by

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ABSTRACT

The Children and Families Act 2014 defines a young carer as anyone under the age of 18 years old who provides, or intends to provide, care for another person of any age. The literature has empirically and anecdotally identified that young carers are a population more vulnerable to poorer outcomes in educational attainment, employment opportunities, and psychological wellbeing. (Becker and Becker, 2008; Warren, 2007; Lloyd, 2010).

This thesis is an account of real-world research drawing on qualitative research methods such as semi-structured interviews to gather the views and perspectives of young carers; young carer project workers; and safeguarding and student welfare officers to identify the systemic factors (Bronfenbrenner, 1979; 2001) that strengthen the educational inclusion of young carers with additional needs.

Findings suggest the important factors at different systemic levels around the carer, such as the role of the key person within the educational setting, the role of external support and social support in strengthening a young carers inclusion in their educational setting. The implications arising from the findings are also discussed, in relation to the role of local authority services and, specifically the role of the educational psychologist.

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CHAPTER 1: INTRODUCTION

1.1 Introduction

1.1.1. The National Context

The Children and Families Act 2014 defines a young carer as anyone under the age of 18 years old who provides, or intends to provide, care for another person of any age. The individual in receipt of care may be a family member, such as a parent or sibling; however, this is no longer an exclusive criteria in order to be classified as a young carer. This legal definition comprises a broad range of care including both practical and emotional support, and a broad range of care needs encompassing physical disability, psychological disorder and substance dependency (Care Act, 2014).

The inclusion of a question regarding the amount of care, unpaid for, provided by a family member in the 2001 and 2011 Census of England and Wales has identified the extent to which care is provided by children and young people (See Appendix 1 for 2011 Census Question on Unpaid Care). The definition of young carer used in this census for a 'young carer' includes children and young people under 18-years-old (aged 5 to 17), who provided unpaid care for any person with physical or mental difficulty or disability.

In 2011, there were 177,918 young unpaid carers (5 to 17-years-old) identified in England and Wales with the bulk of young carers donating between 1 and 19 hours of unpaid care per week (ONS, 2011). Between the 2001 and 2011 Census, the number of young unpaid carers rose by approximately 19%, in England and Wales combined (ONS, 2001; 2011).

Using different criteria for defining young carers, Scotland's 2011 Census identified approximately 10,000 young carers aged under 16 providing care for up to 20 hours a week (SHeS, 2013)

The literature has empirically and anecdotally identified that young carers are a population more vulnerable to poorer outcomes in educational attainment,

employment opportunities, and psychological wellbeing (Becker and Becker, 2008; Warren, 2007; Lloyd, 2013). The complex adversities and challenges faced by young carers puts them at greater risk of poorer life outcomes in both the short- and longer-term (Becker and Becker, 2008; Dearden and Becker; 2004; 1995;). These findings are also supported by the 2011 UK Census (ONS, 2011) which showed that, contrasted with young people not providing care, the number of people who responded with 'Not Good' in response to a question on their general health was greater among those engaged in caregiving. This number increased as larger magnitudes of unpaid care were provided.

   In light of the above findings, as lead researcher, I felt this to be a relevant and important area of study and an appropriate area for further research. My own professional experience as Trainee Educational Psychologist in a Local Authority Educational Psychology Service, coming into contact and supporting children who were also young carers has also served to anecdotally validate these findings that this is a population of children and young people, under-represented in research, policy and practice. As such, I felt that this was an area of research that could bring awareness and support to a vulnerable population.

1.1.2. The growth of interest in young carers

Aldridge and Becker (1993a) consider the Department of Health-funded project, developed by the Carers National Association, to be the initial spark that has since ignited a significant growth in awareness and attention around the issue of young carers, both publically and within professional or academic circles.

The growing interest in young carers has identified the vulnerabilities that young carers face in regard to education, employment and mental health (Becker and Becker, 2008; Warren, 2007; Lloyd, 2013), and as such as has given the issue of young carers as an "at-risk" group a prominent standing on the societal agenda.

Recent evidence demonstrating this growing awareness of young carers is reflected in new legislation such as the Care Act 2014 and the Children and Families Act 2014, which introduce a broad definition of the term young carer, in acknowledgement of a large body of research (Becker and Becker, 2008; Dearden and Becker, 2004; 1995;)

that recognizes that young caring can encompass a wide range of activities. Also, the last twenty years has seen a growth in the number of young carer services and organisations supporting young carers (Spurgeons, Barnardo's, The Children's Society, The Princess Royal Trust for Carers) in response to the growing understanding of the impact that caregiving can have on young lives.

Roche and Tucker (2003) argue that the response to the issue around young carers reflect broader, ongoing concerns and debates about "social exclusion" in the UK. In recognition of the long-term impact of caring, Dearden and Becker (2005: p254) argue that the social exclusion that young carers often face can "cast a long shadow forward and exacerbate young carers vulnerability throughout the life cycle".

Consequently, research also indicates young carers are more at risk of being looked after by the state. According to The Department for Children, Schools and Families (2009) there were approximately 5% of young carers entering state care because of parental illness or disability in 2008. Dearden and Becker (2005) also identify this as the third most common reason for a child entering care in England. Barry (2010) states that the family background of carers often reflect additional disadvantages, such as single-parent households where there is no alternatives, such as to 'buy-in' care.

The complexity of the phenomenon of young caring, and the growing understanding that the difficulties endured by carers is in no way an easily solvable problem, has left young caring as a policy concern for the last two decades (Children's Commissioner, 2016). Thus, the overall aim of this research is to identify factors that make a positive difference for young carers outcomes, particularly in the domains of education and mental health. Recognising the complexity of the young carer phenomenon also means recognising the complexity of effective support, and understanding that positive outcomes are only achievable through considering how different positive factors interact and affect carers and their families. This has led to this research project adopting an eco-systemic framework to observe and understand these interactions and their effects

1.1.3. The Context of the Social Exclusion of Young Carers

Roche and Tucker (2003) have argued that the increase in interest in young carers

must be understood within the context of the changes within academic and political debate around social exclusion.

Current UK policy that has developed to tackle social exclusion include the Troubled Families Programme launched by the UK government in 2011 with the aim to turn around the lives of 120,000 troubled families in England (DCLG, 2014).

The definition of 'troubled families' for the programme was based on households who meet the following criteria: 1.) are involved in crime and anti-social behaviour 2.) have children not attending school 3.) have an unemployed parent 4.) cause high costs to the public purse (DLCG, 2014). In this context, young carers would appear to be eligible for intervention under the criteria of a "troubled family", as findings from research continue to indicate the impact young caregiving can have on education, including attendance and exclusion, and the impact of disability or illness on the employment of the parents in a family (Becker and Becker, 2008; Warren, 2007; Lloyd, 2010).

These criteria were based on earlier analyses of findings from the Families and Children Study (See DCLG 2012a). This study found that many families in England were assessed as meeting several "risk criteria" including: no parent in the family in employment; parent identified as having a diagnosable mental illness and at least one parent suffering a physical illness or disability. As can be seen, these criteria are also likely to feature in the lives and experiences of young carers.

Roche and Tucker (2003) argue the social exclusion agenda needs to be framed within the pan-European emerging rights agenda that is influencing policy across European governments. Due to this agenda being predominantly focused on the experiences of groups of individuals inhabiting perceptible areas in the public realm, this agenda fails to address the difficulties faced by those who experience social exclusion due to their needs being located in the private realm of personal relationships, such as those engendered by personal family conditions in relation to young caring:

 "those with political power tend to shy away from becoming embroiled in what is still seen as essentially the private domain of family life"(Roche and Tucker, 2003; p441)

The needs and support for young carers will fail to be addressed by a social exclusion agenda that does not consider the private domain a matter for its concern. Although many carers experience supportive and nurturing family environments, their experiences are different enough to isolate and exclude them from many sections of social life; however, the systems socially excluding carers are likely to be situated away from public consideration (Rocher and Tucker, 2003).

Reflecting on the troubled families agenda within this context, some young carers may meet the criteria for support under the Troubled Families Agenda; however, the private sphere of children supporting parents with physical or psychological needs remains a space where policy has not translated into practice. A recent evaluation of the Troubled Families Programme (DCLG, 2016) indicates that local authorities only applied 3% of the discretionary payment-by-results (PbR) criteria to work with young carers. This was the smallest application of the local discretionary PbR to all the acute issues not identified by the core criteria. As such, young carers still remain very much a "hidden" population, not only due to the carers' perception of the stigmatising behaviours of others, but due to the failure of policy and practice to engage in the private spheres of families who do not necessarily meet the thresholds of "risk" constructed in policy and discourse. As Roche and Tucker (2003) describe:

"The forms of intervention and support vary but the practice is clear and can be expressed thus – as long as you are 'good parents' your privacy will be undisturbed. The 'successful' family is self-governing."(p442)

The young carer agenda, within the context of the Troubled Families Agenda, also highlights the broader ethical concerns around the issue of young caring (see section 2.3.3.), namely whether public resources should be divested towards support services for young carers themselves or support services for the families of carers.

1.1.4. Young carers with additional needs

Frank and McClarnon (2008) have identified that Young Carers are not a homogenous group, and there are in fact distinct subgroups of carers that are more vulnerable to poorer outcomes such as black and ethnic minority carers, parents

dependent on substances, parents with mental illness, and very young carers. Frank and McClarnon (2008) argue these groups require special consideration as they are rendered twice vulnerable, through their caring role and additional circumstances.

However, there has been no research investigating the experience of young carers with additional educational needs. Whilst there is no specific definition of a "*young carer with additional educational needs", this study has defined this subgroup, as "a child under 18 years old caring for another person (Children and Families Act 2014, Section 17a (3)) who also experiences a specific learning difficulty or mental health need, but whom does not receive additional support through an Education, Health and Care Plan*".

Whilst a label of special educational needs may grant access to further resources and support through an Education, Health and Care Plan (EHCPs), many children with additional support needs do not meet the threshold for EHCPs.

It is this researcher's view that children engaging in a caring role who also have a learning difficulty or a diagnosable mental health condition, but who do not meet the threshold for an EHCP, are possibly twice-vulnerable and may be at greater risk in terms of educational attainment, psychological disorder, and poorer overall life outcomes. Recent evaluation of the support for young carers by the Children's Commissioner for England (2016) also confirms that close to a quarter of young carers in England have an additional need (learning or mental health need), and this both compounds difficulties in accessing education and increases the risk of poorer long-term outcomes in education, health and employment.

1.2 Focus of research and timeline of research inquiry

1.2.1. Context of Research as a Trainee Educational Psychologist

As a trainee educational psychologist (TEP) on placement within a local authority educational psychology service, and a full-time doctoral research student, attending the University of Birmingham, it was deemed appropriate to conduct research that both filled a gap in the current academic and professional literature, and contributed to the current interests of the educational psychology service in terms of supporting

the vulnerable children and families that local educational psychologists are working with.

The Principal Educational Psychologist of the local authority educational psychology service, in which I am placed as a trainee, had identified that a key service priority was to support the current local authority needs regarding Troubled Families. To that end, the focus of the research was negotiated between the Service and myself to identify particular areas of research within the Troubled Families agenda, and the particular local authority needs that would support children and families who do, or could meet, the criteria for Troubled Families Support.

This direction for research intersected with my own professional experiences as a local authority TEP working directly with children with complex needs, who were also identified as young carers. Through discussions with themselves and other professionals (Strengthening Families Workers, Social Workers, key staff at schools), I anecdotally established that these children and families were in greater need of support; however, local authority response appeared inadequate to meet this need in the view of professionals and young people I had engaged through my work as a Trainee Educational Psychologist.

Reflecting upon these professional encounters, I believed this to be a focus of research that could benefit this vulnerable group, support the local authority in their response to this group, and meet the criteria proposed by the Principal Educational Psychologist.

1.2.2. Focus of Research Questions

This research was prompted by initial questions regarding how a local authority responded to the needs of young carers, and in particular young carers with additional educational needs. This led to further questions focused on what effective support systems exist and how could systems be developed to better support young carers.

The scoping literature search, conducted early on in the development of the research project, led to the production of a list of questions to focus the direction of the research.

Figure 1.1. Questions to narrow the direction of the research

- How do professionals, communities, legislation and young people themselves, define and understand the concept of a 'young carer'?

- What is the impact of the caregiving on young carers' education and mental health outcomes?

- What different challenges do young carers face if they also have additional educational needs?

- How do schools and communities respond to the children who are young carers?

- Does this response differ for young carers if they have an additional educational need?

- What is effective in supporting young carers with additional educational needs?

1.2.3. Research Design

This research study is exploratory in design by seeking to generate *a posteriori* hypotheses by examining a dataset and looking for potential relations between variables. In keeping with the constructivist and phenomenological epistemological position that this study has adopted, rather than making empirically-derived generalisations, the objective is to understand the respondent's point of view and, as such, has employed qualitative methods such as semi-structured interviews.

This study constituted three sample groups: 1) Young Carers 2.) Project workers from the local Young Carers Project (Spurgeons) 3.) Student welfare officers employed at schools in the Local Authority. After ruling out other methodological options such as Interpretative Phemenological Analysis (see Section 3.2.3.) this study utilized the Braun and Clarke (2006) framework for thematic analysis: a systematic method for the identification and analysis of themes in emerging from the data.

This study recognises that the educational inclusion of young carers with additional needs develops within the context of the interaction of systemic processes. As such, in order to theorise themes emerging from the data within a systemic perspective on young carers and their educational inclusion, the initial inductive thematic analysis was supplemented with a process of deductive analysis based on Bronfenbrenner's (1979; 2001) bio-ecological systems framework. This dual approach to analysis develops the analysis further by allowing for new theories to emerge, yet also aligns findings with a well explicated theoretical model, which may potentially strengthen claims for theoretical generalisation.

1.2.4. Timeline of project development

The planning phase of the project began in September 2015, as I began my placement as a local authority trainee educational psychologist. Between September 2015 and January 2016, I conducted the initial scoping literature search, to identify gaps for research, and negotiation with supervisors and local authority educational psychology service regarding the focus of the research.

I began planning and designing the approach to the research topic between January 2016 and April 2016, developing research questions, design and methodology, materials and ethical considerations. This ultimately culminated in a successful application for ethical review to the University of Birmingham's research ethics panel. Between May 2016 and September 2016, I began contacting key staff and organizations such as Spurgeons and local schools in order to access sample populations relevant to the study. Formal data collection began in October 2016 with interviews and ended in Feburary 2017. Between March 2017 and July 2017, I began analysis of the data and formal writing up of the research.

1.3. Structure of Thesis

Chapter One, (i.e. this chapter) describes the national context for young carers, and how this emerged from the researchers context as a trainee educational psychologist.

An overview of the research process, research questions and methodology is provided.

Chapter Two provides a review of the literature around the issue of young caring and its impact. The literature draws on theoretical models, such as ecosystemic theory to contextualise the concept of young caring and introduce the theoretical lens through which this project perceives the topic of young carers.

Chapter Three describes the development of the methodology from its epistemological origins to research design and planning. Consideration is given to ethical implications and integrity.

Chapter Four summarises the key findings from the data gathered, organised into the emergent themes revealed in the data.

Chapter Five organises the findings from the data into superordinate constructs representing the different systemic levels (Bronfenbrenner, 1979; 2001) to identify how different factors may interrelate at different levels to produce "flourishing" factors.

Chapter 6 summarises the key findings and reflects upon how these findings could be developed to support policy and practice around young carers with additional needs within the local authority. This chapter also considers the limitations of this study, directions for future research and the overall value of the study in developing understanding of this vulnerable group of children. I also reflect on the personal experience of conducting this research, and how it has affected my own personal and professional development.

<u>**CHAPTER TWO: LITERATURE REVIEW**</u>

2.1 Introduction

In order to establish how previous research has fashioned the direction of the current study, this chapter offers a review of the current literature relating to research around the issue of the educational inclusion of young carers with additional needs.

The focus of this review is to reflect on the current literature to provide direction regarding what is currently known about young carers and their engagement with education, support services and the wider community in order to shape the rationale for the present research and inform the pertinent research questions.

This literature review aims to:

- Synthesise and integrate the key concepts and debates in the literature in order to identify and summarise areas of discussion that will shape the focus of the study;
- Assess the current methodological and theoretical value and limitations of the current research to identify gaps or inconsistencies that will narrow the focus of the current study;
- Building the current literature to develop a key research questions that will contribute to existing knowledge.

This literature review is separated by distinct sections:

- *Section 2.2.1; 2.2.2; 2.2.3:* An overview of the method employed in the literature search, including lists of databases, search criteria and inclusion criteria; A review of the different types of research identified within the literature, including discussion around the methodological subtypes, epistemological orientations, theoretical focus, and limitations and gaps within the current literature;
- *Section 2.3.1; 2.3.2; 2.3.3:* A review of the literature pertaining to how young carers are defined and the conceptual and ethical debates regarding the concept of young caregiving;

- *Section 2.4.1; 2.4.2:* A review of research relating to what is understood regarding the impact of caregiving, specifically, consequences for mental health, social relationships, educational attainment, and life outcomes. This section also explores literature relating to the research that has identified the positive impact of caregiving, for young carers;
- *Section 2.5.1*: A summary of the ecological context of risk and resiliency and how this relates to understanding important strengthening factors to supporting young carers' educational inclusion;
- *Section 2.5.2; 2.5.3; 2.5.4; 2.5.5:* A review of the identified factors that contribute to positive wellbeing for young carers and greater educational participation;
- *Section 2.6.3:* The development of key research questions that this current study hopes to answer

2.2 The process of the Literature Search

2.2.1 The Search Strategy

The literature around young carers that has developed in the last thirty years is both wide and varied (Dearden and Becker, 2001; Newman, 2002; Cree, 2003; Warren 2007). The issue of young caregiving has crossed many different disciplines such as sociology, social policy, psychology, education, nursing, development, and medicine (Gilligan, 2000; Earley et al, 2007; Grant, 2008; Gray 2008;). Beyond the academic literature, new documentation and guidance continues to be published online through such sources as local and national authorities, support services and charities (DoH, 1999; 2008a; DfEE; 1999; Childrens Commissioner, 2016).

In order to ensure a literature review that is both comprehensive, replicable and comprehensible, a systematic approach to the literature search was planned and implemented. The literature search included electronic databases and Internet searches.

Figure 2.1 The electronic databases searched, and the words and phrases employed in the search

Electronic Databases	Key Phrases
Psychinfo	Young Carers
Ebscohost	Young Carers AND Parents
Current education research in UK	Young Carers AND Mental Health
	Young Carers AND School
	Young Carers AND Education
	Young Carers AND Educational Psychology
	Young Carers AND additional needs
	Young Carers AND special needs

A search across civil and third sector institutions supporting children or young carers was also conducted, such as The Children's Society, The Princess Royal Trust for Carers; Department for Education; the Department for Children, Schools and Families and the Department of Health.

Additionally, during the reviewing of the literature, I engaged in reference-checking (as described by Arksey et al., 2002), in which the reference list for articles and documents were checked for information that emerged as pertinent to the focus of the current research.

The strategies employed in the literature search produced a large quantity of articles and documents, so I developed specific inclusion criteria to focus the literature review such as only considering sources from 2007, however, some pertinent publications have been discussed that were published before 2007. These articles, pre-2007, are generally articles considered seminal in the field of young carer research and have been widely cited by authors and researchers. Figure 2.2. identifies the key inclusion criteria for the literature search. As the focus of the study is around the issue of young carers and education, primary consideration for inclusion were key words and phrases in the title and abstract that reflected these issues.

Figure 2.2. Key inclusion criteria to concentrate the literature review

- Definitions of young carers

- Issues around methodologies developed to research young carers

- The impact of being a young carer on education

- Impact of caregiving on mental health and social relationships

- Systemic and structural issues around support for young caregivers

- Protective factors for young caregivers

2.2.2. Sources of literature

The literature review reveals that the topic of young caregiving transgresses the academic disciplines of education, psychology, healthcare, social care and sociopolitical policy development. The subject of young caregiving also crosses the divide between academic and professional/practitioner journals and publications e.g. Journal of Youth Studies, British Journal of Guidance and Counselling, Psychology and Health, Health and Social Care in the Community, Educational Psychology in Practice and Issues in Mental Health Nursing are just a small sample of the range of publications in this literature review that feature topics around young carers.

In addition, the review also revealed a number of articles and publications through public news and media forums, such as the BBC, The Times, The Independent newspapers and Times Educational Supplement. These were pertinent to the literature search because they indicated the level and type of discourse prevalent in the public sphere regarding young carers, and the kind of information about young carers that the public and other professionals were more likely to be exposed to. This served as a useful counterpoint to examine the academic discourse around young carers.

2.2.3. Types of research

The literature on young carers does demonstrate that a broad variety of methodological approaches have been engaged to explore the issue of young caregiving ranging from survey/questionnaire methods (Devine and Lloyd, 2008; Warren, 2007) to individual interview methods (Andreoli, 2008). Indeed, the

literature review of the current study reflects a broad balance between the use of quantitative and qualitative data.

Much of the survey data has generally been concerned with the type of caregiving duties that carers have been performing, and the amount of time spent on caregiving duties. Initial research focused on attempting to discriminate the caring activities of young carers from the caring activities of that of a young person in a household with healthy family members. The time spent caring and the types of task undertaken by over 6000 young carers has been revealed through national surveys of young carers, most notably by Dearden and Becker (2004) which is often considered a baseline in young carer research. Similarly, Becker and Becker (2008) also carried out large-scale random surveys using 2001 Census data. However, limitations of this kind of survey data include the accuracy and reliability of this type of research. Lloyd (2012) questions the reliability and accuracy of large-scale survey data in relation to young carers; that is, do survey responses genuinely reflect the carer's voice (particularly young children), or an adult answering on their behalf?

Some authors have questioned whether the use of survey data skews the perception developed around young caregiving and argue that researchers are more preoccupied with locating examples of risk and difficulty as opposed to looking for examples of young carers' strengths and their successful adaptation to their caring role (Olsen and Wates, 2003). Researchers have also raised the difficulties that, in defining a "young carer", this may lead to the exclusion of unknown or hidden carers.

The literature identifies that there are benefits to the survey studies, such as those of Dearden and Becker (1995, 2001 and 2004), by virtue of the fact that they produce a sizeable volume of information and offer a broad picture of the scope of the role of young carers. However, this observation also presents limitations. Joseph et al. (2008) highlights an important gap in the literature: that there is very little data pertaining to the experiences and outcomes of the wider population of young carers (e.g. "hidden" carers and carers not accessing support services), as nearly all young carer research has drawn upon a sample of carers known to young carer projects. As such, this may skew and narrow our understanding of the young carer experience, in relation to the wider context of the unknown numbers of "hidden" carers within the population. Simply because of the support received through carer projects, Joseph et al. (2008)

speculates that it may be that young carer samples drawn from projects could be more resilient than the general population of young carers. In this context, current findings may potentially be overestimating positive outcomes and underestimating negative outcomes in the broader population of young carers. The author highlights the need for normative data on non-carers and potentially "hidden" carers, in order to ascertain how these children's development differs from children who are identified as young carers.

Some researchers have argued that the survey approach often employed to investigate the lives of young carers is limited in its ability to access accounts regarding the "lived experience" of young carers (Cree, 2003; Roberts et al., 2008). As such, within the literature there are also examples of research with young carers themselves through group discussions and individual interviews, and much of this research has investigated the personal impact of young caregiving on the young person themselves (Earley et al., 2007; Kavanuagh, 2015; Barry, 2010).

Further reflecting the range of research types in the young carer literature, within the current literature there are also some examples of alternative methodologies and novel approaches to investigating young carers, such as Ali et al (2013), who used a mixed methods design (interviews and self-reported questionnaires) to explore how young carers experience and access support services. Whilst using conventional qualitative methods of interview, Odell et al. (2010) and Gray et al. (2008) investigate the perception and construction of young carers from a novel perspective. Rather than focusing on young carers' perceptions, the researchers instead reorient much of the young carer research by looking at how non-caring children (Odell et al., 2010) and other professionals (Gray et al., 2008) perceive and construct the identities and activities of young carers. The authors reflect on how this may affect the discourse around young carers, and how this in turn, may impact on young carers' constructions of their own identities.

2.3. The Concept of Young Caregiving

2.3.1. Definitions of Young Carer's

The difficulty in defining young carers is a common thread across the literature. The Children and Families Act 2014 offers the following legal definition:

'...a person under 18 who provides or intends to provide care for another person (of any age, except where that care is provided for payment, pursuant to a contract or as voluntary work).' (Children and Families Act, 2014; Section 96)

This is an important piece of legislation as the concept of care has been extended to include practical and emotional support that young carers provide for the care recipient. In recognition of the research that has identified the wide range of caring provision that young carers provide, this act allows more children to qualify as young carers than previous legislation. Related to the Care Act 2014, the Children and Families Act 2014 recognises the rights of the young carer to a Young Carers Needs Assessment and puts the impetus on local authorities to proactively identify young carers and their support needs. According to the Children and Families Act (2014) a local authority must conduct an assessment if it appears to the authority that the young carer may have needs for support (Children and Families Act; Section 96:1A) and:

" a young carers assessment must include an assessment of whether it is appropriate for the young person to continue to provide care for the person in question, in light of the young carers needs for support, other needs and wishes" (Children and Families Act; Section 96)

The new legal definition has reduced in its specification, from the previous Carers (Recognition and Services Act) 1995, in acknowledgement that: "*The rights afforded to young carers 'will be extended to all young carers under the age of 18 regardless of who they care for, what type of care they provide or how often they provide it.*' – (The Care Act and Whole Family Approaches, 2015; p4).

Changes in legislation and definition may reflect the growing understanding that definitions of child caregiving have broadened to reflect the adverse effects of caring (e.g. psychological and emotional wellbeing, educational impact), rather than just the level of care (Dearden and Becker, 2001). Cree (2003) argues that there is no absolute definition of a young carer, and organizations may vary in the definition they adopt, and cites the Edinburgh Young Carers Project definition of a young carer as: *"a*

young person aged 5–25 whose life is affected by the illness or disability of someone in his or her family" (Cree, 2003; p301). This definition is much broader in age than the Children and Families Act definition of a "person under the age of 18", but also much narrower in that it cites the care recipient must be a family member. Rose and Cohen (2010) argue the specific agendas of particular institutions are likely to influence how young carers are defined through that institution.

Warren (2007) asks whether young carers are doing caring duties that would be expected of children in most households. Whilst some degree of caring would be expected of similar aged child within a healthy family, the author argues that young caring is distinct from non-carers' caring activities as they are engaging in care activities considered uncommon by societies standards, particularly in relation to the child's chronological age, physical development and emotional maturity. Aldridge (2008) argue that the evidence demonstrates that young carers often have no choice but to engage in the caring tasks that are required, and because of this the caring activities of young carers can be objectively measured as dissimilar from children who are not carers.

Whilst broad legal definitions of young carers exist to allow greater numbers of young people access to assessment and support, the definition of young carers is still conceptually developing, as our understanding of the caring activities and its impact on young carers continues to grow. Understanding and reflecting on the legal and conceptual definitions of young carers is necessary for the current research in order to provide a reference point for how the young carers and other professionals participating in the current study perceive themselves relative to how the law and academic discourse understand them.

2.3.2. What do we know about what Young Carers do?

Becker (2000) has argued that the young carers experience is qualitatively distinct from that of children in other households, as their ability to exercise choice in engaging in caring duties at home is severely impaired. Becker (2000) also argues it is the range and intensity of intimate care activities that also distinguishes young carers from caring duties expected of young people in other households, such as bathing, toileting, emotional support and the provision of medical care (such as administering

medication). Frank (2002) argues for a "continuum of care" whereby all children can expect to fall on this continuum, carrying out some caring duties. However, Frank (2002) suggests we must differentiate between what the author terms "conventional" and "exaggerated" levels of care.

Warren (2007) also investigated how young carers roles differed from children in the general population. Three hundred and ninety participants were interviewed and Warren (2007) identifies distinct differences in the nature, frequency and time spent on domestic and caring tasks, between young carers and other children and young people in the general population. For instance, young carers were found to take greater responsibility for a greater range of domestic and caring tasks, compared to children in the general population, sometimes exceeding 26 hours per week. Some of these tasks range from arranging financial matters, to cleaning and cooking. Similarly, figures that the majority of the sample of 6000 young carers were engaging in care for more than ten hours a week have been much cited from the report by Dearden and Becker (2004).

Uniquely, Warren's (2007) study also demonstrates the high emotional support that young carers provide, above that expected of young people in the general population. In this context, emotional support identified by carers includes keeping someone company, keeping an eye on someone and accompanying someone outside the home. Warren (2007) also identifies the unique impact of young caregiving on educational experiences, the data indicating that due to factors related to their caring responsibilities, young carers are more likely to experience bullying, and also reduced participation in social and leisure activities.

2.3.3 Current issues around the concept of young carers

The findings of Warren (2007) and Dearden and Becker (2004) presented above, as well as the findings regarding the distinct impact of young caregiving (Cree, 2003) are important findings as some authors have questioned whether young carers are engaging in duties and responsibilities beyond what society would normally expect for a child or young person (Olsen, 1996).

The question of what young carers do is situated within the wider context of the debate regarding adult disability *vs.* child rights. That is, some authors such as Newman (2002) and Joseph (2008) have warned that of a conflict of rights within the discourse around young carers between those who advocate for the rights of disabled adults and those who advocate for the rights of children. The perception of disabled people often provides the fuel for debates regarding whether resources for support services should be directed to services for young carers to continue to allow carers to fulfill their caring duties; or, support for adult disability services to support parents in sustaining their parenting role (Banks, 2002; Dearden and Becker, 2001).

Newman (2002) identifies a number of moral concerns relevant to the literature on carers rights *vs.* adult disability rights. Newman (2002) suggests that one of the unintended consequences of the work of young carer services has been the disempowerment and pathologisation of disabled adults, by having the perception raised that their impairments are seriously affecting the welfare of their child. The author argues that child welfare services are preoccupied with identifying and removing "risk factors", but rarely are investigations undertaken to identify positive outcomes for children. Studies that explore and locate the benefits in caring are few (Newman, 2002), but some research has gathered information on the positive experiences of caregiving (Gates and Lackey, 1998). However, I would still argue, based on this assessment of the young carer literature that the central and predominant discourse is still concentrated around a discourse that perceives young caring to be disadvantageous to the development of a child or young person.

Newman (2002) also argues that the preoccupation with children's rights could divert attention and resources to the overall needs of the family. The author argues that appealing to human rights to justify the introduction of young carer services implies that the disabled parent is the "prime suspect" in the breach of carers' rights in the first place. Newman (2002) warns of a "collision" between those who advocate for the rights of young carers and the rapidly expanding movement advocating for the rights of disabled adults to have equal access to services and resources:

"Using an ideology based on the rights of children to propel the expansion of young carer services may have, in retrospect, proven to be a mistaken strategy…. they live in families, social entities that are not easily deconstructed by the individualistic thrust

of human rights discourse (Purdy, 1994; Roche, 1995). The function of human rights legislation is to mediate between the individual and the state, and ensure that the latter is both constrained and compelled to behave in certain ways towards its citizens. Negotiating roles within families on the basis of an appeal to a judicial concept of 'rights' makes little sense to anyone who actually lives in one."(Newman, 2002; p619).

Whilst the literature appears not to have identified the emergence of such a "collision" as described by Newman (2002), I would argue that recent changes in policy regarding funding and resourcing of local authority services, as well as broader initiatives such as the Troubled Families Agenda, have had ramifications for all services, and the issue of where even further reduced resources should be invested still remains.

Newman (2002) also suggests the research regarding the long-term impact for young carers is inconclusive and exaggerated. The author argues the causal relationships between caregiving and long-term impact (educational, social, and psychological) are affected by a number of other extraneous variables not controlled for, such as socio-economic factors and parental mental health factors. The author also argues that by emphasising risk and vulnerability, researchers and practitioners "weaken" the carers' capacity for resilience. Whilst I would support Newman's assertion regarding the lack of research identifying positive outcomes and experiences of young caring (though this is a growing body of research), I would argue that more recent and controlled studies have continued to identify long-term negative consequences for young carers (Kavanuagh, 2014; Lloyd, 2012; Barry, 2010).

O'Dell's (2010) study interviewed 46 young people (non-carers) to investigate their perceptions of young carers. A key theme emerging was the construction of a "normative" childhood, the transgression of prescribed family roles were perceived as "abnormal", and through this lens the dominant construction of the experiences of young carers was one of loss and disability.

O'Dell (2010) also argues that constructions of young carers within the literature and discourse create a rhetoric in which to negatively judge the activities of young carers. Drawing on social-cultural theories and critical developmental psychology, the author

argues that the experience of young carers is evaluated against a supposed "normal" childhood and, as such, there is a risk of ignoring young people's agency and depreciating the experience of disabled parents. The authors suggest that young carers are often characterised as their "parent's parent" and often situated in terms such as "parentified children", which has negative implications for how the disabled parent is being both implicitly and publicly constructed. O'Dell (2010) cites Olsen and Parker (1997) who argue that the disabled parent is seen as passive and part of the "problem" concerning their child: *the rhetoric of much, though not all, current "young carer" service provision involves some kind of substitution of, rather than support for, the parental role* (p127).

As highlighted in the literature above, the issue of who can be classed as a young carer and what they do, touches on broader debates and concerns around the arguments for a children's rights perspective or an adult disability perspective. This will have an ethical impact for whether resources and attention should be drawn to supporting young carers, or supporting adult services. This debate also informs and has implications for the current study. As this study investigates strengthening factors, including external social resources such as support services and carer projects, and it could be implied that this study is tacitly positioned from the perspective of child rights. However, by taking a systemic perspective the research also hopes to explore how services also engage parents and the impact of this for the young carers, and in doing so, indirectly capture the perspective of the disabled parent.

2.4. The Impact of Being a Young Carer

Young carers have reported a variable response to the activity of caregiving, with some describing the experience as "hard, yet gratifying" (Gates and Lackey, 1998; p13), a developing sense of appreciation for their caregiving, and positive feelings towards their care-recipient (Gates and Lackey, 1998). However, many carers also report numerous negative experiences including reduced educational attainment (Warren, 2007), poor peer relations (Earley, 2007), depression, anxiety and poorer self-concept (Thomas et al. 2003; Cree 2003; Aldridge 2006).

2.4.1. Impact on Psychological Well-being

Cree (2003) is an oft-cited study investigating the impact of young caring on carers' mental health. The author explores the problems and worries of sixty-one young carers through both questionnaires and follow-up interviews. Findings from Cree (2003) demonstrate that young carers had significant problems and worries. The author differentiated these problems and worries into: 1.) worries and problems typical of adolescent concerns (worries about body image, relationships, and money); 2.) worries about caring and the person being cared for, in addition to typical adolescent problems; 3.) major disruption and loss in their lives (including family violence, sexual abuse, and homelessness) in addition to typical adolescent problems; and their worries about caring and the person they cared for. Specific difficulties reported by young carers in this study include difficulties sleeping due to anxiety at night, self-harm and attempted suicide:

'It was just through pressure, I just didna feel comfortable in my inner self and was really upset and then I turned to, like, cutting myself and just being really, really, really bad . . .' (Cree, 2005; p305)

Another young carer also reported panic attacks and self-harming behaviour, in relation to punching herself: *"I get angry with myself for being me and having my parents and stuff" (Cree, 2005; p305).*

Cree (2003) also reports that specific problems and difficulties appear to be gender significant. Girls were more likely to disclose difficulties sleeping and eating, higher levels of truancy and worries about school than boys. Peer relationships, self-harming, bullying, and substance abuse also appear to be more significant concerns for girls.

Earley et al., (2007) draws on particular models of stress and coping (Lazarus and Folkman, 1984) to explore themes relating to the mechanisms of stressors in young caregiving. The authors identify four key stressors: feeling different, identity, responsibility and relationships. The young carers in this sample report being made to feel different, through the stigmatisation or trivialisation of their role or capabilities, as a significant stressor. The stigmatising actions of others were understood by respondents as reflecting of a lack of understanding and awareness relating to young carers and the stresses they may endure.

Another finding from Earley et al., (2007) was that these carers adapted to their caring duties by developing a self-concept that integrated their caring role as part of their identity. Carers ascribe a key contributor to the development of stress over their caring role as a result of becoming "immersed" into the role so far as to exclude opportunities for self-validation:

''You're involved all the time . . . to the point of excluding anything else''. (Earley et al., 2007; p75)

"It affects almost everything . . . you get engrossed in doing things and don't want (the caring) to go away." (Earley et al., 2007; p75)

"If you look into the future you might see yourself as old and on your own all the time caring for everyone else in the family so I don't look into the future that much, if you do you might risk scaring yourself more." (Earley et al., 2007; p75)

Other themes contributing to stress and anxiety identified by Earley et al., (2007) was the need for relentless vigilance in performing their caring responsibilities. Difficulty in "switching off" and anxiety about the care recipient's welfare when not with them were contributing stressors identified by carers:

"(at school) . . . you're probably thinking you're not sure if they can cope on their own." (Earley et al., 2007; p76)

Conflicting emotions of guilt and anger over their caring responsibilities were experiences by carers, contributing to further tensions with family and friends:

"You don't want to say your feelings toward one another because you both clash." (Earley et al., 2007; p76)

''If you say you hate your brother it's not like that because you love them whatever happens." (Earley et al., 2007; p76)

Kavanuagh et al., (2014) also used the same stress model to quantitatively isolate stressors to caregiving in forty young carers. The authors found that young carers' self-reported depressive symptoms were higher than the normative sample, and were correlated with caregiving role strains such as problems at school and parental

conflict. The author's findings indicate that stress, anxiety and poor school performance was related to simply having an ill parent; however, poorer psychological wellbeing was not correlated with the caregiving tasks themselves. This is an interesting finding in that research studies examining the impact of caregiving rarely distinguish between the impact of caregiving and the impact of having an ill family member, and thus the causal relationships between impact, disability and caring activity may not have been clearly determined.

Thomas et al., (2007) also report significant psychological and emotional impact for young carers related to the worry, responsibility and stress associated with caring for somebody else:

'I could go out and come back home and there'd be nobody in, and they could have ended up in hospital and I wouldn't have known about it.' (Thomas et al., 2007; p41)

'I worry about my parent dying and living on my own.' (Thomas et al., 2007; p41)

2.4.2. Impact on educational and social experiences

Educational attainment was identified as being detrimentally impacted upon by the caregiving activities of children (e.g. Becker 2007). Staff working with young carer projects in Becker and Becker's (2008) study made concerning observations that a number of young carers' education terminated at 16 years old with no educational qualifications. Similarly, the 2010 YLT survey (ARK 2010) showed that fewer carers attended grammar schools than their peers who had never been carers. Based on findings from these studies, one may infer that many young carers fail to close the educational gap with their peers who do not have caring responsibilities, and do not experience school positively.

Warren's (2007) frequently referenced study examined the lived experience of young caring through structured interviews with three hundred and ninety children. Key findings to emerge from the data, with regard to the effects of caring on educational experiences, demonstrate that due to caring commitments young carers are more likely to miss school than non-caring children. However, contrary to what one might

presuppose, a large majority of young carers do not actually demonstrate poor school attendance; but the research also indicates that young carers are more likely to experience bullying directly related to the nature of their caring role and peer knowledge of the parental disability, thus consequently are more likely to experience peer rejection. Retrospective data gathered from adults who had been young carers indicates that as much as 71% had endured physical, verbal and emotional bullying at school (Bibby and Becker 2000).

Lloyd (2012) also reports similar results to Warren (2007) through quantitative analysis of a survey of 4,212 children, finding that children who had caring responsibilities were more likely to experience bullying, unhappiness, and poorer educational outcomes than similar-aged non-caring peers. Particularly, findings indicate that children who were carers were significantly less likely to have sat a key examination (transfer test) and of those who had sat the examination, fewer were likely to have achieved the highest grade. Carers were also less likely to go on to university following compulsory schooling compared with similar-aged non-caring peers.

Cree (2003) also draws attention to some of the difficulties faced by carers with regard to their educational engagement. For example, the majority of carers reported that they had persistent anxiety over schoolwork due to having missed school to attend to or care for a parent. The experience of being a young carer appeared to produced anxieties and practical difficulties that interfered with a carer's ability to sustain engagement at school:

"He (Stewart) went on to add that teachers at school put pressure on him and this is difficult for him. Nicky, although younger (aged 12 years), also worried about school, because she found it hard to concentrate on her work, and sometimes fell asleep in class."(Cree, 2003; p304)

However, in confirmation of the inconsistent reports regarding young carers' engagement with school:

"Jenny (aged 13) was delighted to be at school; it was a place of refuge, away from the cares of home and worrying about her mother's mental health." (Cree, 2003; p304)

Just as it is has been identified that parental mental health problems can induce psychological distress for young people (Mahon & Higgins 1995), conversely, research indicates that school can be an important protective factor in the lives of troubled children who are young carers (Roberts et al., 2008; Becker and Becker, 2008).

In contrast to children not engaged in a caring role, Warren's (2007) study also highlights that young caring impacts on the young people's capacity to participate in recreational activities and engage with peers due to factors related with their caring responsibilities; for example, supporting at home, difficulties accessing transport, and the financial burden of caregiving.

Bolas et al. (2007), investigating the lived experience of young carers using Interpretative Phenomenological Analysis, identified that "isolation" and "distancing from others" were key themes to emerge from their data. Participants perceived caring to be a difficult and private experience with profound social consequences. Carers revealed they felt stigmatised by both their role as a carer and also by association with people experiencing disability, leading to secrecy around their caring role, the fear of rejection and misunderstanding, which ultimately left carers feeling excluded from the social world and reduced their access to social support.

Consistent with other findings, Barry's (2010) qualitative study of 20 young carers suggests that young carers tend to keep their friends, family, and community networks detached from one another. In particular, Barry (2010) highlights the impact of caring on peer relationships, and the need for carers to cultivate a careful balancing act, between responsibilities to family and relationships with peers, with one carer reflecting that: '*your life's like a set of scales' (Barry, 2010; p530).*

Whilst acknowledging the positive benefits that many young carers report, the evidence for negative outcomes and experiences is both anecdotally and empirically supported and as such I have taken the stance that young caregiving is deserving of attention and support, and is thus worthwhile as the focus of this research study.

With regard to how young carers engage with education and school, some of the anecdotal findings indicate that school can be associated with positive and protective factors, whilst other findings indicate there does appear to have been significant

associations identified between young caring and school bullying, unhappiness at school, reduced social participation and the development of mental health difficulties. The influence of protective factors at school, at home, and the wider community may be the difference that mediates the impact of these negative associations with caring and education, and is a gap in the literature that this current research study hopes to fill.

2.5. Protective Factors to Young Caring

2.5.1. The ecological context of risk and resilience

When considering "protective factors", Corcorcan and Casebolt (2004) suggest adopting a "risk and resilience ecological framework". The authors argue that an examination of models of intervention suggests that practice may more typically be driven by a pathology and problem focus, rather than a commitment to focus on strengths. This seems to fit with the predominant discourse around young carers in the literature, with Newman (2002) identifying that researchers and practitioners around young carers have been preoccupied with focusing on identifying and removing "risk factors", but rarely are investigations undertaken to identify positive outcomes for children. The risk and resilience framework was developed for the understanding of individual behavior, and organises risk and resilience factors into different systemic levels. The framework considers how the risk (contributing forces to a problem behaviour) and protective (resources both internal and external in nature, that defend against the negative impact of the problem) factors at each system that interact to regulate an individual's ability to adaptively cope despite adverse life events (Kirby & Fraser, 1997).

Whilst defining resilience has enticed debate and controversy over how it manifests, researchers are in broad agreement that resiliency can be conceptualised as the *"absence of significant developmental delays or serious learning and behavior problems and the mastery of developmental tasks that are appropriate for a given age and culture in spite of the exposure to adversity"* (e.g. Werner, 2000, p. 116). Protective factors that contribute to the development of resilience have been observed in earlier studies of children facing such barriers and adversity as poverty (e.g.

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Werner & Smith, 1982) and parental psychological illness (e.g. Rutter et al., 1979).

Key adults in schools and young carer projects can successfully meet the needs of young people through environmental changes (Grant, 2008; Richardson, 2009; Barry, 2010), for instance, in the approach they take to empathise and intervene with behaviours that occur as a function of difficulties within the home/family setting (Pellegrini, 2007). Research around young carers has identified the importance of these systems as key protective factors to educational engagement, improved psychological wellbeing, and improved life outcomes (Barry, 2010; Packenham et al, 2007; Richardson, 2009; Grant, 2008). The understanding that circumstances and events are products of interactions between different factors in different systems, rather than being perceived in instances of isolation, serves as the core ideological and theoretical assumption of an ecological model of child development as proposed by Bronfenbrenner (1979).

Bronfenbrenner (1979) ecological systems theory and bioecological theory of human development (Bronfenbrenner, 2001) offers an ecological model that assumes a framework of child development with the child placed at the focal point of the system, interacting with the system at several settings (home, school, neighbourhood) that forms the child's microsystem.

The mesosystem encompasses the interactions and exchanges between two or more of the child's settings e.g. between parents at home and the staff at school. The exo system involves systems that the child does not directly interact with, but nonetheless has indirect impact through interaction with other systems e.g. the processes and activities of the Local Authority. The macrosystem comprises the wider socio-cultural context including the government, society, cultural values, policy and legislation; for instance, key legislation or guidelines within the education sector.

As mentioned, one of the core principles of Bronfenbrenner's (1979) model is the influence of different parts of the system upon the young person, and the ways in which these factors interact to affect the young person's development. For instance, the young carer directly experiences changes as a result of the factors affecting activities in the mesosystem due to developments in the macrosystem (e.g. the formulation of the good practice guidelines for schools to support young carers; see

section 2.5.3. of this review). Similarly, Hamilton and Anderson (2013) also reflect on the lack of research on the wider contextual and structural factors that have pervasive impact on young carers' aspirations, hopes and achievements. The authors argue that interconnected structural factors at the intra-familial and wider policy and service levels impacts upon the nature of care provision and restricts the extent of choice that young carers are able to exercise around their lives.

However, in this context, in what Bronfenbrenner (1979) terms "reciprocity", the child is perceived as a participant with active agency affecting, as well as being affected, by the socio-cultural environment. For example, Grant et al (2008) demonstrate how the young carer can be seen as reciprocally affecting their microsystems and cites the example of some young carers taking the initiative to lead educational involvement regarding the issue of young carers to the broader public (i.e. engagement with the exosystem within their ecological system) having engendered a young carer's impression of meaning and identity through their actions and accomplishments at a carers project.

Figure 2.3. Diagram of Bronfenbrenner's Bioecological model (Bronfenbrenner, 1979)
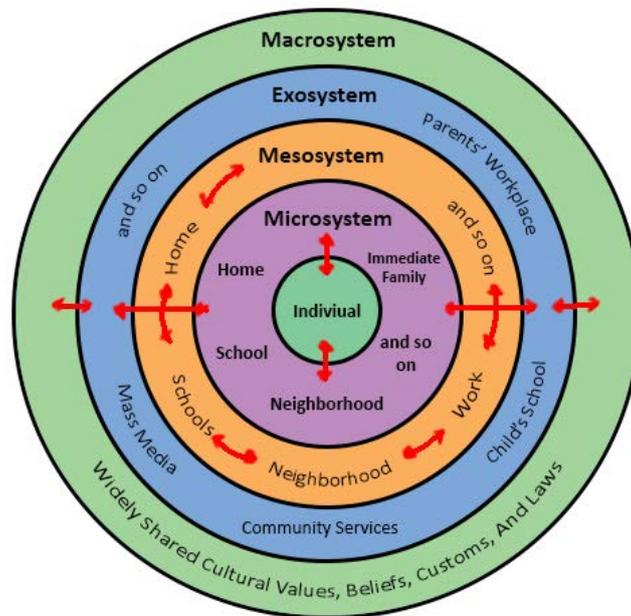
Dearden and Becker (2003) also argue for focusing on resilience and protective factors to support young carers. As such, I propose to explore these protective factors through the lens of an ecological framework of resilience. The ecological model has a number of advantages for exploring the resilience and protective factors for young carers' educational inclusion: 1.) it recognizes the complexity of individuals and the systems in which they are nested; 2.) identified protective factors have been ascribed at their various system levels from a robust and empirically-derived evidence base (Bronfenbrenner, 1979; 2001); 3.) the literature around ecological theory has moved beyond the purely conceptual and theoretical level to encompass real-world applications and interventions (Corcorcan and Casebolt, 2004; Hawley, 2000).

2.5.2. Young Carer Projects as Protective Factors

Bassani (2007) and Barry (2010) note the lack of literature investigating the influence of young carer projects on children's well-being and school engagement. However, Aldridge and Becker (2003) report on the value of young carer projects in regard to providing someone carers can talk to, creating connections with peers with similar shared experiences, and providing access to services.

Grant et al. (2008) also identify the particular support mechanisms young carer projects make available to carers. One of the key supportive mechanisms that allowed carers to participate and engage better with school was offering help to the "looked after" person, which could include signposting to other agencies and the completion of forms and documents sent from school. Grant (2008) also identifies that young carer projects place a high emphasis on building close and trusting relationships with each young person to help them feel relaxed, valued and free to talk about their needs, hopes and anxieties due to the recognition that many young carers face bullying and peer group rejection at school.

Similarly, Richardson (2009) also identifies that a key contribution that young carer projects make is providing peer support for young people who attend the group meetings and positive peer experiences that they may be missing at school. As young carers often miss out on school outings and trips, young carer projects invest much effort to ensure that carers experience special activities such as archery, bowling and

cinema trips which young carers report provides them respite and "time out" from their caring activities.

Barry (2010) suggests that young carers projects were seen as significant in supporting carers both emotionally, with problems related to turmoil experienced as a function of general adolescent development, but also in their practical role of caring for a family member. Carers in the study report a positive perception of the young carer projects for three reasons: 1.) because of the sociability aspect of attending; 2.) because of feelings of 'release' from the home situation; and 3.) because of the emotional support they received:

"When I was younger, it was a lot harder to explain to people why I couldn't do things and why I couldn't go out, because I was embarrassed to explain my situation . . . you kind of felt like there was nobody out there in the same situation as you. But when I came to Young Carers I realised that I wasn't alone (15-year-old female)." (Barry, 2010; p535).

Whilst there has been limited research on the impact of young carer projects, there has been even less research on the relationship between young carer projects and their specific interaction with carers' educational participation and inclusion. By adopting an ecological framework (Bronfenbrenner, 1979), this study hopes to address the relationship between young carer projects, schools, young carers and their families in order to identify interactions that may positively contribute to young carers' educational inclusion.

2.5.3. Schools as Protective Factors

Roberts (2008) suggests that schools could be viewed as important sites of resilience-building for young carers, and Becker and Becker (2008) indicates that, when carers encountered understanding adults who gave them recognition and support, carers were more likely to perceive school as a positive experience. This is consistent with findings from Lilas Ali et al., (2013) that close support from key people in their environment, and the understanding and empathy of these people, was a crucial protective factor.

Warren (2007) and HMIE (2008) identify education professionals as ideally positioned to identify young carers early. However, Banks (2002) and Becker and Becker (2008) suggest that there is a need to increase the awareness of key educational professionals to the issue of young carers. This fits with earlier findings from Altschuler et al's. (1999) study of schools support for children with a physically ill parent. Findings from this study reveal that a key barrier to effective school support was the staff's need to feel confident in responding appropriately. At a practical level, staff identified access to training and resources as an important factor that would mediate their feelings of competence when responding to children with an ill parent.

Barry's (2010) findings indicate that school is an important site for young carers to develop peer relationships, particularly when young carers were unable to fulfill social commitments with peers due to other domestic or caring responsibilities. In contrast, findings also indicate that carers encountered very mixed experiences in their relationships with teachers. For example, several carers felt that teacher's authoritative approach was often unhelpful and unjustified. However, of the young carers who perceived school positively, most indicated that it was the relationship with a particular teacher or the ethos of an educational setting that influenced that perception. For instance, some carers identified specific teachers who were aware of the context of their caring and were empathetic and willing to make allowances in their expectations for schoolwork, if there were factors at home that were impeding the carer from producing work.

The evidence above suggests that young carers can experience an inconsistent and uneven relationship with school. Barry (2010) also identifies that carers relationships to their school experience can be very contrary: on the one hand it can act as a 'safe haven' or respite from caring; but, on the other hand, some carers have suggested that they wanted to create distance and space between school and caring, to avoid the 'contamination' of that safe space:

"my personal life is not in school . . . school is school"(Barry, 2010; p532)

Current guidance for schools has been produced from the Department of Health (DOH 1999), and from the Department for Education and Employment (DfEE 1999) as early as 1999, in relation to supporting young carers. Also, included with guidance

for the education sector was a published report by Dearden and Becker (2003) featuring government-sanctioned guidelines produced by the Children's Society (Frank 2002):

Figure 2.4 Key Good Practice Guidelines

- • **Training** for school staff regarding young carers;

- • Developing awareness of the issue young carers through **lessons/classes;**

- • Having a **key person identified in school**

- • A **specific school policy** to identify young carers

- • A **school-wide response** to meet the needs of carers;

Despite publication of the DOH (1999) and DFEE (1999) good practice guidance for schools in relation to young carers, the literature suggests that the role of school as a protective factor for young carers has been inconsistent and often the outcome of an individual school and staff member's approach to managing relationships with children. As such, this study is interested in, if and how, guidance has been interpreted and implemented by schools and hopes to isolate the key contributions that schools can make to support young carers engage with education. Taking the ecological perspective, the study uniquely focuses on not just the interaction between the carer and school, but the relationships between schools, families, support services and the wider community.

2.5.4. Social Support as a protective factor

Becker's (2007) international review of young carers, cited in Kavanuagh (2015), detailed the need to reduce the burden of caregiving responsibilities on young carers through strengthening the provision of social service programs, health care organisations, and wider community support.

The literature indicates that higher social support is correlated with better adjustment among children providing care for a parent (Pakenham & Bursnall, 2006), while other young carers struggle to access support for themselves and their families (Moore & McArthur, 2007).

In Packenham's (2007) multivariate analysis of coping resources, the level of social support predicted young carer adjustment to their caring role most consistently. Packenham (2007) found greater perceived access to social support and broader networks of informal social support were positively correlated with better outcomes and lower psychological distress. This also fits with findings that support an association between reduced distress in adult carers and perceived access to social support (e.g. Packenham, 2001). This is also consistent with earlier findings from Conrad and Hammen (1993) who examined protective factors for the children of disabled mothers. Social support was found to be a significant protective factor correlated with reduced rates of psychological diagnoses, regardless of the mother's illness.

Barry (2010) also identifies the significance of more informal social support from family and friends as important protective factors in the lives of young carers. This is consistent with findings from Cree's (2002) study that young carers tend to communicate their concerns and worries predominantly with close family, trusted friends and the staff of young carers projects. Participants in Barry (2010) indicate that none of the respondents appeared to resent being a carer and being a young carer was perceived as creating important bonds between the young person and his care-recipient, despite the worry associated with the nature of caring activities. A significant majority of the sample mentioned that they were particularly close to their mothers and fathers, including if the parent had died.

Barry (2010) also identifies the importance of friends, particularly as they take on greater significance in adolescence. Carers tended to develop close friendships with other carers whom they felt they could trust and share their worries with, due to the common experiences of being a young carer:

"My three friends, they've been like the best friends, like four years now or something and we're just like, we're always like there for each other and that and we always

trust each other all the time." (Barry, 2010; p530).

In terms of the impact of positive peer relationships, the young carers identified the importance of a friend who could help take their mind off their caring role. Barry (2010) identifies the importance of schools and young carer projects as sites where friendships and relationships can be formed, or broken, and therefore for schools and young carer projects to have the potential to act as key protective factors in the lives of young carers.

Similarly, Kavanuagh et al., (2015) suggests poor peer support and understanding may lead to being stigmatised and isolated as "dis-ordered" or "othered" resulting in reduced social engagement, poor educational engagement and reduced psychological well-being. Young carers may feel less "normal" contrasted to their peers due to the atypical nature of their caring activities. As such, successful and meaningful peer relationships can have important impact and value as young carers may rely on their friends to "normalise" a relatively unusual and stressful situation through social participation and understanding. (Bukowski, Newcomb, & Hartup, 1996).

2.5.5. Coping mechanisms of Young Carers

Some researchers have looked at the relationship between young carers and their ability to cope with the demands of caregiving from a stress management perspective (Packenham et al, 2007; Earley, 2007).

Packenham et al. (2007) draws on Lazurus and Folkman's (1984) stress and coping theory (derived from research that has examined the role of coping in adaptation to adult caregiving) to guide understanding of the mechanisms that better allow young carers to cope with the demands of their role. This theory is based on the premise that adjustment to caregiving and the care receiver's illness is determined by the caregiving context and three mediational processes: appraisal (self-evaluation and subjective interpretation of the caregiving experience); coping strategies (defined as *'constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (Packenham et al, 2007; p91)*; and coping resources (stable characteristics of a person's internal, e.g. disposition, and external, e.g. social support, environments)'.

Packenham et al. (2007) finds, alongside social support, that a key predictor in young carers' positive adjustment was the perception of choice in their caring role. Greater perceived choice in their caring role correlated highly with more adaptive coping mechanisms, positive outcomes and lower levels of distress. This is of significance as many young carers have often reported the feeling that they had "no choice" in taking on their caring role (Aldridge & Becker, 2003).

Earley et al. (2007) also identified that specific activities such as spending quality time with the care recipient, or taking them out, were strategies that carers adopted to cope with the role. Earley (2007) hypothesises that such strategies are a way to manage distressing feelings related to their caring duties, by relieving feelings of guilt or anxiety related to their caring responsibility.

Bolas et al. (2007), through qualitative analysis of the lived experience of carers, identifies that the integration of caregiving as part of the carer's identity provided a consistent buttress to their self-esteem. The authors indicate that carers draw heavily on idealised positive images of carers to support feelings of normality, self-esteem and pride. Positive self-esteem for many of the participants was also linked directly to feeling useful and capable.

2.6. Rationale for the current study and key research questions

2.6.1. Summary of current literature and research

The current review of the literature on young carers reveals that a broad range of methodologies have been employed to study the phenomena of young caring. Within the literature and practice that exists, there are ongoing debates regarding the definition of young caregiving (Cree, 2003); its nature as distinct from what would be expected of any child (Dearden and Becker, 2000; Warren, 2007; Aldridge and Becker, 2008); and the ethical issue of where resources should be distributed (towards adult disability services or supporting young carers) (Newman, 2002).

Whilst some researchers have questioned the focus of the research as preoccupied with its focus on identifying and removing risk, rather than focusing on positives and

strengths, and as exaggerating the evidence of impact on children's lives (Newman, 2010), the literature review has consistently identified research demonstrating the impact of young caring on educational attainment, life outcomes, mental health and social relationships (Becker and Becker, 2008; Warren, 2007; Earley, 2007; Cohen, 2012; Thomas et al. 2003; Cree 2003; Aldridge, 2006).

The review of the current research also suggests that studies have identified that there are important protective factors to be found in the environments around young carers such as schools (Becker and Becker, 2008; Roberts, 2008; Barry, 2010), young carer projects (Grant, 2008; Richardson, 2009), and social support networks (Barry, 2010; Packenham, 2007). Previous research has identified the ecological model (Bronfenbrenner, 1979) as an effective framework for considering the development of resilience and protective factors, and may provide a useful explanatory lens to explore the development of children who are engaging in young caring (Corcorcan and Casebolt, 2004; Werner, 2000).

2.6.2. Identified gaps and inconsistencies in literature

Despite a robust literature around young carers, the review has identified gaps that the current study hopes to address.

Whilst young carers have been widely acknowledged within the literature as not being a homogenous group (Frank and McClarnon, 2008), and that the impact of social exclusion may be different for different subgroups of carers, there has been no research specifically investigating the educational experiences of young carers who also have additional needs (e.g. learning or psychological) and how their support needs may differ.

Also, Newman (2010) argues, research around young carers has been dominated by a discourse focused around "risk", "abnormality" and "disability" and there has been little research on the positive impact and strengthening factors associated with young caring.

Finally, the literature also lacks research that has explicitly investigated the activity of young caring from an ecological perspective. Specifically, there has been no published research that has looked to develop an integrated understanding of the

needs and necessary support for young carers to access education by investigating how factors at different systemic levels may interact to strengthen young carers' inclusion in school e.g. the relationship of young carer projects to schools.

2.6.3 Key Research Questions

Following from this review of the literature and identified gaps in research and understanding, the overall research question the researcher would like to answer is:

1. What are the key ecosystemic factors that strengthen the resilience and educational inclusion of young carers with additional educational needs?

Specifically, this research is interested in factors at the meso, exo and macro-levels (Bronfenbrenner, 1979) of a young carer's environment that has had a positive impact on:

   a) *Psychological coping strategies and resilience for the demands of education and their caring role;*
   b) *Academic attainment;*

2. Through what interacting mechanisms and processes do key professionals and young carers with additional needs perceive these factors to have been effective?

Chapter 3: Method and Methodology

3.1. Overview

The purpose of this study was to investigate the strengthening factors that supported the educational inclusion of young carers with additional educational needs.
In order to identify factors at different systemic levels, this study explored the research questions from a range of perspectives including young carers with additional educational needs; key staff working with young carers from the local Spurgeons support group; and the safeguarding and student welfare officers from local authority mainstream schools, in order to identify strengthening factors at different systemic levels.
Crotty (1998) proposes the deliberation over four key elements in research design, during the development stage, in order to navigate the confusing labyrinth of approaches, theories, methods and methodologies the researcher could potentially employ: epistemology (a way of understanding and explaining how we know what we know); theoretical perspectives (the philosophical paradigm behind the methodology); methodology (the underpinning approach to understanding how information will be gathered and interpreted); and methods (the specific tools employed during data collection and analysis). Using Crotty's (1998) elements of research design I will outline my research design and provide a rationale for the decisions made.

3.2. Development of the research design

3.2.1. Epistemological and Ontological Assumptions

Cohen, Mannion and Morrison (2011) describe how research needs to be considered within the context of the assumptions that the researchers hold. Given that research is concerned with understanding our world, this is informed by how the researcher views the world.

Hitchcock and Hughes (1995) suggest that an ontological assumption (assumptions

about the nature of reality) give rise to epistemological assumptions (ways of researching and enquiring into the nature of reality and the nature of things); these in turn give rise to methodological considerations; and these in turn give rise to issues of instrumentation and data collection.

For example, an ontological position would be that social reality is external to the individual, and is of an objective nature. This view holds that social reality is not merely made up of objects of thought, its existence dependent on a knower, but is independently accessible from the knower. This would give rise to an epistemological position that knowledge of the social world is hard, tangible and objective and would demand of researchers an observer role, aligned to the principals and methods of the natural sciences such as positivism which assumes a number of tenets, namely that the social world is deterministic, measurable and reducible.

Within a constructionist epistemology, key to the formulation of understanding and meaning, is the researcher themselves. Constructionists argue that the tools of traditional science cannot interpret the social world, due to the view that no one objective truth can be measured or found, thus a different approach and method is required. Constructionists assume different interpretations exist dependent on the perspective of the individual, thus multiple realities can exist. The researcher's suppositions are perceived as an analytical tool and are constructed into the design of the research, within constructionist research. This is referred to as reflexivity (the self-reflection and self-awareness of the researcher's assumptions impact upon the study) and underpins many of the methodologies associated with constructionist research. This often leads to methods closely aligned to a constructionist approach, such as qualitative research methods (Lincoln and Guba, 1985).

Since the research aims to bring about change and improve support for young carers in schools, this study reflects an investigation of a real world problem through social research, by exploring the phenomena through interpreting different perspectives and experiences. As such, this study assumes a constructionist epistemology that knowledge and meaning is fashioned in social exchanges existing within different cultural contexts and thus traditional scientific methods were deemed inappropriate as there is no conclusive truth to be revealed (Crotty 1998).

3.2.2. Theoretical perspectives

Paradigms such as constructivism, exist at the most philosophical edge of the research process. A theoretical lens is required to narrow the research process further (Cresswell and Plano Clark, 2007)

Frequently allied with a social constructionist approach is an interpretivist perspective. The basic tenet of interpretivist research is that research processes should endeavour to comprehend the *"complex world of lived experience from the point of view of those who live it"* (Scwandt, 1994, p.118). The interpretivist paradigms possess a number of distinguishing principles:

- People actively construct their social world (Becker, 1979; Garfinkel, 1967);

- There is more than one interpretation of phenomena;

- The social world is complex and cannot be meaningfully reduced or simplified in its interpretation, thus researchers should reflect that complexity in the way they gather their information about the social world (Gertz, 1973);

- The social world should be examined through the lens of the participants rather than the researchers.

The interpretivist perspective consents to an understanding that an elucidation of a social phemonena is contingent upon the social context, and thus products of the research process are not unconditional and may vary depending on the individuals, role, position or cultural relativity to the phenomena being investigated. The current study explores and interprets the perspective of young caregiving from the multiple perspectives of people inhabiting different roles and positions, thus potentially offering multiple interpretations of the phenomena.

3.2.3. Exploration of methodological approaches

Within this interpretivist paradigm, this study is concerned with comprehending how

individuals perceive and interpret the socio-cultural milieu they inhabit and thus a phenomenological methodology has been embraced in this study.

Phenomenology is concerned with understanding the experience and perception of the participant's world, rather than trying to objectively measure and quantify the object of investigation. This position denies the positivist view that sources of knowledge must necessarily be derived from a scientific method that holds observable experience as the only reliable source of knowledge (Bryman, 2004).

The development of the phenomenological approach has been greatly influenced by hermeneutics, the study of interpretative meaning. Bryman (2004) suggests the hermeneutic perspective focuses on the impact of social and personal context in relation to the individual, arguing for an individual's perception of reality emerging from a socially constructed social reality. In this context therefore, there can be multiple psychological constructions of this socially constructed reality, dependent upon the various social roles the individual may inhabit in society and these different perceptions may not be congruent with each other. Constructionists argue that a reductionist perspective does not reflect or represent the complexity of the social world, and that it is the researcher's goal to attain an understanding of the phenomena that is representative of these multiple perspectives by interpreting these multiple experiences, perceptions and constructions (Gray, 2009).

This research investigates how a variety of people comprehend their experience of the factors that strengthen the educational inclusion of young carers with additional needs and therefore this work embraces an interpretivist/constructivist approach by applying a phenomenological philosophy compatible with a social constructionist paradigm.

3.2.4. Reliability, Validity, Generalization and Reflexivity

The adoption of qualitative methods is a consequence of this study's alignment to an interpretivist/constructivist epistemology.

The criteria by which reliability and validity are evaluated in interpretivist research, differ from the norm-regulated understanding of traditional positivist research such

that there must be a correspondence between the ontological and epistemological assumptions of the research; the hypothesized research goals and outcomes; and the focus of any evaluative benchmarks of reliability and validity.

Glaser and Strauss (1967) suggest interpretative data are exposed to critical reflection centered around questions involving the techniques employed in data collection, analysis and presentation, and how the researcher interprets the data during theory generation. The authors suggest researchers engage in considerable deliberation of key questions such as:

- Has the theoretical framework emerged from the study? (credibility)

- Is an understanding produced that helps to explain a phenomenon? (usefulness)

- Given the context, participants, methods and findings, are the research findings believable? (trustworthiness)

As the lead researcher, I took a range of steps to increase the validity and reliability of the data in this study, in relation to the above criteria. For example, a research diary was utilized to record my reasoning around key choices or changes made during the research process, and my thinking around the findings emerging during the analysis process was independently discussed and verified during supervision. These strategies were based on suggestions from Braun and Clarke (2006) in order to avoid common pitfalls (e.g. failing to deliver a credible analysis, failing to move past reporting descriptively into constructing conceptual associations) in the use of thematic analysis that would decrease the fidelity of the study in relation to the reliability and validity of the data.

Despite the concentration of the research on the participants distinct perceptions (e.g. young carers, keyworkers), Seale (1999) argues by focusing on what a study might be able to inform us about a standing theory, the potential to generalize findings is possible in this kind of interpretivist research. The research aims were to generate an understanding of the factors that strengthen the educational inclusion of young carers, with a specific focus around contributing to an understanding of how eco-systemic theory (Bronfenbrenner, 2001) may help to organize and make sense of these

complex phenomena. Therefore, I have utilized a dual approach to data analysis, integrating the analysis of inductive data (thematic analysis) around a deductive framework (Bronfenbrenner's Ecosystemic Theory, 1979). Through this dual approach to analysis, this study hopes to develop a more comprehensive and integrated understanding of the interaction between young carers and educational systems, at multiple systemic levels, which would improve the potential for theoretical and conceptual generalization of the research findings.

The fidelity of the current study was also developed further, by applying reflexivity during the process of research. Research reflexivity is the process of the researcher considering the impact and influence of their own subjective constructions during the process of research development. (Nightingale and Cromby, 1999).

Reflexive questions that I have considered during the research process (see Section 4.5.) are commensurate with suggestions that Willig (2001) has identified as important in contributing to the underpinning epistemological paradigm of the study:

- *How the development of the research question has impacted on what knowledge could be found?*

- *How have the design and methods "constructed" the data?*

- *How could the research questions have been investigated differently?*

Semi-structured interviews and thematic analysis were acknowledged as fitting methodological tools, in light of the epistemological position of the research, as they both attempt to reveal the individual and authentic realities of the participants (Braun and Clarke, 2006). The methods employed are discussed in further detail, in the following section

3.3. Method

3.3.1 Overview

A method explains a researcher's systematic approach to the recruitment of participants, and the collection and analysis of subsequent data (Gray, 2009). This section of Chapter 3 addressed these concerns by providing a rigorous description and rationale of the sampling techniques, recruitment of participants, data collection procedures and the choice of data collection methods. Following this, a detailed account is provided of the analysis of the data and the generation of meaningful findings.

Figure 3.1: The relationship between my epistemology, theoretical perspectives, methodology and research methods.

| Epistemology: Constructivism | → | Theoretical Perspectives: - Interpretivism - Social constructionism | → | Methodology: - Phenomenological Research | → | Methods: - Interviews - Thematic Analysis |
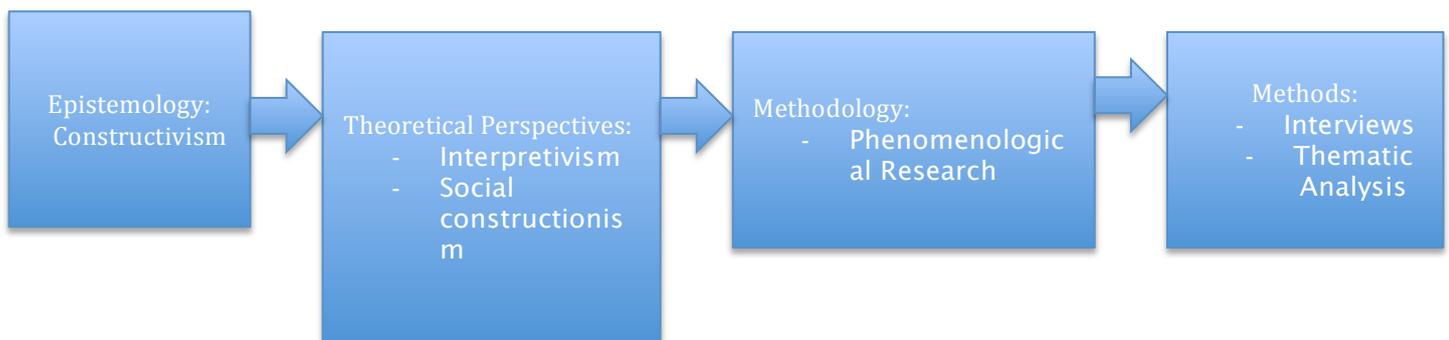
3.3.2. Sampling

Sampling describes the principles and procedures by which participants were identified and engaged in the research process. A purposive sampling criteria was employed which involves the researcher's evaluation of potential participants who have direct knowledge or experience of the phenomena of interest that is the focus of the research. To ensure the research questions were answerable, a purposive sample was considered appropriate in order to capture and reflect important details in experiences between participants (Robson, 2002).

An important aspect of the research is the focus on identifying strengthening factors at different systemic levels. Thus, I felt it appropriate to engage not only young carers in the research process, but key adults that work with young carers. To that end, I had identified a local branch of Spurgeon's as an appropriate site to find participants who work with young carers, but also a suitable site to engage young carers themselves, as there are regular group meetings held between young carers and Spurgeon's staff. These local Spurgeons meetings are held outside of school hours, and thus it was felt engagement with carers at Spurgeons would also reduce the impact of the research participation on the young person's educational engagement.

However, in gathering a range of different perspectives it was also deemed appropriate to gather the perceptions of educational personnel who engage with carers at school. Through an Internet search, a local authority secondary school was identified that had successfully established a Young Carer Support Group. The key person responsible for the support group was identified as the Safeguarding and Student Welfare Officer, through the website.

3.3.3. Participants

The focus of this study was to investigate the views of the strengthening factors to the educational inclusion of young carers with additional educational needs, from a range of viewpoints such as young carers experiencing education themselves as well as key adults involved in the support of young carers in education.

As such, potential participants were required to meet the following sampling criteria:
1.) A young person, over the age of 16 identified as a young carer and accessing full-time education. The rationale for this is that older carers are more likely to have had a longer experience in educational provision, and more likely to have the cognitive development and linguistic maturity to be able to provide detailed information regarding their experiences.
The young person was required to have a legal designation of Young Carer, in accordance with the Care Act 2014. The young person was also required to

have an identified additional educational need, and be on the SEN support register (Spurgeons keep their own register of children on SEN support or with an Education, Health and Care plan, identified through schools).

Table 3.1 Features of the Young Carer participants

Participant	Category of Need	Type of Need Identified	Gender	Age of Participant when consent given
P1	School Action Plus	Specific learning difficulties: Dyslexia	Male	17
P2	School Action Plus	Mental health: Anxiety	Female	16
P3	School Action Plus	Mental health: anxiety and depression	Male	16

2.) An adult key worker employed at Spurgeons. The participant was required to have been employed at Spurgeons for two years, or equivalent to two years working with young carers. The rationale for this is that more experienced staff are more likely to have a thorough knowledge of systems and processes that support and constrain the educational participation of young carers with special educational needs.

The study also required the participant to have regular direct contact with young carers. The rationale for this is that staff with direct contact with young carers are more likely to have an understanding of the lives of young carers and the impact of caregiving on educational participation. In keeping with the systemic focus of the research, at least one participant from this cohort was required to be management level staff. The rationale for this is that management-level participation will offer more perspective from a broader

organizational/strategic level. Three key workers consented to participation in the study.

3.) Safeguarding and student welfare officers employed in this role for at least two years. The rationale for this is that more experienced safeguarding and student welfare officers are likely to have greater working knowledge of issues around vulnerable groups of children and more likely to have had greater contact with young carers. At least one of the safeguarding and student welfare officers was required to have had at least one direct involvement supporting a young carer with additional needs in school, as the safeguarding and student welfare officers can draw on direct experience for identifying strengthening factors rather than just general knowledge or speculation. This will enhance the validity of the data generated from this sample. At least one of the Safeguarding and Student Welfare Officers was required to have had no direct involvement supporting a young carer with additional needs in school, in order to generate comparison data to enhance the meaningfulness of the data from other participants. Two safeguarding and student welfare officers consented to participation in the study.

Table 3.2 Description of procedures during recruitment of participants

Sample Group	Participant Recruitment Procedure
Young Carers	1. Contact and engagement with Spurgeons Area Team Manager 2. Sharing of purposive sampling criteria with team manager. 3. Team manager draws up list of potential participants. 4. Potential participants are approached by keyworkers at group meeting. 5. Keyworker describes research project and provides information

	sheet. 6. If potential participant is interested, meeting is arranged for next group meeting to have discussion with lead researcher regarding involvement. 7. At the meeting between potential participant and myself, research aims, ethical issues (informed consent, withdrawal, distress) and methods are discussed. Participant was asked to sign consent form if they agree to participate. Date was arranged for data collection interview.
Spurgeons Keyworkers	1. Contact and engagement with Spurgeons Area Team Manager 2. Sharing of purposive sampling criteria with team manager 3. Team manager drew up list of potential participants 4. Potential participants were approached by lead researcher 5. Lead researcher described research project and provided information sheet 6. If potential participant expressed interest in participation, meeting is arranged for private meeting to have discussion with lead researcher regarding involvement 7. At meeting between potential participant and researcher,

	research aims, ethical issues (informed consent, withdrawal, distress) and methods are discussed. Participant was asked to sign consent form if they agree to participate. Date was arranged for data collection interview.
Safeguarding and Student Welfare Officer	1. Identified through a website search of local authority schools. 2. Presence of young carer support group at school key indicator of potential involvement with young carers. 3. Initial telephone contact with officer, indicating role, research area, and inclusion criteria as potential participant. 4. If interested in participation, a date was arranged for an initial meeting at school to clarify research aims, ethical issues and methods. 5. Participant was asked to sign consent form if they agreed to participate. Date was arranged for data collection interview.

As at least one of the participants from the safeguarding and student welfare officers cohort was required to have had no direct contact with young carers to generate useful comparison data, a similar procedure was followed to identify a suitable candidate. Through a website search of local authority schools, a local authority secondary school was identified that had not established a support group but maintained a good

reputation within the local authority for providing effective pastoral support for vulnerable groups of children, such as Looked After Children. Information made available through the school's website indicated that the school had not made a permanent exclusion of a child since 2009, and had the lowest school exclusion rate of any school in the local authority. The equivalent safeguarding and student welfare officer was identified through their website.

3.4. Data Collection

3.4.1 Overview

In keeping with the ontological, epistemological and methodological orientation of the study, semi structured interviews were considered suitable to be employed as the data collection method in order to record a richness and depth to the perceptions and experiences described by participants.

LeCompte and Preissle (1993) describe a continuum from standardized interviews to informal conversational interviews. Lincoln and Guba (1985) suggest that a more structured interview is advantageous when the researcher is conscious of what knowledge they do not possess and as such can structure questions that will provide the knowledge needed. In contrast a more unstructured interview is more beneficial when the researcher is not cognizant of knowledge they do not possess, and thus depends upon on the participant to complete the gaps in knowledge.

In relation to this study, due to the comprehensive review of the literature (see Chapter 2) I was able to focus the research goals and the development of the interview questions to direct the interviews around particular areas. However, the literature itself is incomplete, and the gaps where there is little knowledge have formed the direction of research questions. In this regard, the research hopes to fill these gaps through eliciting the participants' experiences around the focus of the research (the factors that strengthen young carers educational inclusion). Thus, a balance was sought between structured and unstructured approaches through the semi-structured approach in order to focus the investigation around the identified gaps in the literature, but allow participants' knowledge to fill those gaps.

Table 3.3 Strength and weaknesses of semi-structured interview (Patton, 1980)

Characteristics	Strengths	Weaknesses
• The question topics can be decided and planned for prior to interview • Interviewer plans the order and organization of questions	• The outline of questions increases the inclusiveness of data • Makes data collection more methodical and organized • Gaps in knowledge can be filled with planned questions • Interviews remain moderately informal and contextual • Interviewer can probe and clarify responses or extend questioning to elicit richer or more detailed responses	• Pertinent topics can be unintentionally neglected • Tractability in organization of questions can have consequences for the consistency of responses, thus diminishing comparison of responses • Interviewer may unconsciously induce socially desirable answers • Difficult to generalize due to individual nature of interview

Table 3.4. describes an example of a pre-prepared schedule of questions. The question schedule for each cohort (carers, Spurgeons staff, student welfare officer) was different, reflecting the varying social roles in relation to the phenomena of interest. The questions developed in the interview schedules mirrored the research aims and questions, in particular the emphasis on understanding the strengthening and systemic factors impacting on the educational inclusion of young carers. In particular, the development of the research questions took into consideration the conceptual relationship the data may provide to Bronfenbrenner's (1979) Eco-systemic theory

and (2001) Bio-ecological model, to capture information that relate to factors that different systemic levels, as presented in Table 3.4.

Table 3.4. Examples of the pre–prepared questions for the focussed semi-structured interviews

Participant	Example of pre-prepared questions/prompts	Link with area of research inquiry
Pupil	• What are the key relationships you have that have helped you to cope with your role as a carer and the demands of school? How would you describe that relationship?	• Coping resources
	• Were there key relationships at school that helped you? How would you describe that relationship?	• Microsystem level factors
	• Do you feel part of the school? Do you feel included in school? Do you feel that you are missing out on anything at school? • If you don't feel included in school, what would "being	• Strengthening factors in school support • Mesosystem level factors

	included" look like for you? What would be different?	
Spurgeons keyworkers	• How do you liase with schools? What kind of challenges and opportunities does this present? • What other supports exist outside of school, within the community, to support young carers with additional needs? • Are these effective?	• Interacting processes and mechanisms which produce strengthening factors • Exosystem level factors
Safeguarding and Student Welfare Officers	• How do you communicate with parents of carers with additional needs, and help parents to participate in school experiences such as parents' evening and pupil events? What challenges do you face in this?	• Exosystem processes interacting with the mesosystem
	• What kind of national guidance and legislation exists	• Macrosystem factors interacting with the exosystem

		guiding schools and agencies to support young carers? • Do these need reconsidering?	

3.4.2. Interview Settings

All participants from the young carers cohort and the Spurgeons staff cohort were interviewed in a designated private room at the Spurgeons offices. Participants from the safeguarding and student welfare officers cohort were interviewed at a convenient time at their respective schools, in a designated room.

Each participant was given the information sheet once more, and the key points of the study along with key ethical considerations (confidentiality, withdrawal and distress) were returned to (See Appendix 2 and 6). The interviews lasted between 40 minutes and 1 hour per interview. To ensure an accurate record, the interviews were recorded on tape using a Dictaphone. Participants were informed of this at the initial meetings. A short debriefing followed the interviews where participants could to ask any additional questions or contribute further information.

3.5. Methods of Analysis

3.5.1 Overview

During the development of this study, I reflected on several methods of data analysis. In keeping with the phenomenological perspective of eliciting the "lived experience", I initially explored the possibility of using interpretative phenomenological analysis (IPA), before deciding that a thematic analysis would be a more appropriate method. IPA was discounted as an analytical approach as it prescribes a homogenous sample in order to engage in a detailed exploration of "convergence" and "divergence" in the

sample. The heterogeneous sample of this research disallowed the use of IPA, as this research explores perspectives and experiences of participants inhabiting a range of different roles and positions relative to the topic of inquiry. Thus, other than the young carer cohort, this sample of participants were not all "living" the experience of being a young carer with additional needs. As such, thematic analysis was selected as the method of inductive analysis.

3.5.2 Thematic Analysis and Thematic Networks

Thematic analysis involves the detailed interpretation and organization of data, into prevalent themes and patterns that the researcher has identified through rigorous and systematic analysis of the datasets (Braun and Clarke, 2006).

The Braun and Clarke (2006) framework for thematic analysis was employed and the emergent themes are presented using thematic maps. The Braun and Clarke (2006) framework offers a systematic method and accessible language for researchers to embark upon the process of thematic analysis in a manner that is systematic and methodologically replicable (Braun and Clarke, 2006). Braun & Clarke (2006) make the argument that thematic analysis should be thought of as a method in itself, rather than just an analytical tool, and recommend the use of key reflexive questions during the analytic process to increase the fidelity of the study's reliability and validity:

Table 3.5. Key Questions for consideration during Thematic Analysis (Braun and Clarke, 2006)

Key Question	Implication for analysis in this study
What counts as a theme?	The identification of themes was influenced by its prevalence and occurrence across multiple participants and multiple sample groups. However, Braun and Clarke (2006) advise taking a flexible approach, and there are no concrete parameters to what counts as a

	theme. It is the researcher's judgement and interpretation of the data that must be made explicit in describing themes.
Offer a full description of the data set or concentrate on one specific part?	In order to allow multiple narratives to emerge I explored the entire data corpus, first looking at the three data sets in isolation (young carers, spurgeons keyworkers, student welfare officers), then identifying themes emerging across the data set.
Classify themes in an inductive or deductive approach?	The inductive thematic analysis was supplemented with a deductive framework for analysis. During the coding that takes place during the inductive stage of analysis, interpretation is steered by the data, rather than to align the emerging themes with any analytic biases or presumptions. Throughout the analytical process Systems theory (Bronfenbrenner, 1979, 2001) was utilized as a conceptual framework with which to align my findings.

3.5.3. Integrating a conceptual framework

The Braun and Clarke (2006) method of thematic analysis was used to inductively derive themes from the data without a theoretical framework to filter the emerging

themes. Due to the research interest in the systemic nature of the young carer phenomena, Bronfenbrenner (1979, 2001) systems theory and later, bio-ecological model is the primary conceptual lens through which I have examined and contextualized the findings. However, consideration of systems theory has permeated my thinking and decision-making throughout the development of this research project, from the development of research questions (see Chapter 2) to the development of the interview schedules (see Chapter 3.4.1.). During the formal analytical process, I have given consideration to how findings from the thematic analysis correlate with theoretical structures present within Bronfenbrenner's (1979) systems theory and (2001) Bio-ecological model (these findings are presented in Table 4.4. and Table 4.5.). These findings are integrated into the discussion sections detailing emergent themes arising from the thematic analysis (see Chapter 4.1.).

Systems models recognise that the behaviour of one component of any system can affect and be affected by the behaviour of other components in the system, albeit not always directly; these complex, non-linear assumed chains of cause and effect relationships are described as circular causality (Dowling, 2003).

When systems theory is applied in educational contexts (as in this study) it seeks to explain how young peoples' behaviours and experiences are influenced by the educational establishment of which they are part, as well as the influence of the relationships between school and home (Dowling, 2003).

In considering this focus of the present study and the interpretation of its findings I considered that systems theory, as reflected in the work of Bronfenbrenner (1979, 2001) afforded a particularly helpful perspective. Bronfenbrenner's original ecological systems theory (Bronfenbrenner, 1979) and its further development within his bioecological theory of human development (Bronfenbrenner, 2001) recognise a child's development within the systems of relationships that form the nested layers of his or her environment. These various systems (described in the Table 2.3) include the influence of the people closest to the young person, their wider community and the cultural and political landscape in which these are situated.

The more recent bioecological theory of human development (Bronfenbrenner, 2001) also included the Process-Person-Context-Time (PPCT) model, which considers

development as a product of increasingly complex reciprocal interactions (processes) between an active and evolving person and objects, and/or symbols within their immediate environment. It further suggests that the form, power, content and direction of proximal processes affecting development vary as a function of personal & environmental characteristics, so emphasising the synergistic interactions between heredity and environment (Bronfenbrenner, 2001). The model also highlights that interactions (proximal processes) must occur on a regular basis over an extended period of time to be effective. Acknowledgement of the significance of both the duration and timing of experience is reflected in Bronfenbrenner's addition of the chronosystem, described as the patterning of environmental events and transitions over the life course (Bronfenbrenner, 2001) to his original (1979) framework.

In summary this model suggests that although proximal processes function as the engines for development, the energy that drives them comes from a range of deeper, subjective forces that exert a particularly strong influence during the formative years (including adolescence) (Bronfenbrenner, 2001). These forces could lie within relationships with close family members and wider family networks, friends and neighbours. At a superordinate level, these more proximal influences on the developmental process and outcomes are mediated by more distal, but powerful influences from the exosystems and macrosystem, which an individual inhabits.

In regard to the current study, this Bioecological model (Bronfenbrenner, 2001) and the associated PPCT model provides a useful theoretical and conceptual framework, as it suggests that a young carers experiences of educational inclusion will be influenced by both their personal characteristics (including their additional educational needs), and the ways in which these interact with the features of their environment. This model reflects an overall conceptual framework that permeates the research study, from its initial conception, to research questions and design, across interview schedule development, and through the analysis and discussion of findings.

3.5.4. The Process of Analysis

The inductive analysis utilized the Braun and Clarke (2006) method to inductively derive themes from the data without a theoretical framework to filter the emerging themes. During the process of analysis, Bronfenbrenner's Systems Theory (1979) and Bioecological model (2001) were utilized to contextualize the research findings. The Braun and Clarke (2006) method divides the analytic process into six stages of analysis:

Table 3.6. The process of thematic analysis outlined by Braun & Clarke (2006).

Phase of Analysis	Description of the Process	Reflecting on Bronfenbrenner's eco-systemic model and Bioecological model during analysis
Familiarization with the data	I transcribed the initial interviews and read through the transcripts	At this stage, the overall conceptual framework of Bronfenbrenner's model was held in my mind as I drew associations between recorded findings and different systemic factors
Generating initial codes	I systematically read through each transcript and identified interesting features of the transcripts, and collated these into "codes"	During this phase of analysis I began to explicitly look for information that explicitly related to systemic factors
Searching for themes	I collated codes into potential themes. I first looked at the themes in	During this phase of analysis, whilst searching and

	isolation in each sample group, then I compared emergent themes from each sample group across all groups	grouping themes, I also began to order and group themes into different systemic levels
Reviewing themes	I checked for inconsistency between themes and data extracts, developing a thematic map of the relationship between themes	I also checked that the thematic networks were also consistent with Bronfenbrenner's model
Defining and naming themes	I refined the thematic map to ensure the themes told a consistent and understandable narrative	I began to integrate the factors emerging within Bronfenbrenner's model with the emergent themes to produce a consistent narrative
Producing the report	I selected extracts from the data to reflect the identified themes, relating these back to the research questions and the literature review.	During the writing process, I selected extracts that reflected the consistent findings across themes and systemic factors to produce an integrated discussion of the findings in light of Bronfenbrenner's model.

3.5.5. The interpretation of findings

The following chapter will provide an account of my findings as revealed through the

process of analysis. Three levels of themes are included and discussed in the following analysis: overarching themes, main themes and subthemes. Data extracts from the transcripts are produced as evidence to reinforce the clarity and cogency of the narrative I am constructing. In Chapter 5, I also offer a reflection on findings relative to the overarching deductive framework (Bronfenbrenner, 1979; 2001) and draw associations between the themes and the research questions.

3.6. Ethical Considerations

The research design and methods were informed by a variety of ethical deliberations. The research was directed by the code of behaviour defined by the Ethics Committee of the University of Birmingham and ethical authorization was approved through the Approved Ethical Review (AER) processes (Appendix 6 for the AER document presented to the review panel). During development of the study, I reflected on pertinent ethical guidelines developed by the British Psychological Society (British Psychological Society, 2009) and responded to the ethical issues raised by the current research in the following ways:

Table 3.7. Ethical issues and processes to address issues

Ethical Issue	Process by which ethical standard was upheld
Informed consent	As all the participants were over 16 years old, parental consent was not needed. All participants were fully informed of the research interests, goals, methods and were required to sign a consent sheet. (See appendix 5)
Confidentiality	All participants were assigned a unique ID code so that their identity remained confidential during the analysis phase and

	in the write-up of the results. No participant's names are used in the production of the research report, and only reference to the participant's unique ID code is made.
Right to withdrawal from the study	I have a record of the ID code/participant name so that data can be withdrawn upon request. The participant was informed prior to data collection that they may withdraw from the study at any point until one month after the completion of the project. Participants were informed when the project reached conclusion.
Risk/Distress	There was minimal risk of distress due to the use of semi-structured interviews and the focus on strengthening factors. However, participants were informed that should distress occur the participant's involvement in the interview will immediately cease and the participant will have access to counselling support available through the Educational Psychology Service. Contact details were provided for counselling support to any participants exhibiting distress during the interview process.
Storage, access, disposal of data	Audio-recorded data from the interviews of participants are stored in digital format on an encrypted USB pen, which will be

	stored in a locked cabinet which only the lead researcher has access to. Transcribed data are typed and stored in digital format on an encrypted USB pen, which will be stored in a locked cabinet that only the researcher can access.

CHAPTER 4: RESULTS AND DISCUSSION

4.1 Introduction

The analysis and written presentation of the research is what Braun and Clarke (2006) define as the final phase of the thematic analysis, when a series of complete and coherent themes has been developed.

In this chapter, I describe the findings from the data emerging from the application of a rigorous analysis, emphasizing the most salient and significant discoveries pertinent to the research questions, developing associations to the research described in chapter 2.

Braun and Clarke (2006) recognize a crucial characteristic of a thorough and precise thematic analysis is the transition from the descriptive to the analytic. Within this chapter, in addition to discussing findings in relation to the thematic map created in the course of analysis (Appendix 14), data extracts are offered as evidence to reinforce the validity of each theme in order to articulate a succinct and comprehensible narrative described by the data, across themes, and I also make connections with the integrated conceptual framework (Bronfenbrenner's eco-systemic. 1979, and bio-ecological model, 2001).

The themes discussed within the chapter have been inductively conceptualized employing the phases of thematic analysis illustrated by Braun and Clarke (2006) (see Table 3.), and attend to the research questions defined in Chapter 2, presented beneath specifically in relation to integrating the Bronfenbrenner (1979) Eco-sytemic model and the later Bio-ecological model (2001):

Figure 4.1. Summary of Key Research Questions

Research Questions:

1. What are the key eco-systemic factors that strengthen the resilience and educational inclusion of young carers with additional educational needs?

Specifically, this research is interested in factors at the meso, exo and macro-levels (Bronfenbrenner, 1979) of a young carer's environment that has had a positive impact

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on:

> *c) Psychological coping strategies and resilience for the demands of education and their caring role;*
>
> *d) Academic engagement*

3. Through what interacting mechanisms and processes, at different systemic levels, do key professionals and young carers with additional needs perceive these factors to have been effective?

I began by analysing the three data sets (young carer, Spurgeons project staff, and Student Welfare Officer) separately. By returning to the data and via the construction of a thematic map, during the following phase, I identified any variances across the data sets, and classified themes manifesting across the entire data (See Appendix 4). During the stages of analysis I reflected on my findings relative to my deductive framework in order to integrate this into my conclusions and build a broader systemic picture of the strengthening factors to educational inclusion of young carers with additional needs. This chapter sums up the consequence of this methodical system, and reflects on the representativeness of the themes.

Table 4.2. Code for participants data presented in report and their role

Participant	Role
K	Young Carer
G	Young Carer
C	Young Carer
P	Safeguarding and Student Welfare Officer
J	Safeguarding and Student Welfare Officer

SM	Project Worker (Team manager)
PW	Project Worker
AO	Project Worker

This report of the key findings is divided into several sections:

1) An overview of the overarching themes and main themes;

2) A detailed a consideration of the main themes and the associated subthemes;

3) The individual consideration of the sub-themes;

4) Following the presentation of each overarching theme I explore the findings, drawing links with the review of the literature from Chapter 2.

The following colour code is utilized for themes in all diagrams:
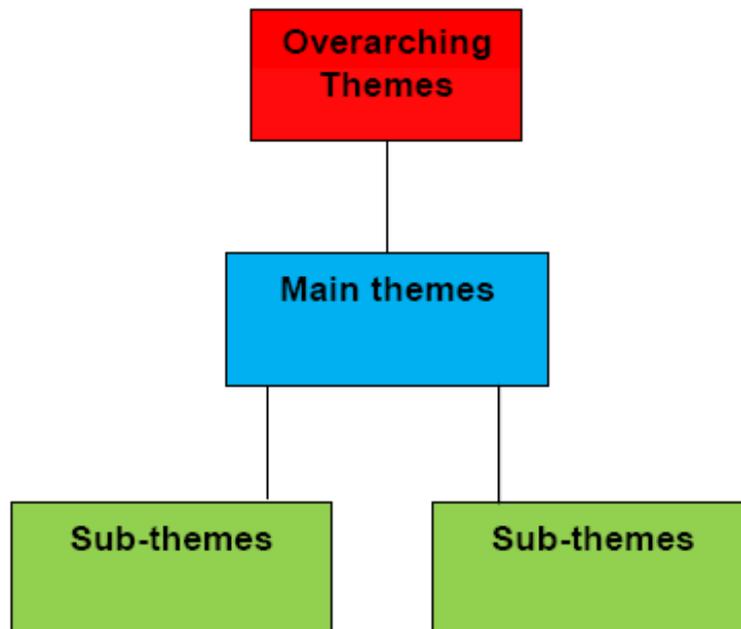
4.2. Overview of Themes

Table 4.2. and Figure 4.1 reveal the three overarching themes, comprising 6 main themes:

Table 4.2. Summary of the overarching themes and main themes.

Overarching Theme 1: Self-determination
The overarching theme of *Self-determination* referred to young carers sense of choice, voice, control and self-advocacy. Within this, two main themes emerged: • Autonomy • Self-advocacy
Overarching Theme 2: The Role of the Key Person
The overarching theme of the *Role of the Key Person* refers to the salience of a key adult support figure in the life of the young carer, excluding their parents, in mediating the young carer's experiences of caring at home and their engagement in school. The key person was likely to be a pastoral member of school staff or a Spurgeons project worker. Within this, two main themes emerged: • Key person's engagement with Young Carer Initiatives • Understanding the needs and concerns
Overarching Theme 3: Belongingness
The overarching theme of *belongingness* refers to young carers feeling of being a part of a wider community, such as school, Spurgeons or the caring community. Within this, two main themes emerged: • Sense of community and social support • The importance of shared experiences

Despite the distinction between the overarching themes and main themes, they appear to interrelate and are not exclusively independent. Figure 4.2. illustrates the interrelations between overarching themes and main themes, and associations between overarching themes are represented with bolder arrows.

Fig 4.2: Diagram showing overarching themes and main themes
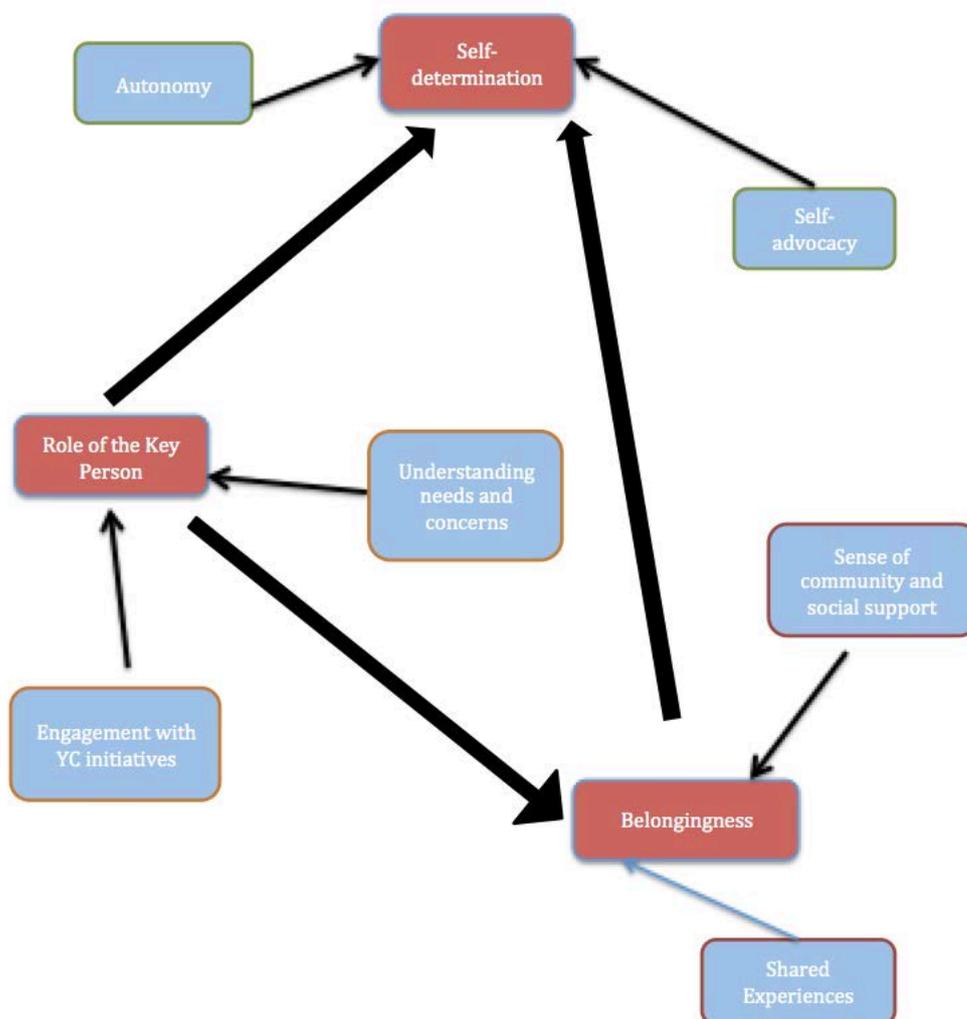
4.2.1. Systems theory as a conceptual framework

Though not always directly, the recognition that any aspect of a system can influence or be influenced by the behaviour of any other aspect, is widely established in systems models (Dowling, 2003).

Within educational environments, such as with this research, systems theory attempts to establish the influence of educational (e.g. school) and other environmental contexts (e.g. home) over the behaviour and experiences of children and young people, as well as how children and young people may exert influence over their environment (Dowling, 2003).

Systems theory in recognizes that a child's developmental progress occurs within the nested layers of their environment, such as individuals around the child to the wider socio-political landscape. Therefore I reflected that the work of Bronfenbrenner (1979, 2001) may afford a particularly constructive perspective to support understanding around the protective and strengthening factors that may support the educational inclusion of young carers with additional needs.

The findings indicate that there are salient factors and relationships appearing at every systemic level, between the macrosystem and the microsystem, as illustrated by Bronfenbrenner's systems theory (see table 4.3).These factors seem to act together, mediating the educational inclusion of young carers with additional needs. This is supported by the evidence from the literature review that also identifies the effect of systems level influences, such as schools and carer projects in influencing educational outcomes for young carers.

Table 4.3. Overview of systems defined within Bronfenbrenner's work (Bronfenbrenner, 1979) in relation to the salient research findings

Name of System	Pertinent Features of the System	Link to themes and thematic levels identified in thematic analysis	Salient findings from the research associated with this system
The Microsystem	The systems in	*4.3.1.*	- *The young*

	which the young person resides; including family, peer groups etc.	*Overarching Theme: Self determination* *4.3.1.1. Main Theme: Autonomy* *4.3.1.2. Main Theme: Self-advocacy* ***4.3.2. Overarching Theme: Role of the Key Person*** *1.) Subtheme: Understanding the care-recipients needs and concerns* *2.) Subtheme: Understanding the carer's needs and concerns*	*person's individual needs* - *Parental disability* - *Key person at school or YC project* - *Peer network and other carers*
The Meso system	Two microsystems interacting with each other. E.g. interaction	*4.3.2. Overarching Theme: Role of the Key Person*	- *Interaction between young carer and keyperson*

	between the young person and a key adult.	*4.3.2.2. Main Theme: Understanding and trust:* *1.) Subtheme: Understanding the care-recipients needs and concerns* *2.) Subtheme: Understanding the carer's needs and concerns* *4.3.3. Overarching Theme: Belonging* *1.) Subtheme: Communicating with other carers*	- *Interaction between parent and key person* - *Interaction between parent and young carer* - *Interaction between young carer and other carers*
The Exosystem	External environments which indirectly effect development. This refers to factors at the community level such as	*4.3.3. Overarching Theme: Belonging* *4.3.3.1. Main theme: Sense of "community" support and*	- *Spurgeons and the provision of safe spaces/social spaces* - *School/LA engagement with young carer*

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	schools and support services,	*understanding* *1.) Subtheme: Feeling a part of something bigger* *2.) Subtheme: Networks of resilience* *4.3.3.2. Main Theme: Shared Experiences* *2.) Subtheme: Identification of other carers*	*initiatives* - *Identification systems* - *School policy on young carers*
The Macro System	The broader socio-cultural context e.g. cultural values, socio-political contexts	*4.3.2. Overarching Theme: Role of the Key Person* *4.3.2.1. Main Theme: Key persons engagement with Young Carer initiatives* *1.) Subtheme: Media/national exposure*	- *Changes in legislation, but not change in practice* - *National exposure/media exposure* - *Socio-cultural values/perceptions around "disability"*

		2.) Subtheme: Change in legislation, but not practice *4.3.2.2. Main Theme: Understanding and trust* *1.) Subtheme: Understanding the care-recipients needs and concerns*	

The Process-Person-Context-Time (PPCT) model (Bronfenbrenner, 2001) introduced in Chapter 3, places further emphasis on the interactions within the systems and the interplay between heredity and the environment. In this research the 'proximal processes' described by this model (which were also the focus of the enquiry) were the transition planning and support experiences of the young people. This study has highlighted how these processes are influenced by features of the person, the context and time in the manner described in chapter 3.5.3. The findings are summarised directly in relation to his model in table 4.5, which also makes links to where the supporting data can be found. This again supports the view that educational experiences and outcomes are a function of the features of the child, the features of their environment and the interactions between them.

The Process-Person-Context-Time (PPCT) model considers development as a product of increasingly complex reciprocal interactions (processes) between an active and evolving person and objects, and/or symbols within their immediate environment. The model also highlights that interactions (proximal processes) must occur on a regular basis over an extended period of time to be effective. Acknowledgement of the

significance of both the duration and timing of experience is reflected in Bronfenbrenner's addition of the chronosystem, described as the patterning of environmental events and transitions over the life course (Bronfenbrenner, 2001) to his original (1979) framework.

Table 4.5: Process, Person, Context time (PPCT) Model (Bronfenbrenner, 2001) applied to this research

Feature of the PPCT model	Associated Research Findings	Links to data and research findings
Process: "Proximal processes": interactions over time between self and environment. In this study the proximal processes of focus were those associated with transition planning and support	The young carers experience of educational inclusion is influenced by a range of interactions between characteristics of features of a young person (including his/her AEN) and aspects of each of the 4 levels of nested systems within his/her life would.	Differential perspectives highlighted in theme 4.3.2. outline the differing narratives in regard to the role played by the key person. The interactions between the pupils and the key person is the key proximal process highlighted by the research, as it emerged as being particularly influential in facilitating young carers educational inclusion. Pupil ⬌ key person (See theme 4.3.2) Supporting quotes from theme 4.3.2; *"Or understand that parents actually can't come into school, t-to have conversations, or y'know they're gonna miss parents evening. It's not that they're not bothered, it's that they can't actually do these things. So it's just, it starts at a very basic"* (project worker) *"which, like, when I felt down he would come to me and he would, like, see, it would be well a couple of students said that you've come down, you felt down or, the, I'd go into his office and sit there and we'd talk about how the days been and he'd write it up and goes, well, what we'll*

		do tomorrow is when you come in we'll sort all these problems out together and see how you feel after that" (Participant K)
Person: Biological aspects of the young person. Demand (e.g. gender, age, ethnicity) Resource (e.g. mental and emotional resources, such as skills and intelligence) Force (e.g. temperament, motivation and persistence)	• The young people's additional needs affected their personal resources in terms of being able to effectively engage in education • More specifically, the young people shared a common feature of lack of involvement and engagement in a meaningful decision-making processes linked to the support for their additional educational needs.	The following themes highlight the aspects of the research findings relating to the personal features of the young people. • The vulnerability of young carers with additional needs to poorer educational experiences: "Um…ah…um I had to be in a different room to do my work." (Participant G) "You had to be in a different room to do your work?" (Interviewer) "Yeah." (Participant G) "Right, OK. Was that because you were a young carer or was that because of your anxiety?" (Interviewer) "Um…um…uh my anxiety." (Participant G) • The relationship between young carers individual additional needs and their need for self-determination (Theme 4.3.1.) "If you could, you know, go back in time and, and, well first of all, were you, you know, did they ever talk to you about, in a sense like, what, you know, what kind of support, euh, every ask you, you know, what kind of support do you, would you need or anything like that? (Interviewer) "No, they never asked me about that.." (Participant K) "No." (Interviewer) "..never got told anything that or, like, asked or anything." (Participant K)

Context: Interrelated systems -Microsystems - mesosystem - exosystem - macrosystem	1) Meso interactions (interactions between Microsystems) were significant in mediating the transition experiences of the young people. 2) Not all of these factors operated directly on the young people. 3) There appears to be significant features of wider systems that influence the transition planning experiences.	Links with the data: 1) Significant meso-system interactions evident in the data: • Young Carer ◄─► Key person (see theme 4.3.2) • Young Carer ◄─► Other young carers (see theme 4.3.3.2 (ii)) • Young Carer ◄─► Spurgeons Project Workers (see theme 4.3.3.1) 2) Indirect influential interactions: • Key person ◄─► Parents (See themes 4.3.2.2. (i) Supporting quotes*:* *" Which is why we have to come in, 'cause a lot of times it's things like, if you're saying 'right, your son has been a bit disruptive in class, he's tired all the time, he's not doing his homework, can you come in please and have a meeting with us?'. No. A lot of the time they can't. And then those parents are then labelled as awkward parents that won't engage…" (Participant SM)* • School ◄─► Carers (see theme 4.3.3.2. (ii) – school systems around identifying young carers. Supporting quote: *"And that's just from a couple of schools, so if were able to go, or a video could be put out or a checklist*

		was done once every six months, how long would that take a school to give a young person a checklist, 'do you have, is this happening in your home?.... And it could make a huge difference for them, knowing that there's other carers out there, y'know, even in their same school, that they could talk too and share things with." (Participant PW) 3.) Other influential factors part of the exo-system and the macrosytem: • Community influences (see theme 4.3.2.2.(ii)) – e.g.: stigmatizing socio-cultural values around disability • Family influences (See theme 4.3.2.2.(ii))– e.g. parental concerns that children will be "taken away" • Policy influences (See theme 4.3.2.1.(ii)) - The influence of the Young Carers Needs Assessment and the incongruence between legislation and practice.

Time (Chronosystem):	1) At a micro and meso-level inclusive educational experiences were, over time, mediated by frequency and consistency of interaction with the key person, other carers and interaction with curricular stages	Links to the data:
Micro time: happens during a specific interaction		1) Micro time
Meso time: the extent to which activities occur with some degree consistency		• Developing understanding between young carer and key person (theme 4.3.2.2. (ii)):
Macro time:		*"And was that something, so, that, with that particular teacher or were there other teachers and stuff like that.*
• the timing of events, experiences within the developmental life span		*There was that teacher and like my head of year...which, like, when I felt down he would come to me and he would, like, see, it would be well a couple of students said that you've come down, you felt down or, the, I'd go into his office and sit there and we'd talk about how the days been and he'd write it up and goes, well, what we'll do tomorrow is when you come in we'll sort all these problems out together and see how you feel after that." (Participant C)*
• specific salient historical events happening at that moment in time.	2) At the exo- and macro-levels inclusive educational experiences were, over time, mediated by developments in social policy, media exposure and school systems for the early identification of young carers	• Shared experiences over time with other young carers (theme 4.3.3.2 (i):
		"Spurgeons is quite good cause, it may be only every two weeks, but it's that release to come away from everything. To actually spend time and talk to other people about it that can understand, and it gives you just some time to realise, like, you're doing something good and you're helping." (Participant K)
		2) Macro time
		• Incongruence between development of young carers needs assessment in practice

			and the administration of the assessment in practice (theme 4.3.2.1.(ii))
			"That there was a standardized, a standardized assessment tool. At the moment each local authority has been left to do it however they want to do it, so if (named local authority) adult carer support are going out to do assessments with adults and on their assessment there isn't a question to ask 'is the young person in the house a carer? A young carer?' Why? Why has that not happened?" (Participant SM)
			• Developing awareness and recognition of young carers in media over time (theme 4.3.2.1. (i)):
			"And I think…I, y'know, in the time that I've been working with young carers there is more awareness, that is a positive thing, y'know in the last year, 18 months it's, that's…and just in the media and y'know now if you go back even 12, 18 months any program about young carers would be on at, y'know, 11 o'clock at night where no one saw it on some obscure channel now it's more in mainstream" (Participant SM)
			• Developing school systems for early identification of young carers, particularly during school transitions (theme 4.3.3.2. (ii)):
			"The new all age carer's strategy in (named Local Authority) has been written very much with young carers in mind. They've consulted with all our young carers, with our help. There's new, there's an implementation group, so the things that the young people were saying,

		they will be put in place, and a lot of that is around schools. Is around schools knowing that they're young carers and being able to support them." (Partipant SM)

4.3. Analysis of Themes

4.3.1. Overarching Theme: Self determination
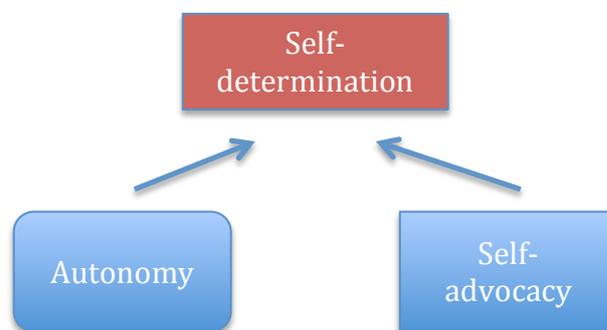
```
          ┌────────────────┐
          │     Self-      │
          │ determination  │
          └────────────────┘
           ↑              ↑
     ┌──────────┐    ┌──────────┐
     │ Autonomy │    │  Self-   │
     │          │    │ advocacy │
     └──────────┘    └──────────┘
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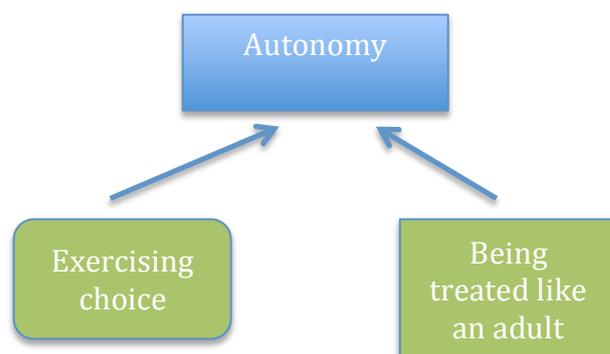
1.) Subtheme: Exercising choice

2.) Subtheme: Being treated like an adult

 Autonomy was a main theme to emerge under the overarching theme of self-determination. The data suggested that a key aspect of young carers positive adjustment in education is the perceived sense of choice and autonomy at school and in decisions made. When asked about the positive differences that schools could make for young carers to support their engagement, participants who were carers themselves spoke of the need to feel "treated differently, but in a good way" and "treated like an adult". One participant identified that he had had no say in the support that was offered to him around his caring duties or his additional needs:

"If I could go back in time and tell my school to do something differently, I would ask them to talk to me, ask me about what kinds of support I want." (Participant K)

Data from participants in the young carers cohort also captured that carers who felt a greater independence and choice in lessons and activities also strengthened their participation in school.

Examples emerging from the data supporting the "exercising choice" subtheme

Participant K
Interviewer: Mmh, mmh. What, what, what made it, what made the experiences, so you said you have, ehm, you had good days and bad days, time when you were very

---

sad, times when you were very happy, what, what characteri-, what made the difference if you were happy or if you were sad?

Participant K: What made the difference is, euh, the teachers and like, actually choosing to do some things that I actually like to do, cause I know every kid says it, that they don't want to do certain lessons, but..

Examples emerging from the data supporting the "being treated like an adult" theme

Participant G

Interviewer: OK. Was it…is there anything else about sixth form that's better? Or making it better for you other than the lessons like, have relationships changed, have teachers changed, that kind of thing?

Participant G: Um…I say uh…um..uh…hard to describe it really. Um…um…um I'd say it's the way I've been treated in sixth form's changed 'cause…

Interviewer: Yeah?

Participant G: Like in school you're treated as children but in sixth form you're treated as adults.

Interviewer: And that's made you feel, better?

Participant G: Yeah.

Interviewer: Yeah. Um, how do you feel? Y'know now..treated...being treated like an adult, I suppose?

4.3.1.2. Main Theme: Self-advocacy
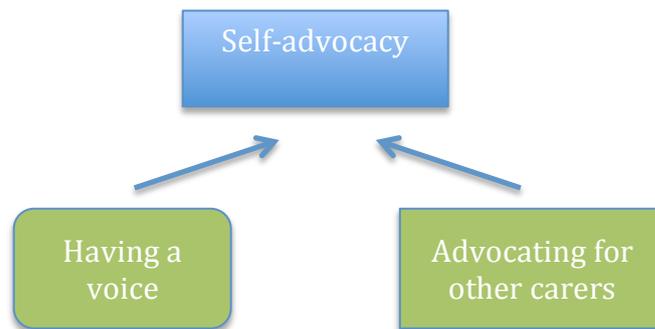
1.) Subtheme: Having a voice

2.) Subtheme: Advocating for other carers

The sense of agency to advocate for ones self emerged as a main theme under the overarching theme of self-determination. Data from participants in the young carer cohort reveal the importance of "having a voice that was heard" particularly in decision- making. The participants in the young carer cohort indicate that schools and young carer projects have a key role in facilitating feelings of self-advocacy and personal agency, as the trusting relationships they built with key adults gave confidence to their growing "voice".

Data from participants in the student welfare officer group reveal that opportunities to advocate for other carers facilitated their overall engagement with school. Young carers had the opportunity to take an active role in awareness-raising and advocacy of young carers through contributions to carers festivals, volunteering for projects and engaging with carer initiatives. This has important implications at the microsystem (Bronfenbrenner, 1979) and the concept of reciprocity (individuals reciprocally influencing the higher levels of their environmental system).

Examples emerging from the data supporting the " having a voice" subtheme

Participant G

Interviewer: No. OK… OK. Just in terms of, sort of, Spurgeons, how have they

helped you, would you say?

Participant G: Well by being here I think I've got my voice.

Interviewer: Got your voice?

Participant: Back. And able to talk a bit more. Well by having um counselling made my confidence um go stronger.

Interviewer: Now has she helped you in any way with those? Or even with the caregiving?

Participant G: There's been like some…She's kind of like been there to like boost up the confidence for like the anxiety.

Interviewer: Is there anything that she does in particular that's very good at all?

Participant G: Not really, but I guess she has just given me the confidence to speak up for myself

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Examples emerging from the data supporting the "advocating for other carers" subtheme

Participant P

Interviewer: What has been important for engaging young carers in your support group and school generally?

Participant P: Well, we give them chances to really share their lives and experiences as young carers and advocate for other young carers, so they become more involved around school and the community. We have ran our own fundraising events, asking carers to become involved and write to supermarkets to raise money. The carers were actively involved in the fund-raising…..one of our young carers also did a presentation for the rotary club because they had made a donation to us. They talked about how this money was being used and where it was going. They learnt a lot about this young person, what he was interested in, the young persons confidence around school grew tremendously. Our carers worked with Spurgeons to make a film….
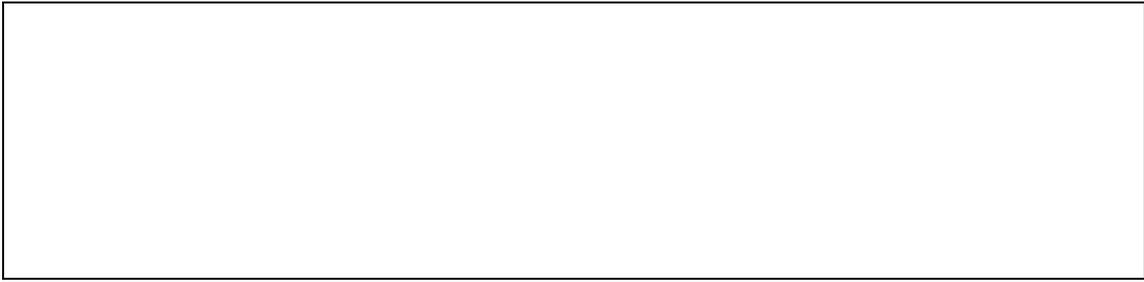
4. 3. 1. 3. Integrating systems theory around the Overarching Theme of Self-determination

Responses organized into the overarching theme of "self-determination" reveal that the sense of agency young carers are able to exercise appears to be associated with carers' motivation to engage with education. Self-determination was also related to the two main themes of choice and control, and self-advocacy.

These findings draw important links to Systems Theory (1979), specifically, the microsystem and Bronfenbrenner's (1979) concept of "reciprocity", that is, these findings suggest young carers can exert some reciprocal influence over systems that influence their engagement with education. In what Bronfenbrenner (1979) terms "reciprocity", the child is perceived as a participant with active agency affecting, as well as being affected, by the socio-cultural environment. For example, Grant et al (2008) demonstrates how the young carer can be seen as reciprocally affecting their microsystems and cites the example of some young carers taking the initiative to lead educational involvement over the issue of young carers to the broader public (i.e. at different levels with their ecological system) having had a their sense of meaning engendered through their actions and accomplishments at a support group. Similarly, in the findings from the current research, the active participation of carers in raising awareness and advocating for young carers was an influencing factor for schools to raise the support of young carers as a school priority, as well as for carers to find greater meaning and purpose in their caring identity.

The concept of reciprocity emerges from the main theme of self-advocacy. Participants in the safeguarding and student welfare officer sample report that positive engagement with the carer support group and school was associated with

opportunities to participate in raising-awareness, fund-raising and advocating for young carers. In one extract, the participant describes how one carer gave a presentation on her experiences as a young carer to the rotary club as particularly strengthening her overall engagement with school and the support group. It is possible that the confidence to self-advocate also emerges from the feeling of "having a voice". In the data, participants speak of the role young carer projects and key persons have in developing their confidence to "speak out". This theme may also be associated with the overarching theme of belongingness, as carers who engaged with the carer projects and support groups report feeling more confident, and less isolated or withdrawn, and together may act to strengthen the carers identity by immersing themselves in the role of a young carer. This is supported by evidence from Bolas et al. (2007) who identified that the integration of caregiving as part of the carer's identity provided a consistent positive enhancement to their self-esteem. The author indicates that carers draw heavily on idealized positive images of carers to support feelings of normality, self-esteem and pride, which young carer projects may provide. Nevertheless, despite this example, the findings from the research generally support the view that young carers have few opportunities to exert influence over systems around education and social support.

In light of previous research that the distinguishing feature of young carers from other children caring for loved ones is the lack of choice in undertaking the caring role (Aldridge and Becker, 2008), the role of self-determination in engagement at school may reflect young carer need for autonomy and the opportunity to "take control" over the destination in which they feel there lives may be moving. This is supported by Packenham et al. (2007) who found that a key predictor in young carers' positive adjustment to caring was the perception of choice in their caring role. Greater perceived choice in their caring role correlated highly with more adaptive coping mechanisms, positive outcomes and lower levels of distress.

Autonomy is the central component in Deci and Ryan's (2002) explanatory framework for human motivation, Self-determination Theory (Deci and Ryan, 2002). Indeed, the perceived sense of autonomy has strong predictive utility in forecasting levels of engagement of school-age children in education (Deci et al., 1991; Jang, 2008).

Participants in the carers sample also expressed the desire to be treated like an adult, by being included in discussions around their support needs and educational experiences. In a reversal of traditional family roles, carers often find themselves caring for their parent, these circumstances, Odell (2010) describes as being the "parent's parent" or "parentified children", and are engaging in duties and responsibilities typically identified as being the province of mature adults e.g. intensive physical care, household duties and management of finances. As such, under these circumstances, carers may feel that due to the reversal of responsibilities and the adoption of adult activities in their family lives they should be afforded the commensurate level of agency in other areas of life such a schooling. To be treated like a "child" may deny the sense of personal growth and maturity that many carers feel they possess due to the activities they typically engage in at home, and may feel like a rejection of their identity as young carers.

4.3.2. Overarching Theme: Role of the Key Person
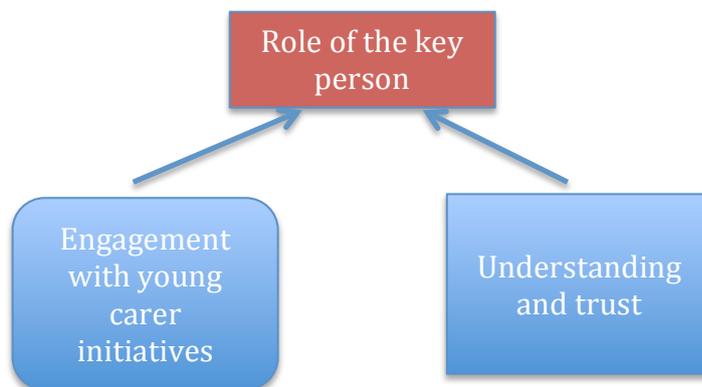
4.3.2.1. Main Theme: Key persons engagement with Young Carer initiatives
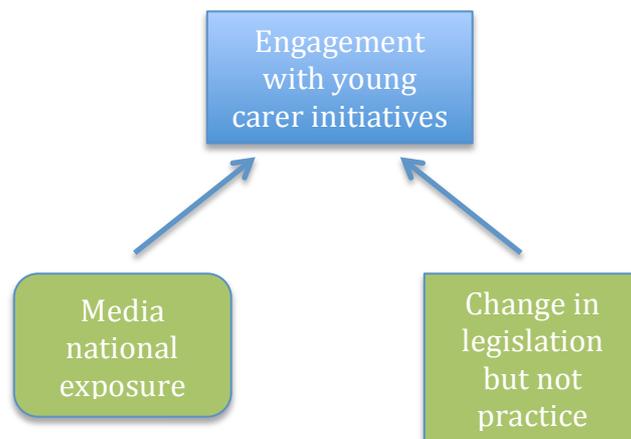
1.) Subtheme: Media/national exposure

2.) Subtheme: Change in legislation, but not practice

The influence of media exposure and national awareness emerged as important themes that had an indirect impact on young carers educational inclusion.

"I think there is a lot more awareness of the young carers and I think really that was because, I think Cameron's son wasn't very well. And they put a little ring fence around things? I think there was a massive big young carers centre and that is obviously, awareness. There is also that JLS pop star, wasn't he a young carer, they did a thing on channel 4 for that and that was in the last 2 years." (Participant AO)

In the examples highlighted, increased media exposure had galvanized some schools response, through the key person, to the issue of young carers and also provided opportunities for young carers to self-advocate and have influence at exo- and macro-systemic levels. Increased media exposure was associated with schools "buying-in" to young carer initiatives (e.g. young carers champion awards) and raising young carers as a priority, through the key person:

"but if it's not a priority in that school then...they're not going to be looking out for them, they're not going to be having, y'know, there's lots and lots of different things that schools can do to support and sometimes you just need someone in school to raise the attention, get some exposure...y'know you can have young carers champions you can be... carers trust do school awards that you can work towards, bronze, silver and gold" (Participant SM)

The findings also indicate the importance of macrosystem processes impacting on the educational inclusion of young carers with additional needs. For instance, data from the project workers sample also highlighted the changes in legislation following the Children and Families Act 2014 which entitles carers to a young carers needs assessment, but also highlights problems with the practical implementation of the policy, as there has been little guidance or direction as to which services should be carrying out assessments. This can have a direct impact on the support carers receive and consequently influence their engagement with school.

Examples emerging from the data supporting the "media/national exposure" theme

Participant AO

Interviewer: Alright, that's fine, I was thinking now at the national context, with young carers as a whole, what is your opinion around if there is any change around young carers in national contexts, new initiatives, drives, public changes in legislation, anything you are familiar with that have had an impact on young carers?

Participant AO: I think there is a lot more awareness of the young carers and I think really that was because, I think Cameron's son wasn't very well. And they put a little ring fence around things? I think there was a massive big young carers centre and that is obviously, awareness. There is also that JLS pop star, wasn't he a young carer, they did a thing on channel 4 for that and that was in the last 2 years. I think there is a bit more awareness. But there is some more, I think I heard some things on the radio, like young carers award, but I don't think there is much else. Some schools really like the press attention, and will get more involved because of it.

Participant SM

Participant SM: Yeah, so then you get that in schools as well. So, y'know, we go into schools, we do assemblies and we still get teachers even now coming up to us and saying "I didn't know, I didn't know that this is what they did, I didn't know that this is what young carers are". And that's, that's really…it's awful, but now, you still have…but if it's not a priority in that school then…they're not going to be looking out for them, they're not going to be having, y'know, there's lots and lots of different things that schools can do to support and sometimes you just need someone in school to raise the attention, get some exposure…y'know you can have young carers champions you can be… carers trust do school awards that you can work towards, bronze, silver and gold,…

Participant SM: To change. And I think…I, y'know, in the time that I've been working with young carers there is more awareness, that is a positive thing, y'know in the last year, 18 months it's, that's…and just in the media and y'know now if you go back even 12, 18 months any program about young carers would be on at, y'know, 11 o'clock at night where no one saw it on some obscure channel now it's more in mainstream. There was something on, was it, Children in Need recently, and it was, Nick Knowles, that program, D.I.Y. S.O.S. and they built, they transformed this old building into this fantastic space for young carers and the amount of people that I spoke to the day after that said 'I saw that program, I wanna do something, can I help? Can I volunteer? '. It's things like that that make a difference because it's suddenly, these are young carers and people are seeing it on mainstream telly at a reasonable time when they can see it and it's suddenly 'I didn't know this, I didn't know this…happened".

Examples emerging from the data supporting the "changes in legislation, not change in practice" theme

Participant SM

Participant SM: That there was a standardized, a standardized assessment tool. At the moment each local authority has been left to do it however they want to do it, so if (named local authority) adult carer support are going out to do assessments with adults and on their assessment there isn't a question to ask 'is the young person in the house a carer? A young carer?' Why? Why has that not happened? So each local authority, yeah we've got this new brilliant legislation, young carers are being recognised but no one's said how this needs to be done. So some people are doing it really well, some people aren't. In (named neighbouring Local Authority) they decided to go through the early help route, so all referrals then go to this early help, single point of access and then the referrals are meant to be allocated out. We're not getting them so, those young carers are being missed. So in terms of national legislation there needs to be a 'this is what you do'. This is a young carers' assessment, this is the way you have to do it. And in schools there has to be some, it needs to be some sort of legislation so schools are required to have…

Participant PW

Participant PW: There's supposed to be. There's supposed to be. I could reel off three or four schools now and just turn around and say… If I go in and say 'can I have a look at your young carers policy?'. 'We don't have one'. I'd like to think that a policy in every school – it could be a bog standard local authority one, you know? I mean (named Local Authority) do a lot for Young Carers because obviously they fund us, you know, it's a big thing in their budget every year to make sure that they're catered for, so I just wish that they could put that policy out there into schools.

4.3.2.2. Main Theme: Understanding and trust
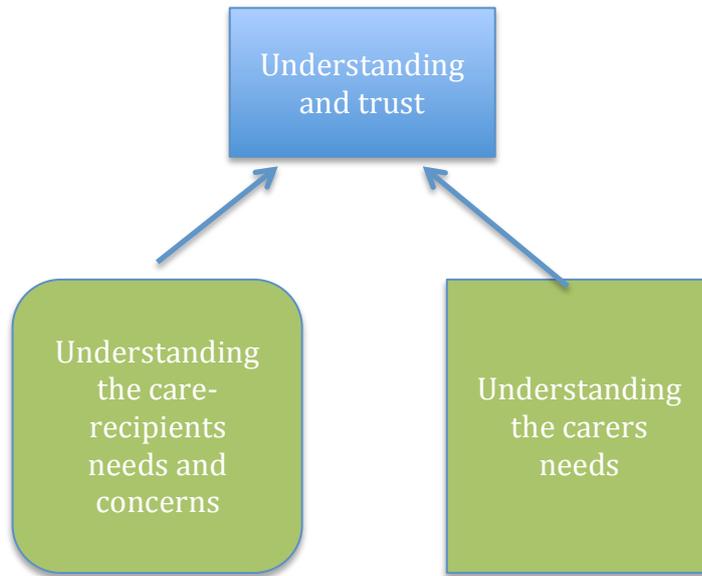
1.) Subtheme: Understanding the care-recipients needs and concerns

2.) Subtheme: Understanding the carer's needs and concerns

An understanding and trusting relationship with the key person in school emerged from the data, as an important theme for young carers' engagement in school. This also has important links with factors at the macrosystem associated with the integration of systems theory during the analytical process. This are also significant proximal processes (Bioecological model, Bronfenbrenner, 2001) as the interactions between the pupils and the key person is the key proximal process highlighted by the research, as it emerged as being particularly influential on facilitating young carers educational inclusion. In particular, the understanding of the parents' needs and disability was a salient factor in bridging the relationship between school and families of carers, reducing stigma around caring and disability, changing perceptions of school as a supportive institution, and facilitating carers in accessing external social support.

"Or understand that parents actually can't come into school, t-to have conversations, or y'know they're gonna miss parents evening. It's not that they're not bothered, it's

that they can't actually do these things. So it's just, it starts at a very basic" (project worker) (Participant SM)

The relationship between the carer and the key person was also crucial to supporting engagement in school. The data reveals that carers perceived approachable and empathetic school staff as providing emotional respite and safe spaces in times of distress. Carers felt they were understood by these key persons, and trusted them enough to "open up".

Examples emerging from the data supporting the "understanding the care-recipients needs" theme

Participant SM

Interviewer: Thank you. Do you know much about how schools communicate with the parents of young carers or families of young carers? If they are aware that the child…

Participant SM: I don't think they do, particularly.

Interviewer: 'cause I was thinking about like, y'know, obviously parents of young carers may find it difficult to obviously go into…

Participant SM: Which is why we have to come in, 'cause a lot of times it's things like, if you're saying 'right, your son has been a bit disruptive in class, he's tired all the time, he's not doing his homework, can you come in please and have a meeting with us?'. No. A lot of the time they can't. And then those parents are then labelled as awkward parents that won't engage, that won't…and there's a reluctance amongst parents to actually say 'well I can't, y'know, this is…' it's secret isn't it a lot of the time, and I think if, if awareness was greater then it wouldn't need to be and parents would not be worried that actually someone's gonna come in and say that 'you're not looking after your children properly, we're gonna take them from you'. So they'd be more willing to say 'I can't' because…and it's not every parent, some parents have good relationships and work well with schools but there's still an awful lot that, that don't, and we have to step in and speak on their behalf

Interviewer: Awareness?

Participant SM: That awareness. And them being able to implement some sort of support. And the schools that work best with young carers are those that go the extra mile, y'know those that have, y'know, a lunchtime drop in for young carers. Those that will have… y'know make allowances around…homework. Or understand that parents actually can't come into school, t-to have conversations, or y'know they're gonna miss parents evening. It's not that they're not bothered, it's that they can't actually do these things. So it's just, it starts at a very basic…

Participant PW

Participant PW: Only if the school know that that person is a young carer. It quite often comes to light in SEN meetings or child protection meetings that the school are not actually aware that we're involved with the young people, 'why are they a young carer?'. A lot of schools disregard drug and alcohol abuse as a disability, which I can't understand, you know mental health that's another one. You know, 'that's just a bit of depression'. It's not just a bit of depression, it's affecting everyday life, if that parent can't function then that child's not going to function.

Participant PW:…..'Cause you're coming home from school and you've got to switch off from student mode and go straight into working mode. This is why people have carers going in to do these jobs, and there's thousands and thousands of young people that are doing it, and they're not known about doing it. And I think that on the census as well, I'll admit it I did it when my daughter was younger, you're scared to tick that box, to turn round and say 'yes I've got a disabled person in this household, and yes we do care for this person alone' because then you become a statistic. And a lot of parents think that because its got that code number at the top that it links them to that address and they're frightened that [inaudible]. It's a lot of loopholes and these parents are frightened that their kids will be taken away

Interviewer: Do you think it's difficult for young carers to be frank with their families I suppose?

Participant PW: I think they're frightened to tell people how they're really feeling because there's a lot of stigma attached to home lives, if a child goes into school and

says 'I really can't cope with lifting my mum in and out of bed and doing this doing that' then the first thing the parents will 'social care is gonna be in now'. The parents don't understand that the help and support is there for them. Because I've spoken to many parents where I've rang social care, disability social care myself and said 'I really think this family could do with an assessment'. They've got no interaction, there's no care packages around them, you could have a 13 year old girl that's dressing and washing dad, which isn't the best, and vice versa, you could have a boy that's dealing with mum. They're too frightened to ask for that help and support and then that in turn makes the young carers frightened to tell the parents how they're actually feeling because they're frightened that they're gonna tip them.

Examples emerging from the data supporting the "understanding carers needs " theme

Participant K

Interviewer: And was that something, so, that, with that particular teacher or were there other teachers and stuff like that.

Participant K: There was that teacher and like my head of year..

Interviewer: Yeah.

Participant K: ..Which, like, when I felt down he would come to me and he would, like, see, it would be well a couple of students said that you've come down, you felt down or, the, I'd go into his office and sit there and we'd talk about how the days been and he'd write it up and goes, well, what we'll do tomorrow is when you come in we'll sort all these problems out together and see how you feel after that.

Participant K: ..Sometimes I'd get pulled over in the school for like, being down, and they'd pull me to the teachers and that, like, I knew got on and they would help me through it, they would sit down and talk to me and they would explain things to me that I didn't get in the first place. Like when I had the argument with my mum

sometimes they would explain why. They actually made me lis-, see sense and see, like, why she did that and why it happened but that's what helped me through it. And knowing that them teachers that helped me, I've already said to them thanks for what they've done.

Participant G

Interviewer: And how would charac…how would describe that relationship?
Participant G: Um…I can trust her…
Interviewer: You can trust her?
Participant: With what I say and tell her.

Participant G: They like say if I need to talk to some then just to go to them.
Interviewer: If you need to talk to someone just go to them?
Participant G: Yeah.
Interviewer: And did you go and talk to them?
Participant G: Yeah.

Participant C

Interviewer: Now has she helped you in any way with those? Or even with the caregiving?
Participant C: There's been like some…She's kind of like been there to like boost up the confidence for like the anxiety.

4.3.2.3. Integrating systems theory around the Overarching Theme of the Role of the Key Person

The narratives in the data indicate that the key person has a crucial role in developing and sustaining the young carers engagement in school and also engaging the wider community in supporting and developing young carer initiatives. Roberts (2008) suggests that schools could be viewed as important sites of resilience-building for young carers, and Becker and Becker (2008) indicate that, when carers encountered understanding adults who gave them recognition and support, carers were more likely to perceive school as a positive experience.

The findings indicate that there are important systemic level interactions involving the keyperson at the mesosystem, exosystem and macrosystem. For instance, at the mesosystem, data from the carers sample indicate that the key person serves an important function in positive school adjustment. Carers identify the relationship they have with the key person as mediating the difficulties between caregiving and the potential stress of schooling. This also links with the chronosystem (Bronfenbrenner, 2001) in that at a micro and meso-level inclusive educational experiences were, over time, mediated by frequency and consistency of interaction with the key person, other carers and interaction with curricular stages.

In particular, carers noted that the recognition, understanding and emotional support that the key person was able to provide, had significance in reframing school as a "safe space" and proved to be a significant strengthening factor for their continuing participation in school. This finding is consistent with previous research that a positive and understanding relationship with a key adult figure can act as a salient protective factor, or "safe haven" (Barry, 2010) from which young carers can engage with the wider school (Barry, 2010; Warren, 2007; Altschuler et al, 1999). Barry (2010) also identifies that of the young carers who perceived school positively, most indicated that it was the relationship with a particular teacher that would most likely influence that perception. For instance, some carers identified specific teachers who were aware of the context of their caring and were empathetic and willing to make allowances in their expectations for schoolwork, if there were factors at home that were impeding the carer from producing school work.

The keyworker at school emerged as an individual well placed to provide emotional and psychological support to young carers, as well as families of carers, and

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coordinate and plan support with other services e.g. Spurgeons. A significant strengthening factor for a carer's educational inclusion related to how well the key person developed their relationship with the young carer. Carers reported that the key person had empathy and understanding for their caring role, and made allowances for carers in relation to the production of schoolwork. The key worker also had an important role in mediating a carer's feelings of agency and autonomy, by being sensitive to carers desire to be "treated like an adult", and by supporting and encouraging carers to engage in self-advocacy activities and awareness-raising initiatives, around the young carers agenda.

The role of the key person is recognized by the Department of Health and the Department for Education in their Good Practice Guidelines for Supporting Young Carers (DoH, 1999; DfEE, 1999), which identifies the key person in school for young carers to link with other services as an important practice. However, an important finding, at the exosystem, was that most of the key practice guidelines were not being implemented, and it appears there is a lack of awareness among schools that these guidelines even exist. In particular, participants from the project worker sample expressed the lack of any particular systems, practices or policies to identify carers in schools.

The understanding of the care-recipients needs was an important meso-level factor to emerge from the data, and the meso-level interactions of the key person in school played a significant role in mediating the reciprocal concerns of the care-recipient and the carer. The reciprocal worries and fears that carers and their disabled family members endure relate to beliefs that local authority social services will "take away" the young person. A consistent finding within the literature is that young carers and their care recipients worry that to the wider community, the circumstances of their caring is "abnormal" or "disordered"(Kavanaugh et al, 2015) and thus secrecy, beyond the family dynamics, is paramount in order to prevent social services from interfering (Cree, 2003; Thomas, 2007; Bolas et al, 2007). Indeed, these fears have some basis in fact as according to the Department for Children, Schools and Families (2009) there were approximately 5% of young carers entering state care because of parental illness or disability in 2008. Dearden and Becker (2005) also identify this as the third most common reason for a child entering care in England. According to the

model identified in the findings of this study, meaningful meso-level interactions can affect the young carers' engagement and motivation in education, either directly or indirectly. These interactions between the school and the families of carers (e.g. care recipient) were highlighted as significant factors impacting on carers' engagement. If the school, via the key person, was sensitive to the parents (care recipients) disability and needs, this positively impacted on carers' engagement in school indirectly by reducing the stigma associated with the disability and mediating parental concerns that the young carer will be taken into social care. In this way, the school and key person have a crucial role to play in how families engage with schools and access social support. This is likely to have important repercussions for young carers as reduced stigma and worries regarding social care, and increased understanding and social support are likely to allow the carer to increase their participation and inclusion in school life.

Acting indirectly on the young person, the broader political and socio-cultural milieu in which the child is located is known as the macro system. The indirect influence of the macro system can occur through mechanisms such as value systems, media, government policy and the broader socio-economic climate. Related to the subthemes above, findings to emerge from the data also indicate that the stigmatization of the care-recipient also has a significant role in how young carers engage in school. Data from participants indicate that school staff can hold obstructive and unsupportive constructions of disability such as pathologising perspectives of disabled parents as "awkward" or "difficult", and substance addiction "as not really a disability". These findings reveal that the wider socio-cultural values and attitudes regarding disability, at the macrosystem created climates of mutual mistrust between schools and parents, and negative constructions of disability that further stigmatized carers and their families, increasing the withdrawal of carers and their families from school and the community. This is supported by Bolas et al., (2007) who found that young carers "isolation" and "distancing from others" were associated with feelings of stigmatization in both their role as a carer and also by association with people experiencing disability, leading to secrecy around their caring role, the fear of rejection and misunderstanding, which ultimately left carers feeling excluded from the social world and reduced their access to social support.

The influence of government policy and legislation around young carers, namely, the Care Act (2014) and the Children and Families Act (2014) was revealed through the research findings to be the most pertinent macro-systemic influence. These laws guarantee that identified young carers have the right to a young carers needs assessment, however, narratives from project workers and student welfare officers reveal significant incongruence between written legislation and espoused practice. Specifically, the admission that whilst the law has guaranteed the young carers needs assessment, it does not specify which service or agency has designated responsible for carrying out these assessments. Project workers and student welfare officers were under the impression that these assessments were implicitly left under the purview of social care services, but competing pressures in these services meant these assessments were under-prioritized by social workers. This also links with the chronosystem, as developments over time in policy around young carers, such as the Young Carers Needs Assessment has repercussions for other systems and the overall support of young carers. These effects on the support of young carers are mediated by the inconsistency and incongruence between the espoused legislation around the assessment, and the administration of the assessment in practice.

Findings also reveal that specific interactions between the macro-system and the meso-system contributed to young carers inclusion in school. Significant positive change in school support and action around young carers, generally emerged after significant media attention or national exposure. For instance, the appearance of a young carer on a national TV programme, advocating for young carers, galvanized their school into developing a young carer support group and liaising with the local young carer project, Spurgeons. This also links with the chronosystem, as developments over time in recognition and awareness of young carers within the media, affirmed positive identity construction around young caregiving and stimulated increasing self-efficacy for young carers to reciprocally affect their environment through their own awareness-raising.

4.3.3. Overarching Theme: Belonging
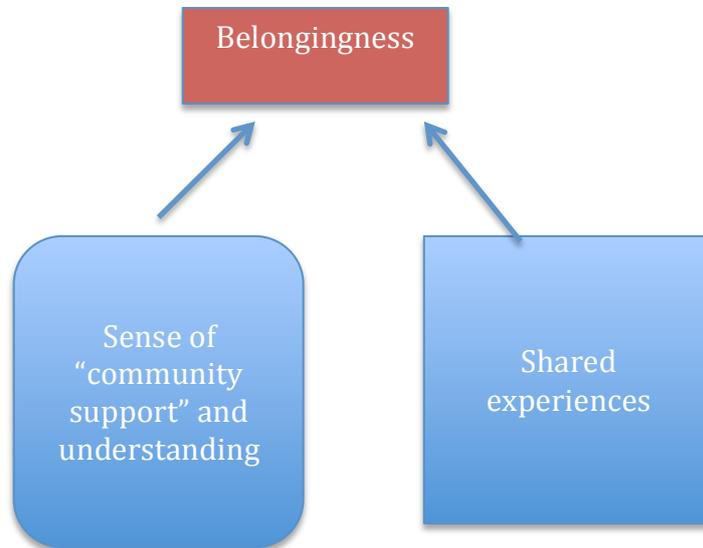
4.3.3.1. Main theme: Sense of "community" support and understanding
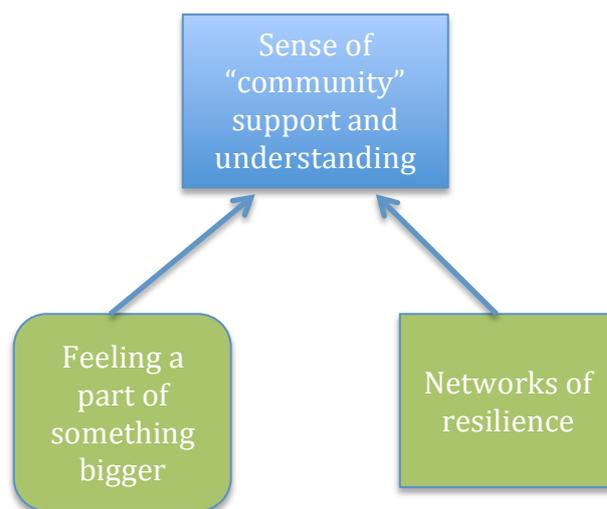
1.) Subtheme: Feeling a part of something bigger

2.) Subtheme: Networks of resilience

The data reveals that carers considered the feeling that they were "part of something bigger" to be a significant strengthening factor to school inclusion. Feeling a part of the school community mediated feelings of loneliness and isolation associated with being a young carer:

"I guess just being like more involved, because you know how you go through like registration, like everybody else will be in their like own different groups, and then there is just me on my own" (Participant C)

The networks of support, through friends, family and key adults were revealed as salient influences on coping and resilience:

Interviewer: "Is there anything that makes some young carers, I suppose, more resilient that others?"
Participant: "It's a combination of things isn't it? It is a combination of your family around you, the support networks you've got, friends, school. It's a whole, combination of different things and there's not one answer to that. Every child, every young person is... " (Participant SM)

Examples emerging from the data supporting the "feeling a part of something bigger" theme

Participant K

Participant K: ..and I'm like, well, am I another student just here or am I part of something bigger? Or should I just stay out the way? So you do feel a bit withdrawn..

Participant K: It would be different because, like, you would get acknowledged a lot more, you'd get picked for a lot more tasks, you'd have a lot more people speaking to you, you'd actually participate in a lot more things, then you did, then I did then. Cause there was one time when I was playing dodgeball and, well we was playing dodgeball, and, you have, you know how you have that, where you have to pick the teams? You can guarantee that you'd be either the last one to be picked or you wouldn't, you wouldn't be picked at all.

Participant C

Interviewer: I suppose, you said you don't feel fully included in life. What would being included look like for you? What would be different? If tomorrow you went back to school and you were included. What would be different? What would that look like? How would things be?

Participant C: I guess just being like more involved, because you know how you go through like registration, like everybody else will be in their like own different groups, and then there is just me on my own.

Interviewer: So, that would have to…need to change. So you would be part of a group. Is there anything the school could do better in that regard? If you were in charge of the school and you saw yourself, what would you do to help yourself in that situation? If you were the head of the school.

Participant C: I'd kind of like make a little group. A bit like a group like young carers but obviously just like, for people who are like lonely or just on their own

Examples emerging from the data supporting the "networks of resilience" theme

Participant SM

Interviewer: Is there anything that makes some young carers, I suppose, more resilient that others?

Participant SM: It's a combination of things isn't it? It is a combination of your family around you, the support networks you've got, friends, school. It's a whole, combination of different things and there's not one answer to that. Every child, every young person is…

Participant SM: Well, what helped me the most is like having people there to talk to and relieve on, to talk to and not bite me up..

Interviewer: Yeah.

Participant SM: ..Ehm, they kind of help me, but myself it was just like sitting there listening to music, by playing video games, just take my mind exactly of all that happened that day and trying to forget the whole day.

Participant SM: Ehm, one of my mates, he was, he was useful in stressful times before and we both were going through nearly the same sort, we would help each other through it..

Participant SM: …We'd be on each other's shoulders, you know what I'm saying..

Interviewer: Mmh. Yeah.

Participant SM: …So it's what I kind of mean, but, like, sometimes his mum and dad would have a fight and argue, so he'd come down here and he'd chill here and, it wouldn't be the best, sometimes it wouldn't be the best times, but we'd think, you know what, we need some time out, we'll chill upstairs and get out the way..

Interviewer: Yeah.

Participant SM: And we'd just put a bit of music on, cause there's a stereo in my bedroom, so we'd put a bit of music on and just literally listen to that and just have a sing along

4.3.3.2. Main Theme: Shared Experiences
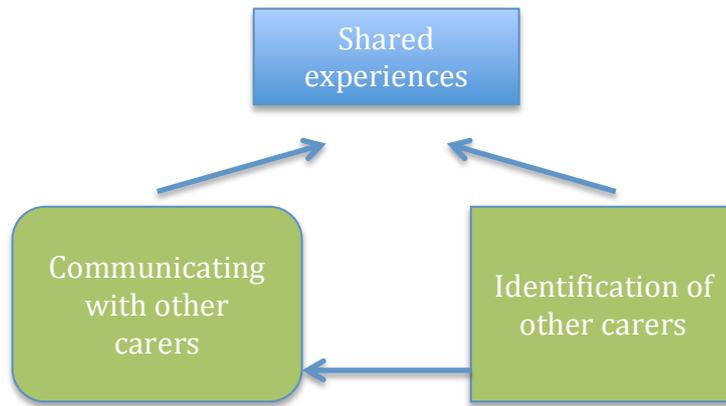
1.) Subtheme: Communicating with other carers

2.) Subtheme: Identification of other carers

The narratives from the data reveal the role of communication and the relationships with other carers as further developing carers feelings of belonging and reducing isolation and withdrawal, thus indirectly affecting school engagement. Schools and carer projects were identified as having a key role to play in providing the social spaces for carers to meet and share their experiences with other carers.

The identification of other carers was a significant theme to emerge, and carers described how knowledge of other carers in their school may have reduced the isolation they endured during school and allowed them to engage more with school. However, data from project workers and student welfare officers also reveal that schools lack appropriate systems for identifying carers and demonstrate poor communication with carer projects, such as Spurgeons in this regard. This has important implications at the exosystem for the support of young carers with additional needs, specifically, between the school, project workers and other agencies. This also links with the chronosystem; the findings for the study suggests that developments in identification of young carers at key developmental and educational milestones such as transitions to secondary or new schools, can have significant influence in how a young carer experiences school:

"…So if were able to go, or a video could be put out or a checklist was done once every six months, how long would that take a school to give a young person a

checklist, 'do you have, is this happening in your home?' When you say that somebody in your home is sick, who's sick and what is the illness, is there anything we can help you with? Or would you like some support? Something that's so simple and would literally take 15-20 minutes if that, and that could be done across every pupil. And it could make a huge difference for them, knowing that there's other carers out there, y'know, even in their same school, that they could talk too and share things with." (Participant PW)

Examples emerging from the data supporting the "communicating with other carers" theme

Participant PW

Participant PW:……We have a lot of them that are, because they know no different, its been their life since they were born or very young. I think there's a lot of them like that, their strengths are always there, their listeners, their friends, their friends are very important to them. Although many of them will tell me they've not got many a true friend in school, but they have true friends in group, the emotions that come out

Participant C

Participant C: Well I do have a friend who comes to young carers as well. I've known him since nursery.
Interviewer: How would you describe that relationship? If you were to…
Participant C: It's pretty good.
Interviewer: What's good about it?
Participant C: Like?
Interviewer: Why is he helpful? Why is he supportive? I mean, like why is that?
Participant C: When I was little in school he always used to like come out of his class and check on me and stuff. So it was always kind of like an older brother kind of

Participant K

Participant K: Euh, Spurgeons is quite good cause, it may be only every two weeks,

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but it's that release to come away from everything. To actually spend time and talk to other people about it that can understand, and it gives you just some time to realise, like, you're doing something good and you're helping, and its not against you, cause, there has been, like, before where I've sat there and talked to 'em, talked to 'em, and they goes look, I feel like you, you're not alone with that kind of feeling

Interviewer:..Was there? That too, you know, kind of, you shared, I suppose he was going through a tough time, you were going through a tough time, so you kind of, or maybe you were able to share in that experience..

Participant K: We were sharing information, we were talking about how, like, he'd be like, he'd be talking about what happened with his mum and dad and I'd be like, again we'd each other through it, we'd give each other advice..

Examples emerging from the data supporting the "identification of other carers" theme

Participant K

Participant K: …And the other things is, I would love to know, like, cause I would love to have known if there was any carers in my school, because that way then I could have talked to 'em but they never was open…

Interviewer: (echoing the participant) They never was open. Yeah.

Participant K: …That's the thing I wish some people would do is open up, I know it's hard to, but opening up, to, like, not even a student, like, maybe a teacher they can trust..

Participant PW

Participant PW: And that's just from a couple of schools, so if were able to go, or a video could be put out or a checklist was done once every six months, how long

would that take a school to give a young person a checklist, 'do you have, is this happening in your home?' When you say that somebody in your home is sick, who's sick and what is the illness, is there anything we can help you with? Or would you like some support? Something that's so simple and would literally take 15-20 minutes if that, and that could be done across every pupil. And it could make a huge difference for them, knowing that there's other carers out there, y'know, even in their same school, that they could talk too and share things with.

Participant SM

Participant SM: The new all age carer's strategy in (named Local Authority) has been written very much with young carers in mind. They've consulted with all our young carers, with our help. There's new, there's an implementation group, so the things that the young people were saying, they will be put in place, and a lot of that is around schools. Is around schools knowing that they're young carers and being able to support them. And as I said before, a lot of the kids, all they're saying is 'we want someone, everyday, to say to us "are you OK?"'. That's all it needs. Just…

4.3.3.3. Integrating Systems Theory around the Overarching Theme of Belonging

The overarching theme of "belonging" emerged from the data, related to themes of shared experiences with other carers, and was primarily associated with engagement with school support groups and carer projects.

This draws important links with the mesosystem, associated with systems theory (Bronfenbrenner, 1979). Young carers interactions with other young carers through school support groups or young carer projects were significant in mediating their difficulties and concerns between school and home life. Young carers related that they developed strong and supportive relationships with other career, and particularly sharing their experiences with other carers reduced feelings of isolation and withdrawal from school. This indicates the likely implication for young carers school engagement, in encouraging more positive meso-interactions. Thus the research

supports recommendations made in light of these findings (Chapter 5), which focus on supporting the meso-level interactions that are salient factors in developing the educational inclusion of young carers with additional educational needs, such as those between the carers and key school staff, those between school and parents, and those between young carers themselves.

This is consistent with previous findings from research such as Aldridge and Becker (2003) who report on the value of young carer projects in regard to providing someone carers can talk to, creating connections with peers with similar shared experiences, and providing access to services. Grant (2008) also identifies that young carer projects place a high emphasis on building close and trusting relationships with each young person to help them feel relaxed, valued and free to talk about their needs, hopes and anxieties due to the recognition that many young carers face bullying and peer group rejection at school. Participants from the carers sample, similarly, report the supportive and understanding relationships they experience amongst other carers in support groups:

"…There has been, like, before where I've sat there and talked to 'em, talked to 'em, and they goes look, I feel like you, you're not alone with that kind of feeling" (*Participant K*)

The findings also underscored the potential impact of exo-systemic factors in educational inclusion. For instance, the role of carer projects and schools in creating social spaces for young carers to interact, and the role of schools in creating systems to recognize and identify young carers. Both these dynamics appeared to play a role in young carers educational experience, albeit indirectly, by the fostering of a sense of belonging within educational systems. Young carers, student welfare officers and carer project staff talked about how social spaces to meet other carers reduced isolation, developed relationships and created communities in which young carers felt they belonged. Carers, student welfare officers and project workers all identified that a significant strengthening factor would be for all schools to have a mandatory policy for the identification and support of young carers.

The data indicate that the subtheme of shared experiences was associated with the subtheme of *identification*, and this relates to the systems and practices that schools

employ to identify carers. Consistent among findings from all sample groups was the sense that a significant strengthening factor to school engagement could have been the knowledge that there were other carers in school sharing similar experiences, however, equal in consistency across the sample groups was the feeling that schools lacked appropriate systems to identify and encourage carers to come forward, thus leaving carers to remain feeling isolated and withdrawn in school. Related to the subtheme of shared experiences and the appropriate systems of identification of young carers in school, research from the literature indicates that a significant protective factor to young carers well-being is the development of close friendships with other carers in school, such as Barry (2010) who identifies that carers tend to develop close friendships with other carers whom they feel they can trust and share their worries with, due to the common experiences of being a young carer:

"My three friends, they've been like the best friends, like four years now or something and we're just like, we're always like there for each other and that and we always trust each other all the time." (Barry, 2010; p530).

Additional exosystemic factors emgering from the findings, were young carer project workers identifying the interaction between themselves, schools and other agencies as an important factor to young carers educational inclusion. The narrative of project workers stressed that they often have useful information around carers and their families that could support their engagement, but schools tend to dismiss the involvement of carer projects, despite project workers reaching out to schools. Project workers described how rarely they are invited to multi-agency meetings regarding carers they are actively supporting, and how they feel that schools and other agencies may devalue their contribution or not see the issue of young caregiving as a priority.

The story emerging from the data in the current study also indicates that networks of resilience are related to a sense of belonging:

"Interviewer: Is there anything that makes some young carers, I suppose, more resilient that others?
Participant: It's a combination of things isn't it? It is a combination of your family around you, the support networks you've got, friends, school. It's a whole,

combination of different things and there's not one answer to that. Every child, every young person is..." (Participant SM)

These findings are consistent with findings that social support is a significant predictor of reduced psychological distress and increased resiliency. Packenham (2007) found greater perceived access to networks social support and broader networks of informal social support were positively correlated with better outcomes and lower psychological distress. Barry (2010) also identifies the significance of more informal social support from family and friends as important protective factors in the lives of young carers. Packenham (2007) reconstructs the notion of social support as "coping resources" to explain the mechanism by which young carers develop resiliency in their caregiving role. In this model, coping resources (social support networks) operate alongside positive self-appraisal and coping strategies to produce lower psychological distress and greater resiliency. Alongside the perception of choice, social support was the greatest predictor of positive adjustment to caring.

The subtheme of "feeling a part of something bigger than yourself" that emerges from the data appears related to carers sense of isolation and identity in school:

".... or am I part of something bigger? Or should I just stay out the way? So you do feel a bit withdrawn.." (Participant K).

"It would be different because, like, you would get acknowledged a lot more, you'd get picked for a lot more tasks, you'd have a lot more people speaking to you, you'd actually participate in a lot more things.." (Participant K).

This would fit with consistent findings in the literature that schools and carer projects can be important sites of resilience-building by increasing social participation and reducing isolation, by developing carers voices and identity and by building positive and trusting relationships (Grant, 2008; Richardson, 2009; Barry, 2010).

4.4. Summary

The integration of a deductive framework to the analytical process has been useful and important in interpreting the findings from the data by drawing together a broad picture of the experience of young carers educational inclusion and highlighting how different contexts can influence this experience.

4.4.1. System-level factors emerging from identified themes

Salient findings at the microsystem level suggest young carers can exert some reciprocal influence over systems that influence their engagement with education. This "reciprocity" is demonstrated in the active participation of carers in raising awareness and advocating for young carers and was an influencing factor for schools to raise the support of young carers as a school priority. However, despite this example, the findings from the research generally support the view that young carers have few opportunities to exert influence over systems around education and social support. The keyperson was also found to be a salient feature of the microsystem, and emerged as an individual well placed to provide emotional and psychological support to young carers, as well as families of carers, and coordinate and plan support with other services e.g. Spurgeons

Salient findings at the mesosystem level were the interactions between the school and the families of carers (e.g. care recipient). If the school, via the key person, was sensitive to the parents (care recipients) disability and needs, this positively impacted on carers engagement in school indirectly by reducing the stigma associated with the disability and mediating parental concerns that the young carer will be taken into social care. In this way, the school and key person have a crucial role to play in how families engage with schools and access social support. Additional significant mesosystem interactions appeared in young carers interactions with other young carers though school support groups or young carer projects. These were significant in mediating their difficulties and concerns between school and home life.

Salient findings at the exosystem were the role of carer projects and schools in creating social spaces for young carers to interact, and the role of schools in creating

systems to recognize and identify young carers. Both these dynamics appeared to play a role in young carers educational experience, albeit indirectly, by the fostering of a sense of belonging within educational systems. Carers, student welfare officers and project workers all identified that a significant strengthening factor would be for all schools to adopt a mandatory approach to the identification and support of young carers.

Salient findings at the macrosystem were the incongruence between legislative developments around the young carers needs assessment and the actual practice of local authorities in administering these assessments. Findings at the macrolevel also reveal that significant positive change in school support and action around young carers, generally emerged after significant media attention or national exposure. Findings at the macro-systemic level also reveal that the wider socio-cultural values and attitudes regarding disability created climates of mutual mistrust between schools and parents, and negative constructions of disability that further stigmatized carers and their families, increasing the withdrawal of carers and their families from school and the community.

4.4.2. Chronosystem factors emerging from the themes

Meso time factors salient to inclusive educational experiences for young carers included the frequency and consistency of contact with a key person able to facilitate positive wellbeing in the school setting. Frequency and consistency of contact with other young carers, often through young carer projects and support groups, appears to be a significant factor in young carers strengthening their own psychological wellbeing and experiencing education positively.

Salient macro time factors affecting inclusive educational experiences for young carers included the incongruence between development of young carers needs assessment in practice and the administration of the assessment in practice, developing awareness and recognition of young carers in media over time, and developing school systems for early identification of young carers, particularly during school transitions.

This analytic process, through the application of a deductive framework has enabled me to make associations between findings from this particular context to a wider research base, in which these complex factors and relationships can be better understood. Thus, in the final chapter I explore the implications of these findings in relation to local authority practice and policy, and identify the issues pertinent to the theoretical generalization of these findings.

Chapter 5: Conclusions and Implications

5.1. Addressing the Research Questions

The aim of the study was an endeavour to attend to an acknowledged gap in young carer research, by investigating the factors that contributed positively to the educational inclusion of young carers with additional needs. The methodological approaches applied allowed the research questions developed to be addressed. The analytical process employed brought to light a thematic narrative highlighting a variety of salient topics in regard to the educational experience of young carers with additional needs. These significant themes were reported and reflected upon in Chapter 4 in relation to these findings.

These findings were presented and discussed in relation to the literature presented in Chapter 2, and advanced in relation to the integration of a deductive conceptual model posed by Bronfenbrenner's (2001) bio-ecological systems framework.

Bringing to a close this reflection on the findings, an overview of the main findings is presented below:

5.1.1. Research Question 1a: Coping and Resilience

Research Question 1: What are the key eco-systemic factors that strengthen the resilience and educational inclusion of young carers with additional educational needs?

Specifically, this research is interested in factors at the meso, exo and macro-levels (Bronfenbrenner, 1979) of a young carer's environment that has had a positive impact on:

  e) *Psychological coping strategies and resilience for the demands of education and their caring role;*

Key facilitators of coping and resilience were identified in the current study as:

- **Key-person who carers felt they could trust**

A key adult staff member in school was identified as well placed to offer emotional support to carers, as well as coordinate the school response to supporting young carers with additional needs;

- **Understanding around parental disability**

School response to parental disability, via the key person, was identified as reducing the stigma around disability, and facilitating access to external social support e.g. social care;

- **Other young carers**

Access to, and communication with, other carers via carer projects or school support groups was identified as a significant factor in developing carers coping skills and resilience to both caregiving and school;

- **Changes in legislation**

Recent changes in legislation such as the Care Act 2014 and the Children and Families Act 2014, which entitle carers to a young carers needs assessment were identified as positive changes and facilitating young carers access to external social support, however, these changes lack specificity and accountability regarding which services should be carrying out assessments;

- **Communication between services**

Coordinated support and information-sharing between services, particularly school, young carer projects and social services was identified as a significant feature in enabling young carers resilience and ability to cope with caregiving demands. However, communication can be limited between agencies, and services such as Spurgeons often feel excluded by schools and social care services, from discussions and involvements around the young carer.

5.1.2. Research Question 1b: Academic Engagement

Research Question 1: What are the key eco-systemic factors that strengthen the resilience and educational inclusion of young carers with additional educational needs?

Specifically, this research is interested in factors at the meso, exo and macro-levels (Bronfenbrenner, 1979) of a young carer's environment that has had a positive impact on:

f) Academic engagement

Key facilitators of academic engagement were identified as:

- **Autonomy, choice and self-direction**

Young carers described how a sense of choice and autonomy in their school lives, but particularly around their learning, had a significant impact on their motivation for school engagement. Carers also described how being treated like an adult, particularly in regard to their involvement in decisions about their support or education, was also a salient feature in terms of their school engagement;

- **School/LA engagement with young carer initiatives**

School engagement with young carer initiatives such as the Young Carer Champions awards, were also associated with positive school engagement;

- **Opportunities for self-advocacy**

Opportunities to become involved with raising awareness or advocating for the young carer agenda supported carers in developing their confidence to engage with school and the wider community, through an activity of deep personal significance for themselves;

- **Sense of community and belonging**

The relationships with staff and peers in school were a crucial factor in young carers engagement. Feelings of belonging, value and acceptance were powerful motivators to increased engagement at school, and mediated the feelings of loneliness and isolation that many carers feel.

5.1.3. Research question 2: Narratives of young carers

Through what interacting mechanisms and processes, at different systemic levels, do key professionals and young carers with additional needs perceive these factors to have been effective?

The key findings to emerge from the narrative of the young carers sample was the importance of the key person in school, and their role in facilitating numerous meso-level interactions (Bronfenbrenner, 2001). Of particular significance were the interactions between the key person and the young carer, in facilitating a sense of autonomy, agency and self-determination. In this sense the key person was central in enabling and developing the "voice of the carer" by providing opportunities for carers to advocate and raise awareness of young caregiving to their school and the wider community. The key person played a significant role for carers in providing emotional and psychological support, and their understanding and empathy with carers was crucial to carers engagement with school.

5.1.4. Research question 2: Narratives of Spurgeons project workers

Through what interacting mechanisms and processes, at different systemic levels, do key professionals and young carers with additional needs perceive these factors to have been effective?

The story emerging from the narratives of the Spurgeons project workers also confirm the importance of the interactions between carers and key persons in school, but also reveal the role of schools, via key persons, in engaging families of carers. Positive school engagement with families were associated with discourses that reveal empathy and understanding of the disabled parents needs and reduced stigmatization of the disability. This is associated with the wider socio-cultural perspectives around "disability" in society. The narrative of the project workers also reveals factors operating at wider systemic levels such as the exo- and macrosystems, namely the inconsistency between written policy and espoused practice regarding the administration of the young carer needs assessment, and the role of media attention and national exposure around the young carers agenda in facilitating an increased school response to the issue of young carers.

5.1.5. Research question 2: Narratives of safeguarding and student welfare officers

Through what interacting mechanisms and processes, at different systemic levels, do key professionals and young carers with additional needs perceive these factors to have been effective?

The narratives of the safeguarding and student welfare officers also reveal many similar narratives to the project workers and young carers in the factors impacting on young carers school inclusion. The student welfare officers, themselves the identified "key person", reveal the importance of the social spaces for young carers to connect and share with each other, and their role in facilitating agency and self-advocacy through engaging with young carer initiatives. The importance of their engagement with both families of carers and additional services such as young carer projects, highlight the importance of the key person in coordinating responses to supporting young carers as per the Department of Health and Department of Education and Employment Guidance on Supporting Young Carers in School (DoH, 1999; DfEE, 1999).

5.2. Methodological Reflections

In the process of conducting research, it is important to acknowledge and reflect on the selected methods and methodology and thoroughly explore the limitations they pose to the current research study. Whilst the application of a pilot interview with the first participant increased the validity of the themes educed from subsequent participants, one must be heedful that due to the additional needs of the participants from the young carers sample their narratives may have been affected by the limitations imposed by variable communicative ability.

Relevant literature has drawn attention to the need for researchers to increase the validity and reliability of narratives elicited by modifying their interview techniques in response to working with young people with additional needs (Lewis, 2009; Lewis and Porter 2007). Some of the techniques proposed by Lewis (2009) include:

- Allowing 'don't know' responses and permitting the young person to ask clarifying questions

- Emphasizing that the researcher does not expect there to be a correct answers to the questions, in order to reduce socially desirable answering

- Consecutive prompting could increase inaccuracy of responses provided as the young person feels they must "fill in" the information.

- Accommodating the young persons' entitlement to silence and acknowledging that some young people may not wish communicate their views on all topics. As Lewis and Porter (2007) describe: *"We need to recognise the choice of a child to be silent but also recognise that silence gives a message of its own that we should hear." (*Lewis and Porter 2007: p230**)**

During the process of data gathering I feel I was able to more carefully accommodate young people with learning difficulties by utilizing some of the strategies explained by Lewis (2009). For example, when participants did not respond I permitted silence rather than using successive prompting, I re-emphasized I was not looking for any particular answers ("there are no right or wrong answers") and also encouraged participants to ask for clarification if they did not understand a question.

Following completion of the data-gathering phase, I have also reflected on the possibility that the fidelity of the narratives could have been reinforced by the provision of written summaries of question topics for the participants to review and consider before and during the interviews.

The methodological approaches employed in this study have allowed this research to bring to light the standpoints and perceptions of a range of young people and professionals around the topic of supporting the educational inclusion of young carers with additional needs. This examination of these perspectives was strengthened by the utilization of thematic analysis that afforded a more organized and methodical approach to analysing these narratives. However, it should be noted that the process of generating themes reflected my "construction" of themes as a researcher subjectively interpreting the data, as opposed to the more objective implication around the language of "emerging themes" as found in the literature on thematic

analysis. Indeed, Braun and Clarke (2006) argue that it is not unusual for researchers to describe themes as 'emerging' or being "discovered" from the data. This is a passive interpretation of the analytic approach, and it denies the active role the researcher has in identifying, selecting and interpreting significant themes:

"The language of themes emerging can be misinterpreted to mean that themes 're-side' in the data, and if we just look hard enough they will 'emerge' like Venus on the half shell. If themes 'reside' anywhere, they reside in our heads from our thinking about our data and creating links as we understand them"(Braun and Clarke, 2006; p4)

The construction of meaningful themes from the data corpus has significant implications when considered in light of the second phase of analysis: the application of a deductive framework, systems theory (Bronfenbrenner, 1979), to the inductively derived data. As the researcher for this study, I had already considered the use of a deductive framework early in the development of the research study, thus the framework, if not consciously, may have implicitly influenced the construction of themes that more easily fit into systemic levels. However, I am confident that during the analytical process the reflexivity applied may have mediated the implicit influence of the deductive framework in the construction of themes. Throughout the process of analysis I reflected on key reflexive questions, identified by Willig (2001), in discussions with my supervisors such as: how has the design of the study and the methodologies employed "constructed" the data and its interpretation?

When considering the limitations of the current study, it is useful to reflect on a limitation common to almost all young carer research including the current study, namely that young carer research consistently uses samples of young people drawn from the population of carers that are accessing young carer support services such as carer projects and support groups. As Joseph et al. (2008) highlights, an important gap in the literature is that there is very little data pertaining to the experiences and outcomes of the general population of young carers, as nearly all carer research has drawn upon a sample of carers known to young carer projects. As such, this may skew and narrow our understanding of the young carer experience, in relation to the wider context of the unknown numbers of "hidden" carers within the population. Simply because of the support received through carer projects, Joseph et al. (2008) speculates

that it may be that young carer samples drawn from projects could be more resilient than the general population of young carers. In this context, the findings from the current study may potentially be overestimating positive experiences for these young carers in the sample group that are not reflective of the broader population of young carers, by virtue of the fact that they are already accessing a young carer project.

5.3. Implications for Local Authority Policy and Practice

The findings to emerge from the data corpus and subsequent analysis indicate that there are significant implications for the local authority in which the research took place and how it can respond to the issue of the educational inclusion of young carers with additional needs.

These potential implications will be considered with relevant professionals (educational psychologists, Spurgeons project workers, safeguarding and student welfare officers) in order to advance the development of support for young carers in education, within the local authority.

The findings indicate that the role of the key person could provide a vital emotional and psychological support for young carers (theme 4.3.2.2. (ii)) but also served an important role in coordinating support to young carers such as through liasing with parents, and liasing with other services/agencies (theme 4.3.2.2. (ii)) to coordinate support for young carers.

Table 5.1. Potential Implications for Policy and Practice

Research Finding	Link between findings and implications	Specific Implications for practice
The role of the key person: - The key person in school can serve an important function in reducing distress	The findings indicate that the role of the person could provide a vital emotional and	• Schools to identify and appoint key person in school; • Schools to provide

and providing emotional support	psychological support for young carers (section 4.3.2.2. (ii)) but also served an important role in coordinating support to young carers such as through liasing with parents, and liasing with other services/agencies (section 4.3.2.2. (ii)) to coordinate support for young carers. Due to the complexity of need within young carer cohort, key persons should look to develop their understanding skills by liasing with other support services and seek relevant training opportunities.	opportunities for continuing professional development to raise the key persons capacities to support carers with a range of additional needs; • Training opportunities may focus on supporting mental health, learning disabilities, and social relationships; • Services that may offer support could include the Educational Psychology Service, Spurgeons and other young carer projects, CAMHS, and other external agencies.
The role of self-determination: – feelings of autonomy, self-direction, personal agency and being treated	Working closely with the young carer, the key person also played a vital role in understanding their	• Key person can liase with school staff to develop opportunities for young carers to exercise some choice

like an adult were key factors in school engagement	needs and facilitating young carers sense of self-determination (section 4.3.1.) and autonomy (section 4.3.1.1.). As such, the key person can play a significant role in supporting other school staff in developing practices that promote wellbeing, and act as an adovocate for the young person and their "voice" (section 4.3.2.2.). The key person also provided an important link for young carers to access specific young carer initiatives e.g. young carers champions., and facilitate awareness-raising of young carers (section 4.3.2.1.)	in school activities and subjects; • Key person can liase with school staff to develop opportunities to provide carers with responsibilities around school, in recognition of their developing maturity as demonstrated through their caring role; • School to include young carers in meetings and decisions about carers, and allow the "voice of the carer" to be reflected in these meetings and decisions; • Key person to develop opportunities for young carers to self-advocate for themselves through engagement in young carer initiatives such as the Young Carer Champions Award or awareness raising within school or local community.
Engagement with other	The identification	• School to establish

| young carers:
 – knowledge of other young carers in school appears to be a significant protective factor to school engagement. Additionally, the implementation of a young carers support group in school was found to be significant protective factor to resilience for caring and the demands of school | and interaction with other carers in school appeared to mediate wellbeing and positive carer identities, opportunities to bond with other carers provide carers with psychological and emotional stability (section 4.3.31.). Project workers and carers suggested that schools with clear policies on carers, systems of identification and support groups would provide a key protective factor for educational inclusion (section 4.3.3.2. (ii)) | mandatory policy on identification and support of young carers – schools can coordinate with carer projects as carer projects will have information on current carers and their needs, as well as advising schools on developing systems to sensitively identify and approach potential young carers;
• Key person to establish support group in school for young carers to meet and engage with other young carers in school;
• Key person to develop opportunities for bonding between carers through extra-curricular activities, trips, and engagement in young carer initiatives. |
| Family Engagement:
 – sensitive and understanding engagement between schools and | The findings indicate that the social stigma of disability is a significant factor in | • Schools should take the responsibility for challenging stigmatizing and |

families of carers, in particular disabled parents, was identified as a significant factor in developing resilience, accessing support, and engaging with school.	facilitating the withdrawal of carers from social spaces such as schools (section 4.3.2.1. (i)). The findings also indicate that schools and institutions themselves may hold stigmatizing and pathologizing views of disabled parents, which creates feelings of mistrust and misunderstanding, and further isolates families and carers (section 4.3.2.2. (i)). Thus, where these views can be challenged, and understanding can be facilitated, more supportive social spaces can be developed that young carers feel they can better engage with.	pathologising discourses around disability, to demonstrate that the school is sensitive and understanding to the needs of carers and their families. Schools can liase with adult disability services for further advice and information; • In particular, schools should challenge demonizing attitudes to mental health and substance-related addiction disabilities; • Key person should liase with Spurgeons and social care in order to be adequately informed about adult disability services available to the care-recipient; • Key person should liase with Spurgeons project workers to better understand the needs of the care recipient.

Coordinated response: - effective and regular communication and information-sharing between school, spurgeons and external support agencies was highlighted as an important contribution to carers resilience and educational engagement	The findings indicate that project workers have often felt marginalized by school processes and systems (e.g. not being invited to meetings regarding the carer) around the young carer, such that key information that may better support the carer is not shared among professionals (section 4.3.3.2. (i)). Thus where possible, it would be appear to be important for school systems and other agencies to engage with project workers who may have valuable information regarding young carers and their families that may impact on their subsequent support.	• Schools should identify and invite the relevant young carer project worker to meetings held about the child, as the project workers often have valuable information regarding the needs of the child and the family e,g, Team Around the Child meetings, Social care meetings, CAMHS meetings; • External services such as Strengthening Families Team or Social Care team should liase with young carer project workers to support child and family. Within the current local authority in which this research is situated, the Strengthening Families Team have a monthly drop-in session to which schools and other professionals working with vulnerable families are

		invited. This can be extended to invite young carer project workers.
Engagement with carer initiatives: – many schools and local authorities are unaware of current young carer initiatives for which they can receive recognition and reward if engaged with. Engagement with these initiatives at school level has been found to be a positive influence on young carers engagement in school	The findings indicate that the key person was an important figure in developing young carers engagement with young carer initiatives. Engagement with these initiatives had a positive impact on carers identity and created awareness raising opportunities for schools to develop as "carer-friendly" schools (section 4.3.2.1. (i)). Young carers engagement with these initiatives provided spaces for carers to express self-determination and self-advocacy, and reciprocally influence their own environments	• The key person in school should take the lead in raising-awareness at management level around young carer initiatives that schools can "buy-in" to and receive recognition for such as the Young Carers Champions Award; • The key person should facilitate identified young carers to take the lead in awareness raising and advocacy at the school and community level.

	(section 4.3.1.1).	
Media attention/ national coverage: - Media attention and press coverage was found to be a significant factor in galvanizing school interest in young carers and facilitating the re-prioritization of the young carer agenda in schools.	The findings indicate that key persons were important in engaging with the media and attracting national interest (section 4.3.3.1. (i)). Positive media attention had positive impact on young carers identity and also provided opportunities for carers to reciprocally influence their own environment. Media attention also had a facilitating role in encouraging schools to adopt a proactive approach to identifying and supporting carers, and thus in the creation of supportive and inclusive school environments for carers.	• Key person and young carers should look for opportunities to engage media e.g. news, television, social media presence in a sensitive manner.

5.4. Final Conclusions

5.4.1. Summary

The literature appears to compliment findings from the current research, such as the finding that the distinguishing feature of young carers from other children caring for loved ones is the lack of choice in undertaking the caring role (Aldridge and Becker, 2008), and a key predictor in young carers' positive adjustment to caring was the perception of choice in their caring role. Greater perceived choice in their caring role correlated highly with more adaptive coping mechanisms, positive outcomes and lower levels of distress associated with their caring role (Pakenham, 2007). In light of this context, the salience of autonomy and self-determination appears to resonate strongly with young carers and may be a function of young carers desire for self-expression and personal agency in their lives.

Young carer research is also replete with evidence suggesting the importance of a key person within the educational experience of a young carer who has power and influence to reframe the carers perception of the school experience, and corresponds to findings in the current study. A consistent finding is that a positive and understanding relationship with a key adult figure can act as a salient protective factor, or "safe haven" (Barry, 2010) from which young carers can engage with the wider school (Barry, 2010; Warren, 2007; Altschuler et al, 1999). Barry (2010) also identifies that of the young carers who perceived school positively, most indicated that it was the relationship with a particular teacher that would most likely influence that perception.

A further finding within the literature is that young carers and their care recipients worry that to the wider community, the circumstances of their caring is "abnormal" or "disordered"(Kavanaugh et al, 2015) and thus secrecy, beyond the family dynamics, is paramount in order to prevent social services from interfering (Cree, 2003; Thomas, 2007; Bolas et al, 2007). This seems to resonate with findings from the current study, whereby the understanding of the care-recipients needs was a sub-theme to emerge from the data, and the key person in school played a significant role in mediating the reciprocal concerns of the care-recipient and the carer. The reciprocal worries and fears that carers and their disabled family members endure relate to beliefs that local

authority social services will "take away" the young person. Related to this were the social-cultural attitudes of disability held by school staff, and how this pervaded into obstructive discourses held about carer's parents, that served to further stigmatize and isolate carers and their families. The literature also identifies how feelings of stigmatization and rejection young carers feel are associated with themes of "distance" and "isolation" (Bolas, 2007).

The responses categorized around themes of belongingness reveal the salience of connection and identification with other young carers as a paramount factor in carers engagement with education. Associated with these themes were the importance of social spaces, such as carer projects and school support groups that facilitated the interaction between young carers. Strongly related to these factors were the systems that schools exercised to identify and support young carers, and the perception of carers that the knowledge that there may be other carers in their school with similar experiences could further enable school engagement. The role of support groups and carer projects has been extensively identified in the literature as a significant protective factor in the lives of young carers (Aldridge and Becker, 2003; Grant, 2008) as they provide spaces for carers to develop close and trusting relationships to help them feel relaxed, valued and free to talk about their needs, hopes and anxieties due to the recognition that many young carers face bullying and peer group rejection at school. The current study confirms findings from previous research that schools and carer projects, providing empathetic and trusting relationships with staff and peers, can be important sites for resilience-building, and serve as a significant protective factor to the demands and distress resulting from significant care-giving in childhood (Grant, 2008; Richardson, 2009; Barry, 2010).

The implications arising from these findings suggest that there are many factors that can facilitate schools and communities becoming increasingly "carer-friendly", and developing an atmosphere and ethos that encourages young carers to self-identify, access support and engage with education. These implications broadly draw on the role of schools, particularly the key person, to coordinate with other professionals, within school and beyond school, in order to communicate and share information, as well as raise awareness and act sensitively towards the needs and concerns of families and carers themselves. There is also a role for external services such as the

Educational Psychology Service, Strengthening Families Team, Social Care Services and CAMHS to support carers directly, and indirectly, through supporting and developing the role of the key person, liasing with young carer projects and responding to the needs of the disabled care-recipient.

5.4.2. Theoretical and Analytical Generalization

In the process of conducting my literature review (see Chapter 2) I was able to identify protective factors within the systems around young carers impacting on their lives. Thus, I considered it important to reflect upon systemic factors within the analytic approach I implemented. The rationale for this was to ascertain if the findings could map on to an existing theory in order to advance the generalization of the findings and develop testable hypotheses for further research. As such Bronfenbrenner's (1979) bioecological theory was employed as the theoretical lens through which the data could be further interpreted.

In light of the systemic factors arising from the narratives elucidated from the data, and consistent with previous findings within the literature, I was able to highlight that the themes did fit well within a systems framework and thus I was able to bring to light the specific systemic effects on strengthening factors influencing the educational inclusion of young carers with additional needs.

Yin (2013) argues that rather than appealing to numeric or statistical generalization, researchers should in their interpretation of findings, focus on making connections with the extant literature and use their findings to explain the gaps and weaknesses in that literature. Thus by doing so the generalization can be interpreted with greater meaning and lead to a greater cumulative knowledge. In light of this, findings in chapter 5 are interpreted with reference to the existing body of knowledge derived from the current literature around young carers, and within the context of an integrated theoretical framework (Bronfenbrenner's eco-systemic, 1979; and bio-ecological model, 2001), in order to increase internal validity and generalizability.

I can thus confidently conclude that there are clear associations demonstrated between the findings of the present research and a current body of literature, research and theory.

As suggested by Morse (1999), it is also the comparability of the findings to the problem or topic, in relation to previous findings that distinguishes the validity and generalizability of the findings in small scale, interpretivist research. Therefore, if the standards for generalizability made by Morse (1999) are employed then a claim can be successfully made for analytical and theoretical generalization.

5.4.3. Ethical Considerations and limitations of the research

As three of the participants were young people with an identified additional need, specific ethical consideration was required in order to ascertain the means by which they were able to provide their informed consent, prior to participation in the research process.

The Health Professional Council's Standards of Conduct, Performance and Ethics (HPC, 2008) respond to the challenge in eliciting informed consent from vulnerable young people with the following guidance: "You must explain to the service user the treatment you are planning on carrying out, and the risks involved".

In light of this, as well as arranging pre-participation briefing sessions with adult participants, I arranged a session with the young people at their young carer project support group to:

- Explain the purpose of the study

- Explain how they will be able to contribute to the study

- How their rights to confidentiality and withdrawal would be protected

- How distress would be minimized

- Provided a written information sheet, parental information sheet and consent form

- Answer any questions or clarify any aspects of the research process

In concordance with the Ethical Guidelines for Educational Research (British Educational Research Association, 2004) researchers must recognize and reduce

distress experienced by the participant during the research process. Thus participants were reminded of their right to withdraw themselves or their data, and were made aware of counselling services they could access if any distress occurred.

5.4.4. Context of emerging policy

During the final stages of development and implementation of this research, the Children's Commissioner for England published a review of the current provision and support for Young Carers in England (December 2016), which has significant implications in relation to the current research study.

Key findings from the Support provided for Young Carers in England report (Childrens Commissioner, 2016) relevant to the current study include:

- Approximately 4 out of 5 young carers may not be receiving support from their local authority
- 27% of young carers had an additional disability of their own
- There are young carers under the age of 5 years old
- Not all local authorities are taking steps to identify children who may be providing care in the area

Many of these findings are consistent with findings from this current study. In particular, the study identifies the double-vulnerability of carers with an additional need and identifies that they compose over one quarter of the population of carers. The finding that local authorities are not taking appropriate steps to identify and support young carers is also a finding to emerge from the current study, in particular the administration of the young carers needs assessment was found to be inconsistently and ineffectively implemented by local authority services:

"The data suggests that many children who are identified as having caring responsibilities and are subject to referral to their local authority do not receive an assessment…..More work is needed on effective practice in provision of support for

this specific group of vulnerable children and young people, involving both their views and testing and learning in formal efficacy terms" (Childrens Commissioner, 2016: p23).

The potential policy implications following this relate to many of the identified strengthening factors found in this current research such as:

- Closer working with families

- Greater multi-agency communication

- Greater consideration for the voice of the carer

- Systemic level changes in how young carers are identified and assessed, with greater specificity and accountability relating to how young carer needs assessments are administered

In light of this published report, much of the findings from this current study are consistent with the findings of the Children's Commissioner's report (2016) and concurs with the recommended policy implications of the report such that future government policy and guidance may well correspond with the findings and implications discovered in the current study.

5.4.5. Implications of the research findings for Educational Psychologists

The literature indicate very little accounts and research describing educational psychologists work with young carers (Altshuler, 1999), and no research specifically around the work of educational psychologists supporting young carers with additional educational needs (AEN). However, anecdotal accounts from EP colleagues reveal that this work does take place (i.e. children referred for casework have been identified as young carers) however, the child's status as a young carer is rarely a salient feature of case formulations. Thus in order to develop and promote this field of work as an embedded area of EP practice, it is imperative that consideration is given to the means by which the outcomes from this research could be applied.

The existing competencies of the EP could be extended to supporting young carers with additional educational needs in light of the fact that educational psychologists

are often included in supporting young people with additional educational needs across nursery, primary, and secondary settings (Qualter, 2007). Acknowledged capabilities of the EP include consultation, assessment, organizational research and development, direct intervention, staff training and multiagency working. It is this researchers supposition that these capabilities could be utilized in supporting and enhancing the educational experiences of young carers with additional needs.

A number of pertinent implications arising from this study, that EPs could take a role in supporting through the exercising and extension of current capabilities to this issue could include:

- Increasing the quality of young carers educational engagement and participation;

- Supporting and developing the engagement of families of young carers;

- Supporting the role of the key person in school via training and supervision.

Table 5.2. suggests the means by which EPs could apply and extend their knowledge and skills to develop the support of young carers with additional needs as an embedded area of practice

Table 5.2. Potential Educational Psychology contribution to supporting young carers

Area of Development	Potential Educational Psychology Contribution
Increasing the quality of young carers educational engagement	• Consultation with schools regarding increasing the quality of young carers participation e.g. consideration of the application of Self-Determination Theory as a theoretical evidence-based approach to communicating to staff, the needs of young carers around autonomy, and belonging

	(Deci and Ryan, 2000)
	• Individual work with young carers with additional needs to develop collaborative formulations to inform targeted school support e.g. support for learning needs, mental health needs
	• Including the child's status as a young carer, and their caregiving responsibilities as a feature of case formulations included in reports and discussed with professionals
	• Advocating for the attendance of young carers at meetings held regarding them, and supporting them in communicating their views.
	• Group work with young carers investigating feelings towards school and giving voice to young carers regarding their planning for support
Supporting the engagement of families of carers	• Consultation with schools regarding supporting the engagement of parents of young carers, and supporting school

	staffs understanding of the needs of the disabled care recipient
	• Supporting school in challenging pathologising discourses around disability across the school
	• Consultation with parents of carers, which may include visits to the family home
	• Supporting and facilitating multiagency meetings and the sharing of information between parents, school and other professionals
	• Advocating for disabled parents and supporting them in sharing their perspectives at meetings in school.
	• Signposting parents to available adult disability services within the local authority
Supporting the work of the key person in school	• Deliver bespoke training for the key person around mental health, learning, communication and physical needs and how these needs may impact and interact with young carers caregiving and experience of school
	• Supervising the key person

	directly or facilitating the development of a model of group supervision between the key person, other school staff and professionals involved with the carer
Developing links and liasing with charitable support agencies supporting young carers such as Spurgeons, Barnardos and the Children's Society	• Extending the provision of EP practice to include consultation with project workers from these agencies and charities. • Developing and supporting the professional skills of these project workers with training, particularly around supporting carers mental health needs. • Including the issue of young carers and their educational inclusion into the training courses of Trainee Educational Psychologists

5.5. Concluding Comments

At the heart of this research project is a moral endeavor to develop, advocate and advance support for a vulnerable group of children and young people. By focusing on strengthening factors and positive outcomes, the strengths and resiliency of young carers also became apparent to myself, and is reflected in the research findings. Reflecting on my experience of conducting this research project, I have been struck by the resiliency of young carers whom, whilst enduring additional difficulties related

to education, relationships and adolescent development, bear a heavy responsibility with incredible dignity. The young carers participating in this research, whilst acknowledging the hardships and adversities of caring for a loved one, never spoke of abandoning their caring role or wishing for a life without their care-recipient. Rather, these carers only spoke of the love they have for their family member they care for, as the motivation to continue to care, and the drive to continue to seek better outcomes for themselves and their families. Speaking as a researcher, a professional, and more personally, it has been a privilege and a pleasure to work with, and know, the carers that I have come into contact with during the process of this research, and through my professional practice.

This process of conducting this research has illuminated the complexity of the phenomena of young caregiving, and highlighted some of the additional adversities and obstacles to the educational inclusion of young carers with additional needs. But perhaps the strength of the current research, lies in its contribution to a developing understanding of the factors that impact on the successful educational inclusion of young carers. Through identifying the intricacies that lead to successful support and positive outcomes, this study has also developed a picture of what successful educational inclusion may look like for young carers with additional needs, educed through the narratives of key professionals and young carers themselves.

What does the successful educational inclusion of young carers look like? As described, the phenomena of young caring, the difficulties and successful support are complex, and involve the integration of many different systems. However, as one young carer described, when asked: if he could go back in time to when he was first identified as a carer, what advice would he give to his school to make his educational experience more positive? He responded:

"I wouldn't say much to be honest. They don't really need to do much. It's the little things you see, that make a huge difference."(Participant K).

Triangulating this with other comments during the interview, I interpreted this as meaning that: how we as professionals listen, speak and interact with young carers is fundamental to their successful educational inclusion, and all systems involved with their support must retain this as a central and guiding principle in our exchanges with

young carers.

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Appendix 1. Unpaid care question included in 2001 and 2011 Census (ONS, 2001; 2011)

" Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- long-term physical or mental ill-health/disability?
- problems related to old age?

*Do not count anything you do as part of your paid employment*

(Tick appropriate box below):

No

Yes, 1 - 19 hours a week

Yes, 20 - 49 hours a week

Yes, 50 or more hours a week"
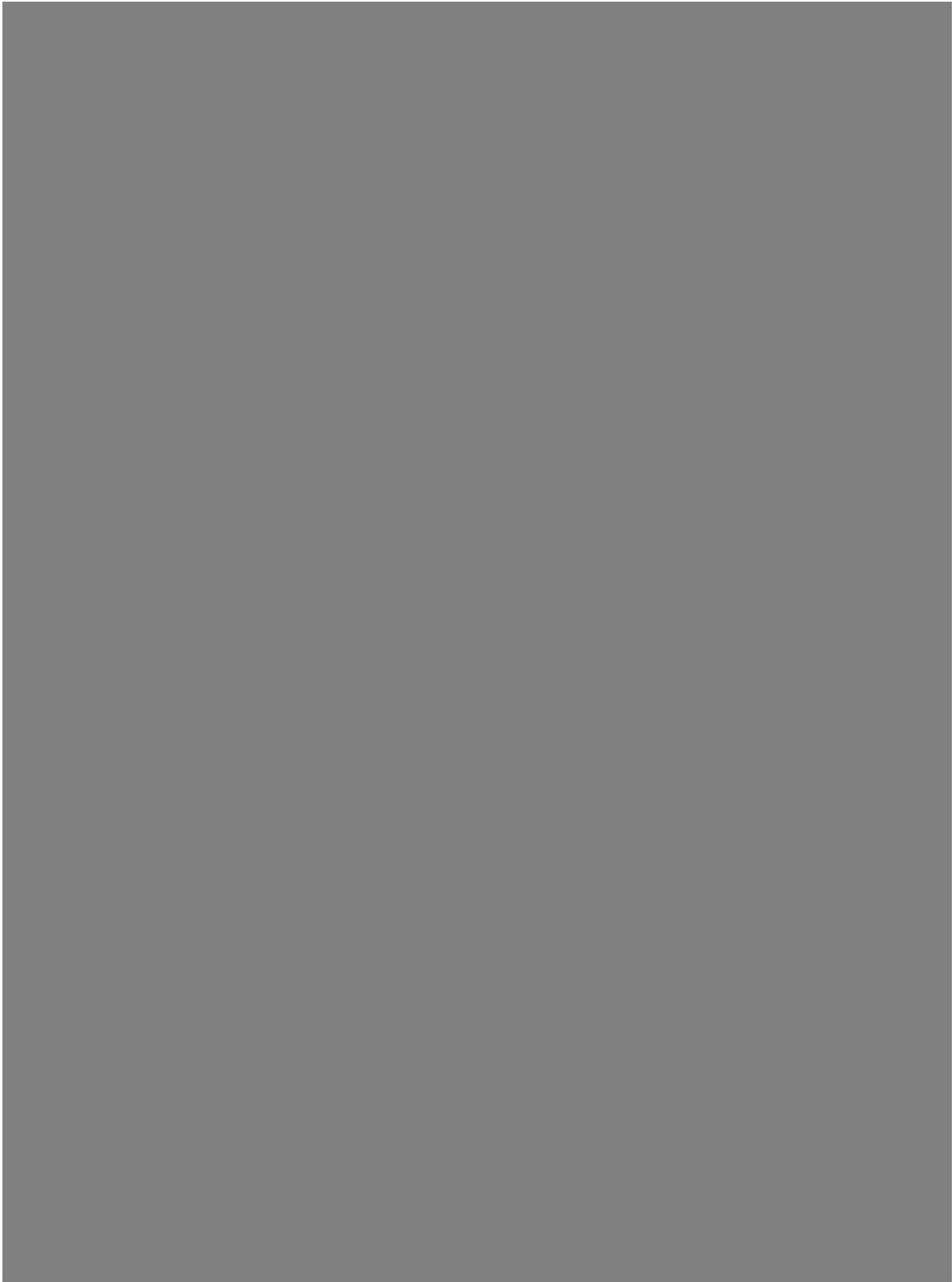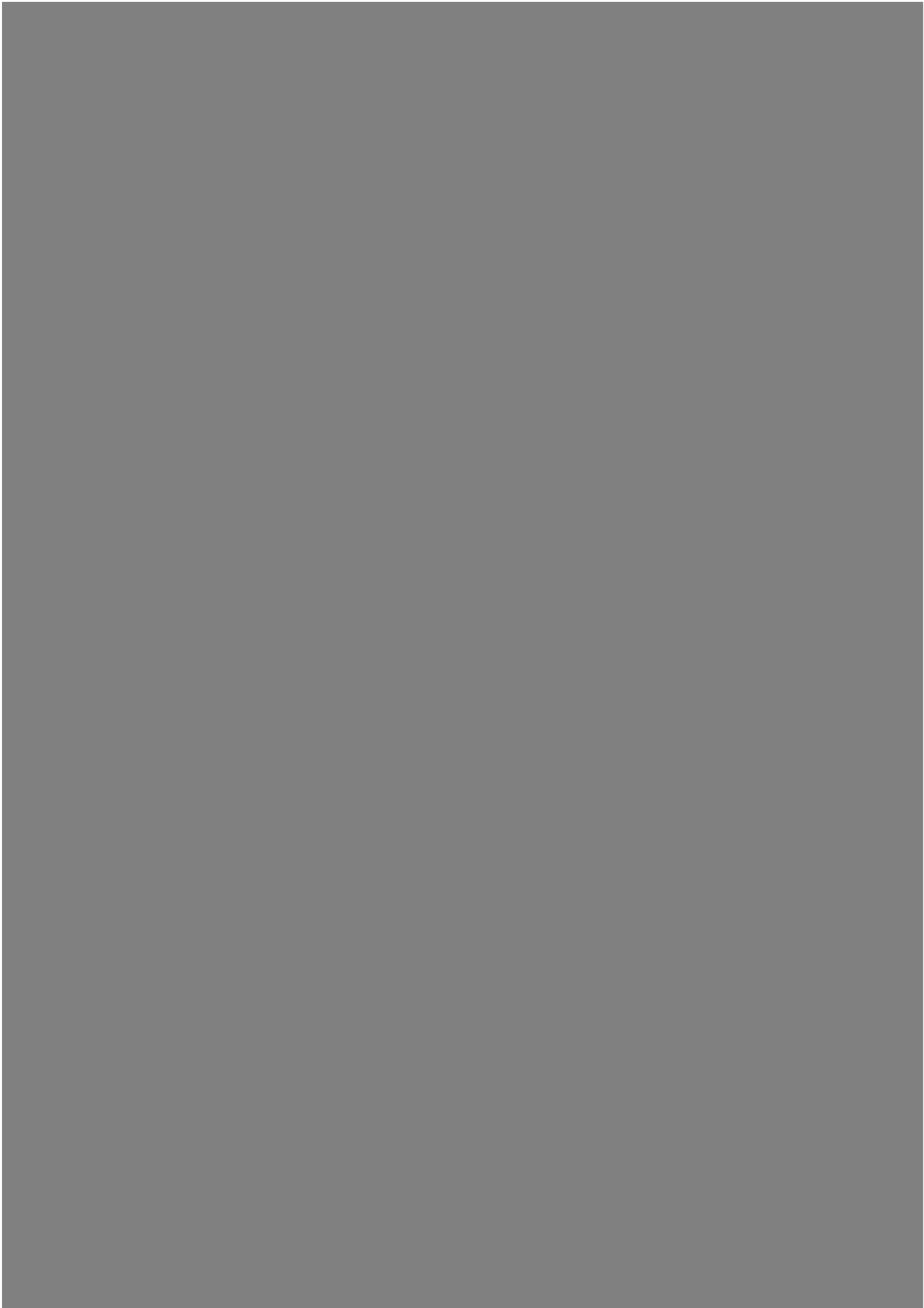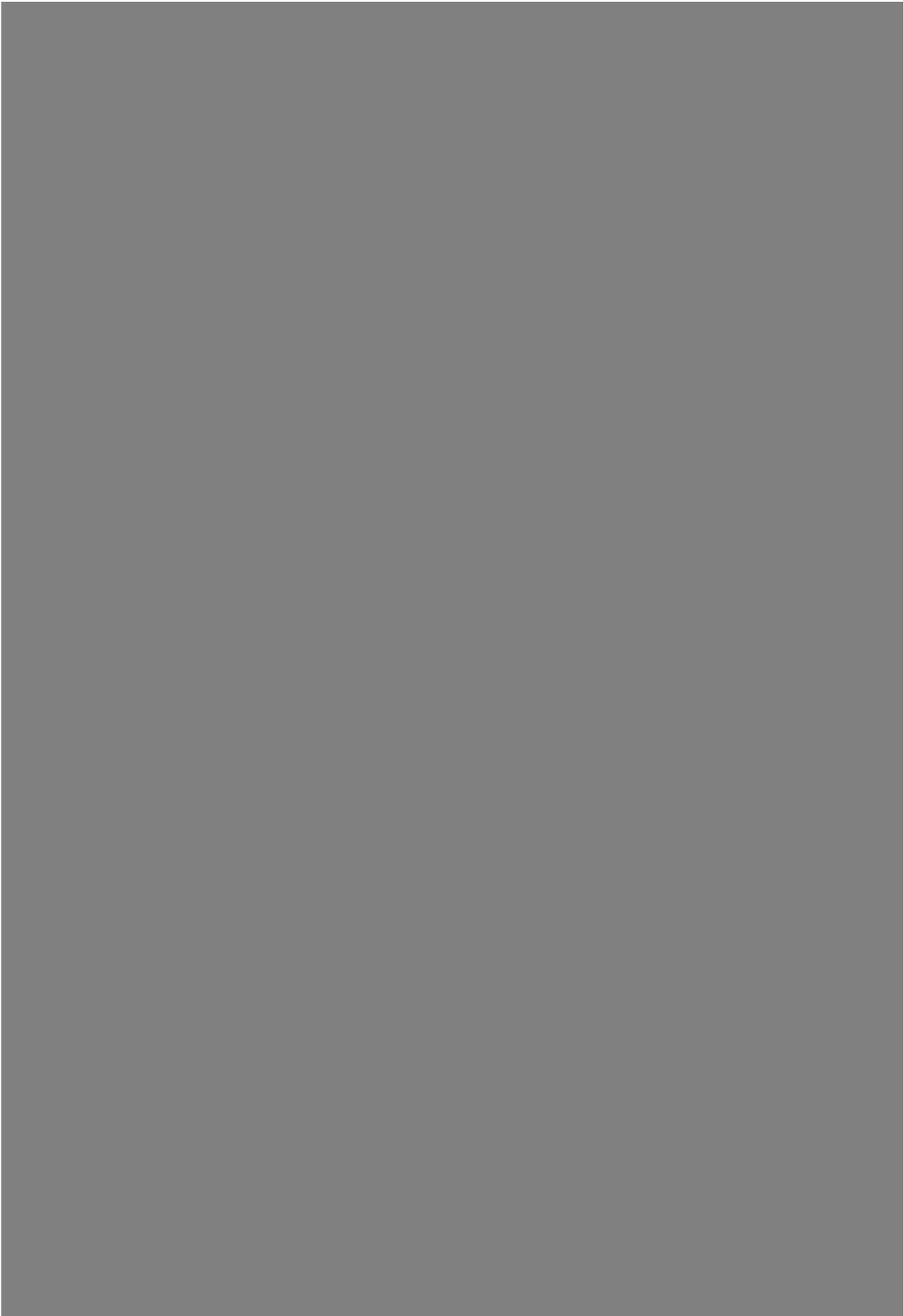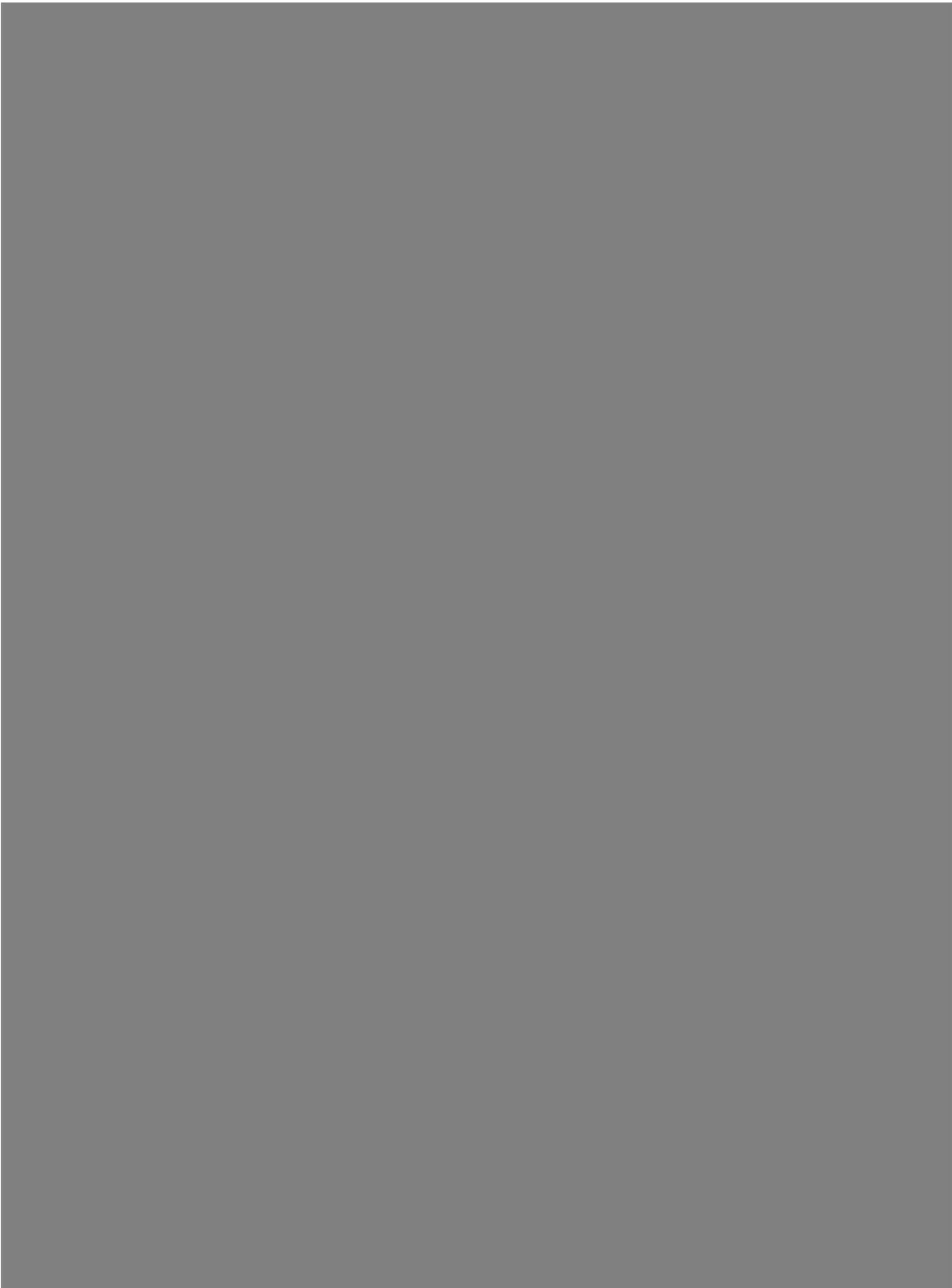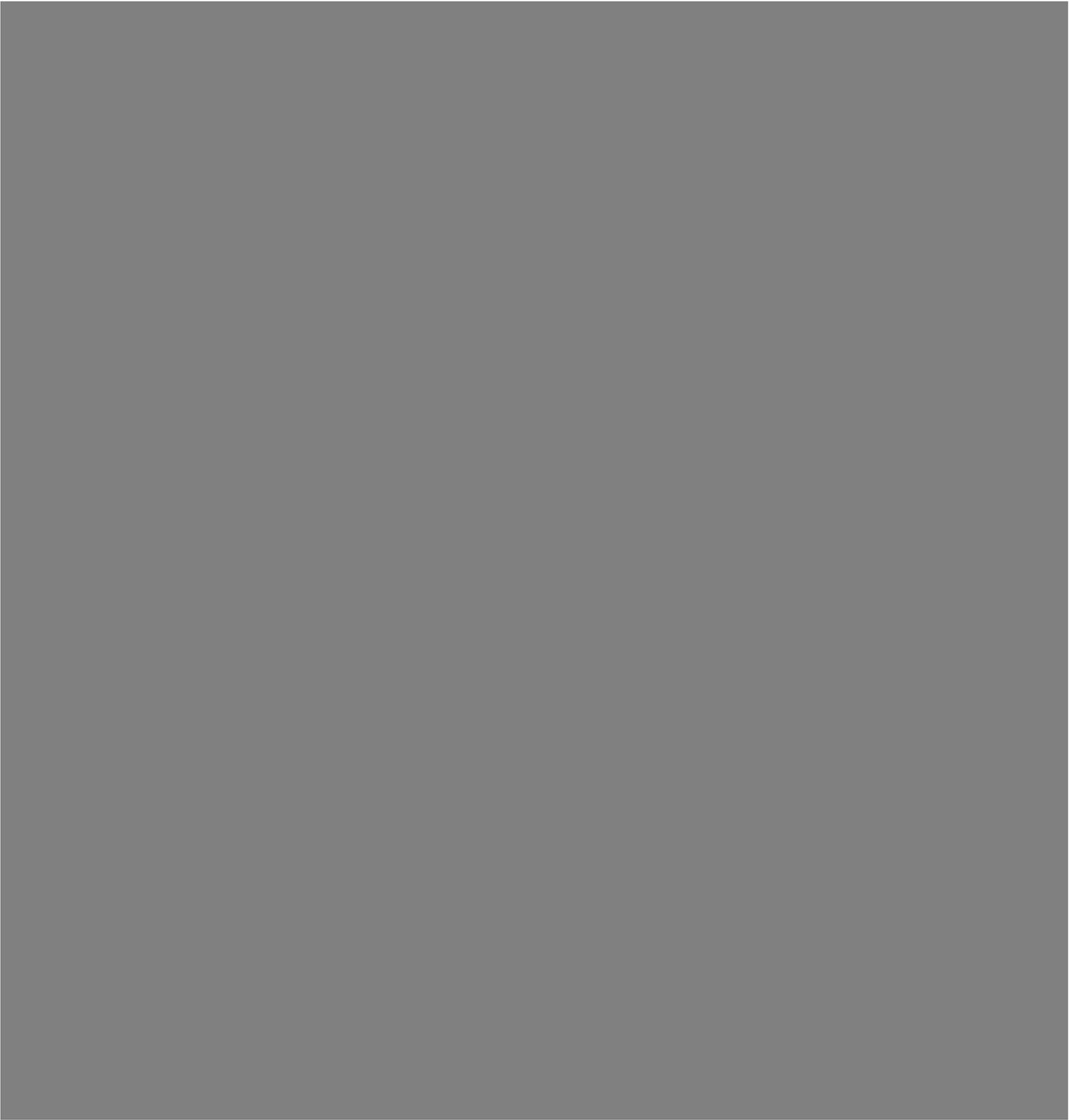
Appendix 7. Interview Questions (questions highlighted in red are additional questions developed after pilot interview)

Young Carers interview schedule

1. Questions about Caring activities and their impact on the carer

  a) Who do you care for?
  b) What kind of care do you provide?
  c) How many hours of care do you provide?
  d) How does this affect your life? (health, home, school, friends)
  e) If you weren't doing this, how would your life be different?
  f) (health, home, school, friends)
  g) When did u first become aware u were carer? How did you become aware you were a carer?

2. Micro system level questions

  a) As a young carer with additional needs, do you feel that your experiences (in school, home, relationships, mental health) differ much from young carers without additional needs? If so, in what ways?

  b) What kind of personal qualities and internal strengths do you feel you possess, that has helped you to cope with your role has a carer and cope with the demands of school?

  c) What are the key relationships you have that have helped you to cope with your role as a carer and the demands of school? How would you describe that relationship?
  d) Were there key relationships at school that helped you? How would you describe that relationship?
  e) How was your relationships with yr care-recipient change?

  f) What was your overall experience of school?
  g) What made the experience positive?
  h) What made the difference if you were happy or sad?
  i) Was their anything I school that helped you during the bad days?

  j) Do you feel part of the school? Do you feel included in school? Do you feel that you are missing out on anything at school?
  k) If you don't feel included in school, what would "being included" look like for you? What would be different?

l) In your school, do you feel that you receive adequate support for your caregiving?
m) What does this look like?
n) What about additional needs?
o) Were your support staff for your additional needs also aware of your caregiving? How would you describe this relationship?
p) Would anything have made it easier to open up about your needs to staff or peers?

q) How do staff respond to the knowledge that you are a carer?
r) If they treated u differently, how? Can you be specific?
s) Did you have a statement? Did this reflect your caregiving needs?
t) Did your support change over time?

u) How do other pupils respond to the knowledge that you are a carer?
v) Do you feel you can talk about being a carer in school?
w) Do you feel included in discussions about your support?

4. Exo-systems level questions

a) If you could go back in time, and advise your school about how they could better support your needs, what would you tell staff?
b) Do you think there is anyways that school could improve the way that they identify carers?
c) What is important for you to enjoy and participate in school?

d) What additional support do you receive outside of school?
e) Does your school coordinate with these agencies? In what ways?
f) How does school communicate with your parents/care-recipient about your experiences in school?
g) Do your parents get support to attend meetings, parents evenings, events?
h) Could anything have been done better in liasing with school?

i) What community supports and policy are you aware of that may support you at home and school?
j) Could these be better at supporting you?
k) What kind of additional support would you like to see in the community for YC?
l) If I could u lots of money to set up support, what would u do with it?

5. Macro-system level questions

a) What national supports and policy are you aware of that may support you at home and school?
b) Why do you think you are unaware of these initiatives/policy? Would you like to more about this?
c) What do you think would be an important change in terms of helping yc?

d) Post-18 transitions – how does that impact on you?

Spurgeons project workers interview schedule

1. Questions about Caring activities and their impact on the carer

a) What is your role at Spurgeons, and how do you support young carers?

2. Micro system level questions

a) Do you feel that young carers with additional needs are uniquely impacted on in terms of school, relationships and mental health?

b) From your experiences, what kind of internal strengths do the young carers with additional needs possess that allow them to cope with caring and the demands of school?

3. Meso-system level questions

a) How do school staff identify and respond to the knowledge that a young person may be a carer?
b) What supports exist in schools to support young carers with additional needs?
c) Are these effective?
d) How do you liaise with schools? What kind of challenges and opportunities does this present?
e) How do schools communicate with parents, and help parents to participate in school experiences such as parents evening and pupil events?
f) How could schools better support young carers with additional needs?

4. Exo-system level questions

a) What other supports exist outside of school, within the community, to support young carers with additional needs?
b) Are these effective?
c) What kind of support would help you to better support young carers with additional needs?

5. Macro-system level questions

a) What kind of policies at the national level affect young carers with additional needs, that you are aware of?

b) Do these need reconsidering?
c) What improvements could be made at a national level to better support young carers with additional needs in school, in terms of policy, legislation and initiatives?

Safeguarding and student welfare officer interview schedule

1. Questions about the participant's role

a) What is your role within the school, and what contact have you had with young carers?

2. Micro system level questions

a) Do you feel that young carers with additional needs are uniquely impacted on in terms of school, relationships and mental health? In what ways?

b) From your experiences, what kind of internal strengths do the young carers with additional needs possess that allow them to cope with caring and the demands of school?

3. Meso-system level questions

a) How do school staff identify and respond to the knowledge that a young person may be a carer?
b) What supports exist in school to support young carers with additional needs?
c) Are these effective?
d) What kind of support in the group provide?
e) What barriers are there in developing a YC support group, and how did u overcome these?
f) What differences made your support group successful?
g) If another SENCo asked for your support in developing a young carer support group, what advice would you give them?
h) Leadership?
i) Listened to?
j) External Agencies?

4. Exo-system level questions

a) How do you liase with external support agencies such as Spurgeons, in supporting these carers? What kind of challenges and opportunities does this present?
b) How do you communicate with parents of carers with additional needs, and help parents to participate in school experiences such as parents evening and pupil events? What challenges do you face in this?
c) How could schools better support young carers with additional needs?

d) What other supports exist outside of school, within the community, to support young carers with additional needs, that you are aware of?
e) Are these effective?
f) What kind of external support would help you to better support young carers with additional needs, in school?

5. *Macro-system level questions*

a) What kind of policies at the national level affect young carers with additional needs?
b) Do these need reconsidering?
c) What improvements could be made at a national level to better support young carers with additional needs in school, in terms of policy, legislation and initiatives?
d) What kind of national guidance and legislation exists guiding schools and agencies to support young carers?
e) Is this different locally?

Appendix 8. Pilot Interview Questions

Young Carers Interview schedule

1. Questions about Caring activities and their impact on the carer

   a) Who do you care for?
   b) What kind of care do you provide?
   c) How many hours of care do you provide?
   d) How does this affect your life? (health, home, school, friends)
   e) If you weren't doing this, how would your life be different?
   f) (health, home, school, friends)

2. Micro system level questions

   a) As a young carer with additional needs, do you feel that your experiences (in school, home, relationships, mental health) differ much from young carers without additional needs? If so, in what ways?

   b) What kind of personal qualities and internal strengths do you feel you possess, that has helped you to cope with your role has a carer and cope with the demands of school?

3. Meso-system level questions

   a) What are the key relationships you have that have helped you to cope with your role as a carer and the demands of school? How would you describe that relationship?

   b) Do you feel part of the school? Do you feel included in school? Do you feel that you are missing out on anything at school?
   c) If you don't feel included in school, what would "being included" look like for you? What would be different?
   d) In your school, do you feel that you receive adequate support for your caregiving?
   e) What does this look like?
   f) What about additional needs?

   g) How do other pupils respond to the knowledge that you are a carer?
   h) Do you feel you can talk about being a carer in school?
   i) Do you feel included in discussions about your support?

   j) What is important for you to enjoy and participate in school?

4. *Exo-system level questions*

a) What additional support do you receive outside of school?
b) Does your school coordinate with these agencies? In what ways?
c) How does school communicate with your parents/care-recipient about your experiences in school?
d) Do your parents get support to attend meetings, parents evenings, events?

e) What community supports and policy are you aware of that may support you at home and school?
f) Could these be better at supporting you?

5. Macro-level system questions

a) What national supports and policy are you aware of that may support you at home and school?