

The Experiences of Young People who move from Child to Adult Mental Health Services with support from a Transition Service

"...it's just kind of like throwing a little fish into a massive pond."

(Connie, participant)

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ABSTRACT

The transition from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) can be a challenging time for young people with mental health difficulties. Currently, much of the available research examining transition from CAMHS to AMHS is based on service providers' perspectives with limited focus on perspectives of young people. Therefore, the aim of this research was to explore how young people experience transition between CAMHS and AMHS. In addition, the experience of being supported by a Transition Service (TS) was also explored.

Seven participants were recruited purposively from a third-sector organisation TS. Semi-structured interviews were conducted and Interpretative Phenomenological Analysis was used to interpret participants' accounts. Four superordinate themes emerged from the data: *Being a young person with mental health difficulties* — capturing feelings associated with being seen in mental health services; *The process and immediate impact of change* — encompassing thoughts and feelings as young people were ending their involvement with CAMHS; *Life after CAMHS* — capturing the changes and challenges associated with receiving services from AMHS; and *Bridging the gap* — highlighting aspects of additional support during the transition process.

Findings are considered in relation to existing literature. Developing an understanding of how young people experience the move from CAMHS to AMHS with support from a Transition Service enabled a number of clinical and service recommendations to be made, which focus attention to how young people can be best supported in the transition from CAMHS to AMHS. Recommendations for future research are also discussed.

TABLE OF CONTENTS

1.	INTRODUCTION	1
1.1.	Focus of Study	1
1.2.	Overview of Chapter	1
Part	One: Setting the Scene	2
1.3.	Definition of Terms	
1.3.1	L. 'Adolescence' and 'Young People'	2
1.3.2	2. 'Mental Health Difficulties'	3
1.3.3	3. 'Transition'	4
1.4.	Developmental Transitions	4
1.4.1	L. Erikson's Theory of Psychosocial Development	5
1.4.2	2. Levinson's Theory of Adult Development	6
1.4.3	3. Arnett's Emerging Adulthood (EA)	6
1.4.4	l. Summary	7
1.5.	Mental Health Difficulties in Children, Adolescents and Young People	8
1.5.1		
1.5.2	2. Mental Health and Transition to Adulthood	9
1.5.3	B. Provision of Mental Health Services	10
1.5.3	3.1. Child and Adolescent Mental Health Services (CAMHS)	10
1.5.3	·	
1.5.3		
1.6.	Service Transitions	13
1.6.1		
1.6.2	Physical Health Service Transitions	15
1.6.3	B. Mental Health Service Transitions	16
1.6.3	3.1. Existing research	17
1.6.3	3.2. Barriers and Facilitators to Successful Transition	18
1.6.3	3.3. Services to Support Transition	20
1.7.	Theoretical Framework of Transition	21
1.7.1	Transition Theory – Meleis <i>et al.,</i> (2000; 2010)	22
1.8.	Summary of Part 1:	25
Part '	Two: Systematic Review of the Literature: Young People's Perspectives	26
1.9.	Overview of Systematic Review	
1.9.1		
1.9.2	2. Search Terms	27
1.9.3	B. Inclusion and Exclusion Criteria	27
1.9.4	l. Search Process	28
1.10.	. Summary of Included Studies	30

1.11.	Quality of Research	
1.11.1.	Narrative Quality Review	41
1.11.1.1	L. Research Aims, Methodology and Design	41
1.11.1.2	2. Recruitment and Data Collection	41
1.11.1.3	3. Reflexivity	42
1.11.1.4	1. Ethical Considerations	43
1.11.1.5	5. Data Analysis	43
1.11.1.6	5. Findings and Outcomes	43
1.11.1.7	7. Summary of Quality Review	44
1.12.	Narrative Synthesis	
1.12.1.	Practical and Procedural Processes	45
1.12.2.	Being informed and involved	
1.12.3.	Expectations and feelings around transition	
1.12.4.	Requiring support	
1.12.5.	Importance of therapeutic relationships	48
1.13.	Summary of Part Two: Systematic review	48
1.13.1.	Implications for Future Research	49
Part Th	ree: Rationale and Aims for Current Research	50
1.14.	Rationale for Current Research	50
1.15.	Research Aims and Objectives:	51
	THODOLOGY	
2.1	Overview of Chapter	52
2.2	Design	
2.2.1		52
2.2.1	Rationale for using a qualitative methodology	
2.2.2	Rationale for using a qualitative methodology	52
		52 53
2.2.2	Interpretative Phenomenological Analysis (IPA)	52 53 54
2.2.2 2.2.3	Interpretative Phenomenological Analysis (IPA)Rationale for using IPA in this research	52 53 54 54
2.2.22.2.32.2.4	Interpretative Phenomenological Analysis (IPA)Rationale for using IPA in this research Ensuring scientific quality and rigour in qualitative research	52 53 54 54
2.2.2 2.2.3 2.2.4 2.2.4.1	Interpretative Phenomenological Analysis (IPA)	
2.2.2 2.2.3 2.2.4 2.2.4.1 2.2.4.2	Interpretative Phenomenological Analysis (IPA)	
2.2.2 2.2.3 2.2.4 2.2.4.1 2.2.4.2 2.2.4.3	Interpretative Phenomenological Analysis (IPA) Rationale for using IPA in this research Ensuring scientific quality and rigour in qualitative research Owning one's perspective Situating the sample Grounding in examples	
2.2.2 2.2.3 2.2.4 2.2.4.1 2.2.4.2 2.2.4.3 2.2.4.4	Interpretative Phenomenological Analysis (IPA) Rationale for using IPA in this research Ensuring scientific quality and rigour in qualitative research Owning one's perspective Situating the sample Grounding in examples Providing credibility checks	
2.2.2 2.2.3 2.2.4 2.2.4.1 2.2.4.2 2.2.4.3 2.2.4.4 2.2.4.5	Interpretative Phenomenological Analysis (IPA) Rationale for using IPA in this research Ensuring scientific quality and rigour in qualitative research Owning one's perspective Situating the sample Grounding in examples Providing credibility checks Coherence	
2.2.2 2.2.3 2.2.4 2.2.4.1 2.2.4.2 2.2.4.3 2.2.4.4 2.2.4.5 2.2.4.6	Interpretative Phenomenological Analysis (IPA) Rationale for using IPA in this research Ensuring scientific quality and rigour in qualitative research Owning one's perspective Situating the sample Grounding in examples Providing credibility checks Coherence Accomplishing general versus specific research tasks	
2.2.2 2.2.3 2.2.4 2.2.4.1 2.2.4.2 2.2.4.3 2.2.4.4 2.2.4.5 2.2.4.6 2.2.4.7	Interpretative Phenomenological Analysis (IPA) Rationale for using IPA in this research Ensuring scientific quality and rigour in qualitative research Owning one's perspective Situating the sample Grounding in examples Providing credibility checks Coherence Accomplishing general versus specific research tasks Resonance with the reader	
2.2.2 2.2.3 2.2.4 2.2.4.1 2.2.4.2 2.2.4.3 2.2.4.4 2.2.4.5 2.2.4.6 2.2.4.7 2.2.5	Interpretative Phenomenological Analysis (IPA) Rationale for using IPA in this research Ensuring scientific quality and rigour in qualitative research Owning one's perspective Situating the sample Grounding in examples Providing credibility checks Coherence Accomplishing general versus specific research tasks Resonance with the reader Acknowledging the researcher's position Researcher's position statement	
2.2.2 2.2.3 2.2.4 2.2.4.1 2.2.4.2 2.2.4.3 2.2.4.4 2.2.4.5 2.2.4.6 2.2.4.7 2.2.5 2.2.5.1	Interpretative Phenomenological Analysis (IPA) Rationale for using IPA in this research Ensuring scientific quality and rigour in qualitative research Owning one's perspective Situating the sample Grounding in examples Providing credibility checks Coherence Accomplishing general versus specific research tasks Resonance with the reader Acknowledging the researcher's position Researcher's position statement Ethical Considerations Gaining Ethical Approval	
2.2.2 2.2.3 2.2.4 2.2.4.1 2.2.4.2 2.2.4.3 2.2.4.4 2.2.4.5 2.2.4.6 2.2.4.7 2.2.5 2.2.5.1	Interpretative Phenomenological Analysis (IPA) Rationale for using IPA in this research Ensuring scientific quality and rigour in qualitative research Owning one's perspective Situating the sample Grounding in examples Providing credibility checks Coherence Accomplishing general versus specific research tasks Resonance with the reader Acknowledging the researcher's position Researcher's position statement Ethical Considerations Gaining Ethical Approval Informed Consent	
2.2.2 2.2.3 2.2.4 2.2.4.1 2.2.4.2 2.2.4.4 2.2.4.5 2.2.4.6 2.2.4.7 2.2.5 2.2.5.1	Interpretative Phenomenological Analysis (IPA) Rationale for using IPA in this research Ensuring scientific quality and rigour in qualitative research Owning one's perspective Situating the sample Grounding in examples Providing credibility checks Coherence Accomplishing general versus specific research tasks Resonance with the reader Acknowledging the researcher's position Researcher's position statement Ethical Considerations Gaining Ethical Approval Informed Consent Confidentiality and Anonymity	
2.2.2 2.2.3 2.2.4 2.2.4.1 2.2.4.2 2.2.4.3 2.2.4.4 2.2.4.5 2.2.4.6 2.2.4.7 2.2.5 2.2.5.1 2.3.1 2.3.2	Interpretative Phenomenological Analysis (IPA) Rationale for using IPA in this research Ensuring scientific quality and rigour in qualitative research Owning one's perspective Situating the sample Grounding in examples Providing credibility checks Coherence Accomplishing general versus specific research tasks Resonance with the reader Acknowledging the researcher's position Researcher's position statement Ethical Considerations Gaining Ethical Approval Informed Consent	

2.4.1	Participant Information Sheet	61
2.4.2	Consent Form	61
2.4.3	Semi-Structured Interview Schedule	61
2.5	Participants	
2.5.1	Sample	62
2.5.2	Service Context	63
2.5.3	Inclusion Criteria	63
2.5.4	Description of Participants	63
2.6	Procedure	
2.6.1	Recruitment	65
2.6.2	Interview Procedure	65
2.7	Data Analysis	
2.7.1	Stage 1: Reading, re-reading and noting	
2.7.2	Stage 2: Developing emerging themes	67
2.7.3	Stage 3: Searching for connections across emergent themes	67
2.7.4	Stage 4: Summarising themes in a table	67
2.7.5	Stage 5: Moving to the next case	67
2.7.6	Stage 6: Identifying patterns across cases	68
2.8	Dissemination of results	68
3. F	RESULTS	69
3.1	Overview of Chapter	69
3.2	Overview of Themes	69
3.3	Superordinate Theme One: Being a Young Person with Mental Health Difficulties	
3.3.1	"You're mental"	72
3.3.2	"It's OK to not be OK"	74
3.3.3	"What about what I want?"	76
3.4	Superordinate Theme Two: The Process and Immediate Impact of Change	
3.4.1	"You don't know how it is"	
3.4.2	"They think something magic happens"	
3.4.3	"Tossed out on my own"	85
3.5	Superordinate Theme Three: Life After CAMHS	
3.5.1	"In the deep end"	87
3.5.2	"You're supposed to care"	
3.5.3	"I feel like an adult"	92
3.6	Superordinate Theme Four: Bridging the Gap	
3.6.1	"Having someone there"	
3.6.2	"Taking hold of your own care"	
3.6.3	"All in it together"	100
3.7	Summary of results:	101

4.	DISCUSSION	103
4.1	Overview of Chapter	103
4.2	Interpretation of Results	103
4.2.1	Superordinate Theme 1: Being a young person with mental health problems	103
4.2.2	Superordinate Theme 2: The process and immediate impact of change	105
4.2.3	Superordinate Theme 3: Life after CAMHS	107
4.2.4	Superordinate Theme 4: Bridging the Gap	110
4.3	Implications of the Findings	112
4.3.1	Theoretical Implications	112
4.3.2	Clinical and Service Implications	113
4.3.3	The role of Clinical Psychology	117
4.4	Dissemination of findings	118
4.5	Strengths and Limitations of the study	118
4.5.1	Methodology and Design	119
4.5.2	Recruitment and Sample	119
4.5.3	Data Collection and Analysis	121
4.5.4	Ensuring credibility	122
4.6	Future Research	123
4.7	Conclusion	124
REFI	ERENCES	126
APP	ENDICES	145
	endix i: Search terms used in Systematic Review	
	endix ii: Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist	
	endix iii: Extract from Reflective Journal	
	endix iv: Example extract of analysis of transcript	
	endix v: Cardiff University Ethics Committee Approval Letter	
	endix vi: Third-sector organisation Ethics Committee Approval Letter	
	endix vii: Participant Information Sheet	
	endix viii: Participant Opt-in Form	
	endix ix: Participant Consent Form	
	endix x: Participant Debrief Form	
	endix xi: Semi-structured Interview Schedule	
Арре	endix xii: Frequency of Subordinate Themes within Transcripts (including line numbers)	171

LIST OF FIGURES

Fig. 1. A. Contine France and Con CANAUC to Made	4.4
Figure 1: Service Framework for CAMHS in Wales	
Figure 2: Service Framework for AMHS in Wales	12
Figure 3: Transition: A middle-range theory. Modified from Meleis et al., (2000)	23
Figure 4: Systematic Search Process	
LIST OF TABLES	
Table 1: Systematic Review: Description of included studies	31
Table 2: Systematic Review: Summary of Quality Review	37
Table 3: Narrative Synthesis: Occurrence of themes across studies	44
Table 4: Participant Details	64
Table 5: Summary of Superordinate, Subordinate and Emergent Themes	71

1. Introduction

1.1. Focus of Study

Young people in the UK who develop mental health difficulties and are referred for treatment are usually seen within Child and Adolescent Mental Health Services (CAMHS). The upper age limit for young people to access CAMHS within Wales is currently 18 years (Welsh Government [WG], 2012; 2013) after which, if a young person requires ongoing input, their care is provided by Adult Mental Health Services (AMHS). For young people, their families and services, the transition from CAMHS to AMHS has recently been documented as an area of concern (National Assembly for Wales [NAW], 2014).

Currently, there is a paucity of research exploring the experiences of young people who have transitioned from CAMHS to AMHS, particularly within Wales. It is intended that this research will contribute to the limited research base by providing an in-depth insight into the lived experience of young people as they move from CAMHS to AMHS with support from a third-sector Transition Service (TS). The use of a qualitative design enabled the researcher to obtain young people's views about the process of transition and their experience of being supported during the move between child and adult mental health services. This is in line with current guidelines that identify the need to collaborate with young people, and to put their views at the centre of decision making in order to improve service delivery.

1.2. OVERVIEW OF CHAPTER

This chapter contains an overview of the relevant literature relating to the transition from CAMHS to AMHS. The chapter is presented in three parts. Part one provides an introduction to the literature regarding young people's mental health and the transfer of care from CAMHS to AMHS, along with current national and local policy and practice guidelines. Literature pertaining to transition in the context of developmental frameworks and Transition Theory is also presented. A systematic review of the literature exploring young people's experience of the move from child to adult mental health services is described and critiqued in Part Two. Finally, Part Three provides the rationale and aims for the current study.

1.3. DEFINITION OF TERMS

Prior to exploring the current literature, a number of key terms will be defined.

1.3.1. 'ADOLESCENCE' AND 'YOUNG PEOPLE'

The developmental stages of childhood, adolescence and adulthood pose difficulties in their conceptualisations and age distinctions. Setting age boundaries for categorising people into different stages of development offers confusion, as no clear distinction regarding the age ranges that constitute adolescence and/or adulthood appears to exist.

In the UK, legal definitions of 'child' or 'children' are used to define a person under the age of 18 (Children Act, 1989). Within the UK, the definition of 'adult' is similarly defined in legal terms, as someone over the age of 18. Yet, 'becoming an adult' is socially constructed and defined where legal responsibilities are acquired, such as being able to vote, and through expectations such as maturing out of education, and leaving the family home (Billari & Wilson, 2001; Heinz, 2009). Schlossberg (1987) argues that chronological age is not an accurate indication of biological, psychological or social maturity, instead progress may be more determined by a psychological clock. This view is supported by Arnett (2007) who claims that rates of maturity and indeed, moving into adulthood, vary greatly from person to person, particularly for those with additional needs.

The definition of 'adolescence' is even less clear. It is argued that adolescence is a socially constructed developmental stage between childhood and adulthood, rather than something defined strictly by age (Galazter-Levy, 2002). However, the World Health Organisation (WHO, 2012) defines adolescence as a stage between the ages of 10 to 19, and the Royal College of Paediatrics and Child Health (2003) regards people between the ages of 10 and 20 as adolescents. Further, Arnett (2007) suggests that the length of adolescence has increased in recent decades, in that, young people are remaining in education and living at home longer. Yet, child and adult services are often demarcated by rigid aged boundaries, indeed, health services within the UK define adulthood from 18 years; leading to transition from child orientated to adult focussed services.

Within the literature terms such as 'transitioning youth', 'late adolescents' and 'young adults' are used interchangeably to describe the cohort moving from adolescence into adulthood, with no clear definition given (Gaudet, 2007). Currently, mental health literature appears to subscribe to the view that youth in transition from adolescence to adulthood are between the ages of 16 and 25 (Brodie *et*

Chapter One: Introduction

al., 2011; Davis & Van der Stoep, 1997; Davis, 2003; Singh et al., 2008). There is also a growing body of literature regarding this developmental stage as a distinct period known as 'emerging adulthood', lasting from 18 to 25 (Arnett, 2000). Conversely, some researchers have adopted a more flexible view of young people by identifying them within the range of 12 to 25 years (McGorry, 2007; Patel et al., 2007).

Due to the plethora of terms that are used interchangeably within the literature, the terms 'adolescent' and 'young people' will be used in this chapter in line with their occurrence in the literature, and where possible, will be illustrated by the age ranges cited.

1.3.2. 'MENTAL HEALTH DIFFICULTIES'

Definitions of mental health vary widely, with many interpretations, and there is much debate around how to best describe mental health difficulties. Throughout the literature, the terms mental disorders, mental health difficulties and mental illness are used interchangeably.

The World Health Organisation (WHO) defines mental health as:

"...a state of well-being in which an individual realises his or her own abilities, can cope with the normal stresses of life, can work productively, and is able to make a contribution to his or her community." (WHO, 2016)

and mental illness as:

'...a broad range of problems, with different symptoms. However, they are generally characterized by some combination of abnormal thoughts, emotions, behaviour and relationships with others.' (WHO, N.D).

Within a recent Child and Family Clinical Psychology Review 'mental health difficulties' are defined as:

'...conditions which affect a person's mood, thinking and behaviour to such a degree that they have a significant effect on their ability to function as they would like to within different areas of their lives.' (Division of Clinical Psychology [DCP], 2015a, p.8)

For the purpose of this research, the definition proposed by the DCP, above, will be used by the researcher to define mental health difficulties in children and young people. In line with guidelines on language in relation to functional psychiatric diagnoses set out by the DCP (DCP, 2015b) the term 'mental health difficulties' will be used, unless citing research where the term adopted by the researchers will be used.

Chapter One: Introduction

1.3.3. 'TRANSITION'

Broadly, the word 'transition', as defined by the Compact Oxford Dictionary is: 'The process or a period of changing from one state or condition to another.' (Soanes, 2013 p. 1101).

In the context of healthcare services, the definition of transition that is adopted at a policy level, for example, by the National Institute of Clinical Health Excellence [NICE] (NICE, 2016) is:

'The purposeful and planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems.' (Blum et al., 1993, p.570).

Within the literature pertaining to transition from child to adult mental health services, the concept of transition can be viewed from two distinct perspectives (Singh *et al.*, 2010). Firstly, from a developmental perspective, the transition to adulthood is a crucial stage of emotional, physiological, psychosocial, and personal developments as young people embark on adult roles through tasks such as separating from family, deciding on a career path and defining self in a social context (Lee, 2001; Levinson, 1986). Secondly, from a health care perspective, transition involves the movement from one service to another, upon reaching certain age milestones, typically at the age of 18. Within this research, both perspectives of transition will be considered. Theoretical frameworks of transition will also be drawn upon, and are discussed later in this chapter.

1.4. DEVELOPMENTAL TRANSITIONS

Singh (2009) claims that mental health service transitions are often '...too focused on service transfer rather being part of a holistic process of moving into adulthood and independence' (p.387). He cautions that viewing transitions merely as an administrative healthcare event can lead to developmental needs being unmet.

For many young people the transition from CAMHS to AMHS is a critical period of time (Murcott, 2014). It is also a time where young people are moving from adolescence to adulthood, which in itself, can add a further level of complexity. Whilst this research is predominantly interested in mental health service transition, developmental theories are relevant and inextricable due to developmental age and stage at which mental health service transitions occur.

The concept of transition is embedded within developmental theory and describes the process whereby people move from one stage to another across the life span (Lenz, 2001). The transition to adulthood is recognised as beginning in adolescence and continues until an individual becomes an adult (Furlong, 2009). Yet, how these life stages are conceptualised differs between theories. The literature pertaining to human psychosocial development is vast, and the exploration and critique of such is beyond the scope of this thesis. Therefore, the dominant models of psychosocial development that capture the developmental tasks associated with transition from adolescence to adulthood will be explored briefly; in particular, theories proposed by Erikson, Levinson and Arnett.

1.4.1. ERIKSON'S THEORY OF PSYCHOSOCIAL DEVELOPMENT

Erikson's (1963) theory of psychosocial development comprises eight separate stages in which individuals have to negotiate during their lives in order to attain healthy growth and development. According to Erikson (1963) each developmental stage is associated with a dilemma or turning point which individuals need to master in order to successfully move to the next stage. Erikson (1963) suggested that these dilemmas are of a psychosocial nature resulting from the interaction between an individual and the context in which they are embedded. Central to his theory, adolescence is regarded as the most critical stage in psychosocial development, and contains the dilemma of identity versus role confusion. Within this stage Erikson proposes that the search is for a new sense of continuity and sameness, whilst reworking 'hope, will, purpose and competence' into a coherent set of values and beliefs (cited in Sugarman, 2001, p.95). Thus, during this stage, the adolescent begins to explore and implement various expressions of 'self' in order to form their personal identity.

According to Erikson (1963), in order to meet the criteria necessary to succeed in this stage, the individual must develop a strong sense of self. The danger in this stage is identity diffusion or role confusion, i.e. uncertainty about who one is and what one is about to become (Sugarman, 2001). In considering risk factors for poor mental health, it has been suggested that for some young people, attempts to counteract such uncertainty may lead to withdrawal from others, or temporarily overidentifying with an undesirable group of peers (Sugarman, 2001). Building on Erikson's theory Marcia (1980) proposed that the development of a self-destructive identity may be preferable to no identity at all, thus, the young person may cling to a socially undesirable identity if socially acceptable alternatives are deemed unavailable. Despite Erikson's theory receiving criticism (see Franz & White, 1985), such claims have possible implications for the ongoing mental health needs of the developing

adult, and may therefore be borne in mind when considering service interventions addressing the specific developmental needs of young people.

1.4.2. LEVINSON'S THEORY OF ADULT DEVELOPMENT

Building upon Erikson's theory of psychosocial development, Levinson (1986) proposed that the adult life course evolves across six stages. Levinson *et al.*, (1978) claimed that between each stage, a transitional period exists, in which existing life structures, such as, the 'sense of self' are reappraised and rebuilt. The Early Adult Transition (EAT), is the developmental bridge spanning the ages of 17-22, which overlaps the stages of pre-adulthood and early adulthood. It is within this period that young people leave behind adolescent life and prepare for an adult life (Levinson, 1986). Key tasks within this transitional stage include the need to modify or end relationships to make way for new adult relationships, and the development of autonomy and responsibility (Levinson, 1986). This view is supported by Baltes and Silverberg (1994) who propose that autonomy, that is, disengaging from parental control and developing self-governance, is a key developmental task belonging to this period. However, to achieve positive well-being, Baltes and Silverberg (1994) suggest that there is a need for a negotiated balance between an emerging autonomous sense of self and feeling connected with others. How services manage the transition from CAMHS to AMHS will therefore be key to whether there is opportunity for a perceived and negotiated balance between autonomy and connectedness.

1.4.3. ARNETT'S EMERGING ADULTHOOD (EA)

The notion of 'emerging adulthood' (EA) has gained prominence in research exploring young people and transition. In his writing, Arnett (2000) provides a clear definition and understanding of EA by developing a theoretical, culturally constructed concept regarding this specific stage of development. Arnett (2000) proposed that this life stage occurs between the ages of 18 and 25 years and has distinct features that make it different from adolescence and adulthood, which include: identity explorations; an age of instability; a self-focussed age; an age of feeling in-between; and an age of possibilities (Arnett 2000; 2004; 2007; Arnett & Tanner, 2009).

Arnett and Tanner (2009) suggest that there are a number of important developmental features that distinguish adolescence from EA, encompassing cognitive, behavioural and emotional elements to reveal underlying neurological and physiological development. This is supported by the literature in brain development (Bennett & Baird, 2006; Giedd *et al.*, 1999) demonstrating specific regional

changes in the brain structure, especially during times of life transitions, and research exploring the associated risks for mental health difficulties within this age period (Tanner *et al.*, 2007).

Contributions to Arnett's theory have been made by Tanner (2006), who states that EA is not only a distinct stage but a pivotal period of development. It is proposed that a shift to adulthood is achieved through a process of 'recentering through three stages' (Arnett & Tanner, 2009, p.40). At stage one, Emerging Adults (EAs) are still reliant and based within their family of origin, with shifts occurring in their own and others' expectations about self-reliance and self-directedness. The second stage encompasses 'identity exploration', whereby commitments made by EAs are transient and fleeting in nature as they explore a number of options available to them whilst simultaneously working towards independence. At the end of this stage and entering stage three of the recentering process, EAs are making lasting decisions and commitments to all aspects of their lives (Arnett & Tanner, 2009).

According to Arnett (2000; 2004) EA is characterised as a period whereby young people experience some of the most significant transitions in their lives, such as the first formation of intimate relationships, building meaningful links with a social network, moving from secondary to post-secondary education and transitioning from education to employment opportunities and then a career. Arnett (2007) proposes that chronic illnesses and disabilities, including poor mental health, may interrupt identity explorations and intensify the sense of instability that young people face during this period, whilst at the same time, reducing opportunities to achieve vocational and academic success.

1.4.4. SUMMARY

In summary, the developmental theories explored in this section differ in the way that transition to adulthood is conceptualised, however, all agree that a sensitive process is occurring. Taking into account the developmental and social needs of the young person appears to be a necessity when supporting young people during transition from child to adult services, considering that adolescence and emerging adulthood is a vulnerable period for the materialisation of mental health difficulties and risk-taking behaviour (Kessler *et al.*, 2005; Dodgson & Ross, 2011).

1.5. MENTAL HEALTH DIFFICULTIES IN CHILDREN, ADOLESCENTS AND YOUNG PEOPLE

1.5.1. PREVALENCE

At present, there is a dearth of up-to-date data regarding the prevalence of mental health difficulties in children and young people, particularly within the United Kingdom (UK). The most recent national systematic survey of mental health difficulties for children and young people was carried out for the Office of National Statistics in 2004 (Green *et al.*, 2005). This survey estimated that one in ten children and young people in the UK aged between five and 16 years have a diagnosable mental health problem. A prospective longitudinal study has also reported that more than half of adults accessing mental health services at the age of 26 had met the criteria for a diagnosable mental health condition between the ages of 11 and 15, and more than three quarters had received first diagnosis by the age of 18 (Kim-Cohen *et al.*, 2003).

On a global level, the World Health Organisation reports that 20% of adolescents (aged between ten and 19) may experience mental health difficulties in any given year (WHO, 2012). A study in the United States found that for children aged between 11 and 16 the prevalence of mental health disorders is 12% (Kessler *et al.*, 2005), with the rate estimated to increase to between 20-39% for young people aged between 16 and 24 (Kessler *et al.*, 2005; Wittchen *et al.*, 1998). Kessler and colleagues (2005) concluded that 50% of all lifetime cases of mental health disorders start by the age of 14 and 75% by the age of 24.

It is important to consider that the figures reported may not offer a complete reflection of the number of young people who experience mental health difficulties, since, as with much mental health research, only young people meeting a clinical threshold for diagnosis are included. It may be likely that there are a large number of young people experiencing mental health difficulties which would fall below the diagnostic threshold but which may develop into more serious difficulties if they do not have access to appropriate support. Ongoing concerns regarding the prevalence of mental health difficulties in young people exist, yet, in the absence of up-to-date epidemiological data it is difficult to ascertain whether there has been there has been a rise in the rates of mental health problems. Despite little up-to-date knowledge, there appears to be some consensus that 'mental health difficulties are one of the biggest problems facing children and young people today' (Law et al., 2015 p.10). According to the National Assembly for Wales (NAW) specialist CAMHS is 'under more pressure than ever before', reporting an approximated two-fold increase in referrals for treatment between April 2010 and July 2014 (NAW, 2014).

1.5.2. MENTAL HEALTH AND TRANSITION TO ADULTHOOD

Adolescence is a risk period for higher psychological morbidity (Murphy & Fonagy, 2012). There is evidence to suggest that it is a time when mental health difficulties such as psychosis or eating disorders may emerge (Lamb *et al.*, 2008; Wittchen *et al.*, 1998). For example, first episode schizophrenia has been found to generally occur between the ages of 16 and 25 years (Andreasen, 1999). Similarly, eating disorders tend to emerge in early to mid-adolescence (Winston *et al.*, 2012). Further, the majority of people who self-harm (usually through deliberate cutting or scratching) are aged between 11 and 25 (Association for Young People's Health, 2013; Mental Health Foundation, 2006). Adolescence is also a time where pre-existing difficulties, commonly anxiety and depression, become more complex or severe (Hagell, 2004; Kessler *et al.*, 2005).

Mental health difficulties in adolescence are likely to continue into adulthood. Green and colleagues (2005) found that children and young people with a mental health difficulty were three times as likely to have a mental health disorder in adulthood. For example, adolescent depression has been found to be associated with a high risk of depressive relapse later in adulthood (Fombonne *et al.*, 2001). Similarly, adolescents who have three or more episodes of anxiety are reportedly three and a half times more likely to have an anxious disorder in adult life (Woodward & Fergusson, 2001) and those presenting with obsessive compulsive disorder (OCD) in childhood show recurrent episodes into adult life (March & Leonard, 1996). There is also evidence to suggest that trends in mental health difficulties have increased over the last 30 years, with more adolescents diagnosed with anxiety and depressive disorders than previously (Hagell, 2012). Longitudinal research has also indicated that young people who experience mental health difficulties are more likely to experience poorer life outcomes, such as being excluded from education, leaving school with little or no qualifications and a lack of peer networks (Department for Children, Schools and Families [DfCSF] & Department of Health [DoH], 2008; Parry-Langdon, 2008).

There does not appear to be a clear consensus regarding underlying causes of problems occurring between the ages of 12 and 25 (McGorry, 2007). Cohort studies such as Jaffee and colleagues (2002) and Kessler and Magee (1993) have found that young people exposed to multiple childhood adversities (e.g. poor socialisation, family instability, perinatal traumas) are at a higher risk of developing adult affective disorders. It has been suggested that a number of further risk factors for developing mental health difficulties exist; such factors include adaptation to the developmental stage, identity formation, increased pressures regarding academic achievement, and increased risk taking behaviours such as substance misuse and sexual promiscuity (Arnett, 2005; Dogson & Ross, 2011; Lamb *et al.*, 2008; Young Minds, 2006). Indeed, the use and misuse of alcohol and drugs is a

major problem for a high majority of adolescents, with many young people accessing CAMHS who have co-morbid substance misuse problems (Aldridge *et al.*, 2008).

As highlighted above, many young people who experience mental health difficulties in adolescence will continue to experience difficulties and require specialist support into adulthood (Kim-Cohen *et al.*, 2003). The potential detrimental effects mental health difficulties could have upon a young person's future (e.g. in terms of their social and occupational functioning) indicates the importance of ensuring that appropriate, accessible and effective support is made widely available to young people. Lamb and colleagues (2008) suggest that mental health services should engage and treat young people who have severe and enduring mental health difficulties, and facilitate the likely transition for ongoing treatment to adult services when the young person reaches adulthood. Thus, effectively managing the transition between child and adult mental health services should be a priority, to ensure that young people are able to access appropriate sources of support when needed.

1.5.3. Provision of Mental Health Services

Historically, mental health services in the UK have been provided for adults only, and it was not until the late 1940s that mental health services specifically for children and young people began to emerge in a meaningful way with the development of child guidance (Black & Gowers, 2005). Since that time, services for children and adults have largely existed in isolation of each other. The following sections will explore service provision of CAMHS and AMHS in Wales predominantly, as the research was conducted in South Wales.

1.5.3.1. CHILD AND ADOLESCENT MENTAL HEALTH SERVICES (CAMHS)

Child and Adolescent Mental Health Services (CAMHS) are generally health-based (National Health Service, NHS) specialist services, offering assessment and treatment when children and young people up to the age of 18 have emotional, behavioural or mental health difficulties (Anderson, 2006). A broader definition of CAMHS named the 'CAMHS Concept' is adopted in Wales to encapsulate all dedicated service provision (including third-sector agencies) that aims to meet the mental health and emotional well-being needs of children and young people (Williams & Kerfoot, 2005). At present, CAMHS in Wales is delivered via a four-tiered framework, which is well embedded within the culture and systems of health services. The tiers are outlined in Figure 1, overleaf.

Chapter One: Introduction

Tier 1: Primary or direct contact services

Tier 2: First-line specialist services provided by professionals from Specialist CAMHS whose primary role is mental healthcare.

Tier 3: Second-line specialist services provided by teams of staff from within Specialist CAMHS

Tier 4: Very specialist interventions and care, including inpatient mental health services for children and young people

Figure 1: Service Framework for CAMHS in Wales (Welsh Assembly Government [WAG], 2005a; Welsh Government, 2013)

Guidance on the shape and nature of comprehensive CAMHS is provided via the National Service Framework for Children, Young People and Maternity Services (WAG, 2005a). In brief, Tier 1 consists of universal services provided through primary care. Tiers 2 and 3 provide targeted support through services such as: youth offending teams; school and youth counselling; and specialist community based psychiatric and psychological services. Finally, Tier 4 consists of specialised services, including inpatient care (Joint Commissioning Panel for Mental Health [JCPMH], 2013)

Across the UK variations in practice exist in terms of the age ranges adopted by services, with respect to which services are responsible for young people aged 16-18. Since 2012, CAMHS services in Wales provide services to all children and young people up to and including the age of 18 (Welsh Government [WG], 2013). Individuals who require ongoing mental health services when they reach the age of 18 may therefore need to access Adult Mental Health Services (AMHS).

1.5.3.2. ADULT MENTAL HEALTH SERVICES (AMHS)

As with services for children and adolescents, mental health care for adults within the UK, including Wales is predominantly provided by the NHS. Following the launch of a number of policy initiatives (e.g. 'All Wales Mental Health Strategy', Welsh Office, 1989, followed by 'Raising the Standard': The National Service Framework for Adult Mental Health, WAG, 2005b), and more recently, 'Together for Mental Health', WG, 2012) mental health services for adults in Wales have largely been delivered in the community when practical, allowing inpatient services to be used most effectively (WG, 2012). Akin to the delivery of services to children and adolescents, Adult Mental Health Services (AMHS) are typically delivered via a four-tiered service framework, outlined in Figure 2, overleaf.

Tier 1: Primary Mental Health Care teams, Counselling and support services

Tier 2: Community Mental Health Teams (CMHTs) including Specialist Community Teams including Crisis Resolution Home Treatment (CRHT); Assertive Outreach and Early Intervention for Psychosis and Acute Inpatient Care

Tier 3: Specialist inpatient services e.g. low and medium secure care

Tier 4: Highly specialised inpatient, high secure and residential services

Figure 2: Service Framework for AMHS in Wales (WAG, 2010a)

UK prevalence rates suggest that one in four adults have a diagnosable mental health disorder (WG, 2012). This infers that many people will access mental health services at some point in their lives. Within Wales, adults who experience mild to moderate mental health difficulties are typically seen at Tier 1, where primary mental health services are provided. Those with severe, complex and enduring mental health difficulties are referred to secondary mental health services (Tier 2). Services within Tier 2 (Secondary Mental Health Services) are provided under an integrated management framework, enabling the sharing of expertise and resource from both NHS and social care services. Finally, if specialist, secure inpatient treatment is required, individuals access Tiers 3 and 4 (WAG, 2010a).

1.5.3.3. IDEOLOGICAL DIFFERENCES BETWEEN CAMHS AND AMHS

Historically AMHS have provided services to people who have severe and enduring mental health difficulties with a focus on diagnosis-led treatment (Singh & Tuomainen, 2015). This is in contrast to CAMHS where a more developmental approach is adopted, offering services to children and young people presenting with emotional, behavioural and emerging mental health problems as well as those with more complex mental health difficulties (Lamb & Murphy, 2013; Singh *et al.*, 2005; Singh *et al.*, 2010; Tantum, 2005). Moreover, a systems focused approach is central to CAMHS, where young people are seen as existing within part of a wider support system, whose involvement is helpful, if not essential (Hovish *et al.*, 2012; Tantum, 2005). Ordinarily, interventions offered in CAMHS involve parents, carers and professionals from education and social care. By contrast, treatment in AMHS tends not to be offered without a diagnosis, is individually orientated and would be not be likely to include the wider network (Hovish *et al.*, 2012). Lamb and colleagues (2008) suggest that the ideological differences between CAMHS and AMHS, such as differing conceptual views of diagnostic categories and treatment focus may create complex challenges in negotiating the transition between services.

Within Wales, attempts have been made to lessen the difference between child and adult mental health services via the introduction of an all-age Mental Health Strategy: 'Together for Mental Health' (WG, 2012) and with the implementation of the Mental Health (Wales) Measure (WAG, 2010b). When young people transfer from secondary CAMHS to AMHS continuity of care aims to be ensured by a process of holistic Care and Treatment Planning which is co-ordinated by a named professional. Care and treatment planning is documented in a 'Care and Treatment Plan' which is recognised by both CAMHS and AMHS. The document aims to end the artificial barriers that exist between services, attempting to ensure that individuals are not at a disadvantage when they move from one service to another (WG, 2013). Despite these aims, to date, there is no known research into the extent at which the implementation of 'Together for Mental Health' and the Mental Health (Wales) Measure has improved the continuity of care between child and adult mental health services in Wales.

1.6. SERVICE TRANSITIONS

1.6.1. POLICY AND PRACTICE GUIDANCE

The concept of moving young people's care from child to adult settings is not new, and is regarded as an accepted element of health service and delivery (Blum *et al.*, 1993). Transition from child to adult health care has been subject to considerable policy discussion in the UK. Umbrella organisations, charities and governmental agencies throughout the UK, including Wales, have sought to raise transition as an issue of importance in their published material (Department of Health [DoH], 2006; Young Minds, 2006; Social Care Institute for Excellence [SCIE], 2011; DoH, 2008; NAW, 2001; WAG, 2005a). The purpose of many of these documents is typically fourfold. Firstly, such documents seek to quantify and raise awareness of the key areas of concern within a transitional care context. Second, the documents tend to provide advice and guidance in terms of service planning, organisation and delivery. Thirdly, most of the documents advocate multi-disciplinary and multi-agency working. Finally, the documents advocate for and embed the need to develop transitional care pathways.

The DoH good practice guide 'Transition: Moving on Well' (2008) outlines a number of characteristics of good transition planning for health services, including mental health services. It proposes needs for: an agreed process for joint strategic planning between child and adult services; clear transition pathways; a skill mix ensuring the availability of adolescent health expertise; professional/clinical leadership; key working (where required); and a service that is flexible and responsive to the needs of young people.

However, notable concerns within publications from charities that advocate for young people with mental health difficulties, such as the Mental Health Foundation (2008) and Young Minds (2006) stress that despite services having robust transition protocols, many young people and their families find themselves without a continuing mental health service. As a result of concerns, policy and guidelines specifically addressing the needs of young people moving from CAMHS to AMHS have been developed. Following a national review of CAMHS in England (DfCSF & DoH, 2008), the UK Government's mental health strategy 'No Health Without Mental Health' (DoH, 2011) stated that service transition from CAMHS to AMHS would be improved through early planning, listening to the views of young people, providing appropriate and accessible information and by jointly commissioning services. However, there are continuing concerns. A more recent government mental health policy document 'Closing the Gap' (DoH, 2014) claims to end the 'cliff-edge' of lost support by assisting NHS England to develop service specifications for transition from CAMHS. Further, to address widely documented difficulties, NICE has recently produced guidelines on health care transitions, covering both health and social care services, including mental health (NICE, 2016).

In Wales, the transition of young people's care from CAMHS to AMHS has been a documented concern for a number of years. The national CAMHS Strategy 'Everybody's Business' launched in 2001 (NAW, 2001) reported that transition between child and adult mental health services was an area of concern due to difficulties at the interface between the services. Particular issues highlighted included differing policies about service priorities and consequent difference in approaches to the core business of AMHS compared to CAMHS. Specific core principles within the document suggested that CAMHS and AMHS should together clarify current service provision in order to reduce uncertainty and ensure that there are no gaps between services.

Furthermore, the National Service Framework (NSF) for Children, Young People and Maternity Services, Standard 5 - Transitions (WAG, 2005a) recommends:

'Young people who require continuing services, such as those who are disabled or chronically ill, young people with persistent mental illness or disorders, vulnerable young people and their families and carers, and care leavers, are offered a range of co-ordinated multi-agency services, according to assessed need, in order to make effective transitions from childhood to adulthood.' (WAG, 2005a, p.54).

Key principles outlined within the NSF include: the appointment of a key transition worker to ensure that young people, their families and relevant agencies are involved in the transition process; information regarding access to services and facilities should be made available to young people and their families; and that a joint organisation transition plan should be produced which specifies arrangements for continuing support.

Despite concern and subsequent recommendations, little change has been highlighted. In 2009, a review completed by Wales Audit Office and Health Inspectorate Wales (HIW) highlighted inadequacies in terms of arrangements to ensure effective transitions from CAMHS to AMHS (Wales Audit Office, 2009). In particular, the review reported that no additional guidance regarding transition had been established since the inception of 'Everybody's Business', however it was acknowledged by the authors, that transition was on the agenda in terms of being reviewed in the period leading up to 2011. A recent National CAMHS inquiry launched by the NAW and undertaken by The Children, Young People and Education Committee (NAW, 2014) concluded that transition from CAMHS to AMHS continues to be a key issue that needs to be addressed.

1.6.2. Physical Health Service Transitions

Service transition has also become a clinical and research priority. Research examining transition has been conducted predominantly within a physical health care context (e.g. for chronic health conditions, see Soanes & Timmins, 2004; Dovey-Pearce *et al.*, 2012). The literature pertaining to generic healthcare transition is growing, and a comprehensive review of the literature is beyond the scope of this thesis. However, briefly drawing upon literature regarding generic health care transition offers insight into successes and challenges of the move from child-focused to adult oriented services.

The goal of health service transition is to optimise health and assist adolescents to acquire independent health care skills and prepare for an adult model of care (National Alliance to Advance Adolescent Health, 2014). A number of systematic and narrative reviews for a range of chronic health conditions (e.g. cystic fibrosis, Tuchman *et al.*, 2010; diabetes, Nakhla *et al.*, 2009; cerebral palsy and spina bifida, Blinks *et al.*, 2007) have identified that the transition between paediatric and adult health services is a risk period for deterioration in health and disengagement from health services.

Research into chronic health conditions, including complex physical disabilities highlights the importance of developmentally appropriate information, treatment adherence and the involvement of young people in the design of transition services (e.g. Shaw *et al.*, 2004; Clarizia *et al.*, 2009). For example, Shaw *et al.*, (2004) conducted focus groups with young people (12-30 years) with complex physical health conditions to determine their experiences of transition and their ideas for improving

transition services. Study participants called for a more co-ordinated service that focused on both developmental and health needs and which prepared them to carry out the transfer competently. The study demonstrated how the difference between the child and adult setting could negatively affect the young people's transfer, especially if they were not prepared to cope with such a change. Shaw *et al.*, (2004) concluded that the inclusion of these young people was invaluable to understanding their specific needs at this time of significant change in their lives. Within the literature, successful transition has been linked to optimal health and healthcare (Schwartz *et al.*, 2011); the assumption of appropriate adult roles and functioning (American Academy of Paediatrics, 2002); and the maintenance of self-esteem and confidence (Smith & Wallace, 2003). Poor transition planning has been linked to harmful medical and psychological consequences including declines in treatment adherence and health status (Dugueperoux *et al.*, 2008).

There is current evidence to suggest that transitional care services, such as implementing an educational transition programme or having a transition care coordinator may slightly improve clinical outcomes for young people with chronic health conditions (Campbell *et al.*, 2016). However, Campbell and colleagues (2016) propose that ongoing research is required to fully evaluate the effectiveness of transition interventions and to further explore the lived experiences of health care transition for young people with chronic health conditions. Overall, the research within the physical health context appears to be predominantly descriptive, with no theoretical models drawn upon to explore the lived experience of young people who move from child to adult services.

1.6.3. Mental Health Service Transitions

With evidence suggesting that mental health difficulties emerge in adolescence and continue into adulthood, the need for effective service provision across the boundary between child and adult services is essential, as 'Poor transition can lead to frankly disastrous health outcomes for both physical and mental health' (Children and Young People's Health Outcomes Forum, 2012 p.28). Indeed, Kennedy (2010) reports that young people may experience transition as 'a disruptive discontinuity to their care' (p.37), with many young people failing to meet thresholds for adult services and falling through gaps between services, despite continuing need. Akin to physical health care transition, the move between mental health services is also a risk period for disengagement with services and deterioration in mental health (Singh, 2009; Singh & Tuomainen, 2015).

1.6.3.1. EXISTING RESEARCH

Despite the wealth of UK policy documentation, there appears to be a lack of empirical evidence to suggest the ways in which the principles of transition are being implemented in mental health clinical practice. Specifically, little research exists exploring ways in which young people's experiences of transition between child and adult mental health services are reflective of the key principles consistently outlined. Moreover, descriptions of services are more readily available than studies to evaluate or explore practice. Unlike physical health research, the literature regarding transition from CAMHS to AMHS appears to consist largely of professional opinion and discussion rather than primary research (e.g. Bruce & Evans, 2008; Tantum, 2005; Murcott, 2014). As a result, research regarding mental health service transitions is in its infancy, and its focus has generally been on mapping services and exploring the perspectives of practitioners and policy makers (e.g. McNamara et al., 2014; Singh et al., 2010).

One of few studies that focus on transitions from CAMHS to AMHS within the UK is the TRACK study conducted by Singh and colleagues between 2007-2009 (Singh *et al.*, 2010). This large scale study was completed across six mental health trusts in England and examined policy, protocol and service delivery relating to the transition of young people with mental health difficulties. It is noteworthy that the outcomes from this comprehensive study have been published by several authors, thus the findings highlighted below are gleaned from a number of sources citing the same study.

Initial findings of the TRACK study revealed that despite the existence of protocols relating to the transition of young people with mental health difficulties, a number of variations of practice occurred. For example, practical aspects of transition such as which professionals would be involved, the timing (e.g. age) of transition and duration of transfer differed across services (Singh *et al.*, 2010). Furthermore, Singh and colleagues (2010) found although protocols placed service users centrally in the transition process, none specified ways of preparing them for their transition. Rather, protocols focussed on more practical and procedural processes. A recent, separate study conducted in Ireland by McNamara and colleagues (2014) revealed critical gaps between operational practice and best practice guidelines, with only three CAMHS and three AMHS teams out of a total of 57 teams operating with written guidelines regarding transition and transfer of care.

Via a survey of case notes, Singh and colleagues (2010) found that in a sample of 154 young people, 58% were accepted by AMHS whereas 42%, who were classified as potential referrals to AMHS, did not transition. For those who did transition (n=90), optimal transition was experienced by only four

young people. Optimal transition, in this case, was defined as fulfilling the following criteria: continuity of care (i.e. the young person was engaged in AMHS three months' post-transition or appropriately discharged); at least one transition planning meeting; good information transfer and experiencing a period of parallel care. For those who did not transfer to AMHS, a number of reasons were cited. Singh and colleagues found that often CAMHS practitioners viewed that AMHS would not accept a referral, believing that AMHS would not deliver appropriate support, as such, referrals were not made. Despite these beliefs, Singh and colleagues (2010) revealed that over 88% of referrals made to AMHS were indeed accepted, highlighting that a lack of knowledge of AMHS thresholds by CAMHS services may lead to misconceptions which, may in turn, create a barrier for young people accessing appropriate support if needed. Interestingly, Singh and colleagues (2010) found that the best predictors of being accepted into AMHS included having a diagnosed severe and enduring mental illness, being prescribed medication at the time of transition, or if a young person had been admitted to hospital whilst receiving care from CAMHS. Such findings are supported by McNicholas and colleagues (2015) who report that in Ireland, young people with psychosis or a mood disorder were somewhat more likely to be referred to AMHS. These findings may infer that positive aspects of transitional care exist, as young people with the highest risk appear to be making the transition successfully. Simultaneously, it raises concerns regarding those who do not make the transition at all.

1.6.3.2. BARRIERS AND FACILITATORS TO SUCCESSFUL TRANSITION

A number of barriers to successful transition from CAMHS to AMHS have been proposed. One such barrier is the age boundary between services. For example, some adult services do not accept referrals for young people under the age of 18, yet in some areas of the UK, CAMHS services may only accept referrals for young people up to the age of 18 if they are accessing education. Governed by the young person's life choice alone, some 16 and 17 years olds may therefore find themselves without access to services (Appleton & Pugh, 2011; Murcott, 2014).

Continuity of care between child and adult services can also be inhibited due to differences between care planning systems. In Wales, the Care and Treatment Planning process spans secondary CAMHS and AMHS, which may potentially ameliorate the divide between each service's care approach (WAG, 2010). Several service developments have been proposed and implemented to bridge the divide between services, and these will be discussed later in this chapter (see section 1.6.3.3).

Moreover, findings from the TRACK study (Singh *et al.*, 2010) revealed that differences in professional backgrounds can contribute to poor experience of transition for young people. For example, professionals claimed that having a poor understanding of each other's roles and responsibilities often led to poor communication, lack of partnership working and ineffective, uncoordinated transfers of care. This also appeared to lead to an inhibition of referrals, even when a need had been identified (Belling *et al.*, 2014).

Furthermore, research suggests that the training of professionals may exaggerate differences between specialities rather than leading to the development of areas of mutual interest (Anderson, 2006). For example, it has been highlighted that young people least likely to have their care transferred to AMHS were those classified as having difficulties such as neuro-developmental disorders, emotional difficulties or emerging personality disorders (McLaren *et al.*, 2013; Belling *et al.*, 2014). A number of neuro-development disorders, for example, Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) are found to persist into adulthood, yet such diagnoses often do not meet the criteria for referral to adult mental health services and therefore leave some young people's needs unmet following discharge from CAMHS (Lamb *et al.*, 2008; Munoz-Solomando *et al.*, 2010).

The difficulties associated with young people's transition between CAMHS and AMHS are not just restricted to the UK; rather there is global concern. In the United States and Canada, positive experiences of service transition have been found to be sparse, due to poor communication between child and adult services and differences in referral criteria (Davis & Sondheimer, 2005; Davis *et al.*, 2006; Dimitropolous *et al.*, 2013). Similarly, in Australia, Cosgrave and colleagues (2008) found that mental health needs of young people were significantly unmet, which was attributed to the financial constraints on adult provision that force services to cater only for young people with the most severe and enduring mental health difficulties. Further, in Sweden, Lindgren and colleagues (2013) conducted focus groups with CAMHS and AMHS professionals and found that in addition to barriers cited in the research referred to here, experiencing discontinuity in the therapeutic relationship (between the young person and CAMHS professional) was a precipitating factor for young people's disengagement from adult services at the point of transfer.

Less evidence regarding facilitative factors for success of transitions can be gleaned from the literature. A focus on what constitutes a successful transition offers insight into how services may continue to best meet the needs of young people. Examples of good practice tend to mirror the policy guidance outlined in section 1.6.1. of this chapter. Successful transitions have been noted as

such when young people have been given the opportunity to be introduced to the adult services that they will be moving to, which includes meeting a named professional usually well in advance of the transfer of care (Paul *et al.*, 2014). Further, providing information regarding what to expect and being fully involved in the preparation for transfer have also been found to be conducive to successful transition (Singh *et al.*, 2010, Fegran *et al.*, 2014). Additionally, Singh and colleagues (2010) proposed that successful transitions involved the young person learning about their condition, understanding the rationale for treatment and the need for transition. Furthermore, professionals consulted in the TRACK study (Singh *et al.*, 2010) highlighted that where co-working between adults and child professionals took place (for example, completing joint assessments) transfers of care were successful.

Overall, the limited research exploring CAMHS to AMHS transitions suggests that the move can often be problematic, with poorly defined procedures and a lack of co-ordinated care planning, all of which affect the success of transfers of care (Singh *et al.*, 2010; Paul *et al.*, 2014). Yet, the findings of such research should be interpreted with caution. The TRACK study focused only on samples from six sites across London and the Midlands, thus findings may only be generalised to the specific service provision from those areas. Limitations are also noted by the researchers in regards to ascertaining of cases from clinicians, on which the findings from the TRACK study are based. It may have been that cases that clinicians were likely to recall were those where transitions had been problematic, thus skewing the results towards a negative bias (Paul *et al.*, 2013). Furthermore, it can be argued that the studies cited above appeared to focus on the success of 'transfer' of care rather than the experience of a transition. Despite this, findings from the research (e.g. Singh *et al.*, 2010 & McNamara *et al.*, 2014) illustrate evidence for successful and unsuccessful transitions, upon which policy and practice guidelines can, and have been developed (Singh *et al.*, 2010).

1.6.3.3. SERVICES TO SUPPORT TRANSITION

The Royal College of Psychiatrists (RCP) note that the mental health needs of young people are diverse and distinct from those of both children and adults (RCP, 2013). The way in which CAMHS services are organised does not always fit easily with the ways in which mental health problems are experienced by young people. Some argue that the best way forward is to develop specialist youth health services for young people aged 16 and over (Viner & Barker, 2005). Following concerns related to the transition between CAMHS and AMHS, detailed recommendations about configuring service delivery models and the commissioning of services to meet the needs of young people have been developed (Lamb *et al.*, 2008; JCPMH, 2012). As yet there is no prescribed 'best practice'

model to meet the needs of young people in transition, however, the overall aims of transition services are that they are age appropriate and flexible in order to meet the specific needs of young people who are moving from CAMHS to AMHS (JCPMH, 2012).

Good practice examples of statutory and voluntary transition services have been documented in a number of publications (e.g. SCIE, 2011; Young Minds, 2006; JCPMH, 2012). Such services vary across the UK, with some operating as stand-alone transition services, often provided by third sector organisations; disorder specific services, such as Early Intervention for Psychosis services; designated transition teams within either AMHS or CAMHS services; or designated staff trained in working with young people seconded to AMHS teams (Richards & Vostanis, 2004; Lamb *et al.*, 2008; JCPMH, 2012). The TRACK study findings suggest that, when available, transition workers were highly successful in managing smooth transitions between CAMHS and AMHS. Singh and colleagues (2010) highlight however, that there is a paucity of such staff with the necessary skills and a further lack of training where existing staff may gain such skills and that often, cost pressures have been such that posts of this nature have been abolished. Nonetheless, benefits of transition services have included limiting the number of young people who are lost to services, reducing periods of untreated illness and reducing poor outcomes (JCPMH, 2012).

To date there appears to be a scarcity of research exploring young people's perspectives on the effectiveness of approaches to support transition between CAMHS and AMHS. NICE (2016) recommends that research could usefully focus in particular on transition interventions, in order to highlight areas of good practice to aid service development.

1.7. THEORETICAL FRAMEWORK OF TRANSITION

Thus far, the term transition has been used to define the move from one service to another, and moving from one developmental stage to another. More broadly within the literature a number of conceptualisations of the transition process exist. For example, Bridges (1994) characterises transition as a time span with an identifiable end point, extending from the first signs of anticipation, perception, or demonstration of change; through a period of instability, confusion, and distress; to an eventual 'ending', with a new beginning or period of stability. Similarly, Van Gennep (1960), proposes a three-phase view of transition. Firstly, the separation phase, when an individual begins to withdraw from the familiar and prepare to move from one place to another. Secondly, the transition phase, which may be experienced as unstable or as 'not belonging', which occurs between leaving

one context, experience or identity and joining the next. Lastly, the reincorporation phase, whereby an individual has taken on their new identity and becomes part of a new group. Theories of change are arguably relevant to transition, yet models such as the transtheoretical model of change (DiClemente & Prochaska, 1998) offers understanding of an individual's behavioural change rather than exploring contextual factors that may or may not affect the process of transition.

It is important to note that in the review of existing literature, no theory or conceptual model surfaced to explain the transition process experienced by young people when moving from child to adult mental health services. The following section aims to explore transition from a theoretical viewpoint, drawing upon Meleis and colleagues (2010) Transition Theory in the context of how the co-occurring transitions from adolescence to adulthood and from CAMHS to AMHS may be negotiated by young people. Although not intended to wholly explain the transition process from CAMHS to AMHS, and in the absence of a directly applicable model at present, this theoretical framework may be considered useful in making sense of the results obtained within this research.

1.7.1. Transition Theory – Meleis *et al.*, (2000; 2010)

Meleis and colleagues (2000) developed a theory of transition which provides a framework to describe the processes experienced by individuals who are coping with an event, situation or a stage in development that requires new skills, goals, behaviours or functions. According to Meleis and colleagues, the goal of transition is to achieve a state of well-being, reformulated identity and mastery, whilst avoiding vulnerability (Meleis *et al.*, 2000). It is not within the scope of this literature review to fully expand upon this model, but a full explanation is available from Meleis (2010). However, it can be hypothesised that this theory aligns well with the literature regarding young people's transition from child to adult mental health services, as it recognises that transition experiences of young people are processes that require a longitudinal and multidimensional approach (Meleis & Trangenstein, 1994; Singh *et al.*, 2008).

Through collective research, Meleis and colleagues developed an emerging framework of transition consisting five components: a) types and patterns of transitions; b) properties of transitions; c) transition conditions; d) patterns of response; and e) supportive, therapeutic interventions. See figure 3, below. Each of the components will be discussed below and where possible, examples of its application to the transition from CAMHS to AMHS will be highlighted.

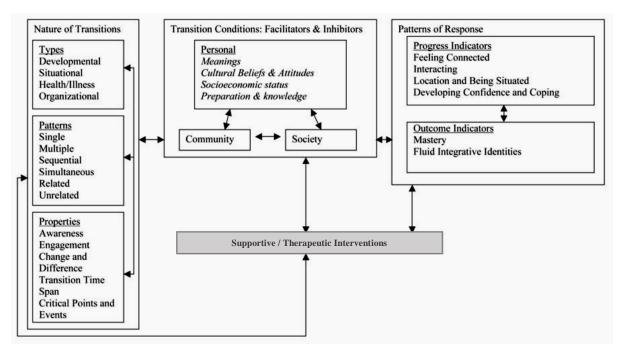


Figure 3: Transition: A middle-range theory. Modified from Meleis et al., (2000)

Types and patterns of transitions

Meleis and colleagues (2000) suggest that transitions can be developmental, health-illness, situational or organisational. Examples highlighted by Meleis and colleagues to illustrate components of their theory include immigration, becoming a mother and menopause. The theory identifies that transitions are not discrete or mutually exclusive events, but that multiple transitions can take place simultaneously, overlap, and can be related to one another (Meleis *et al.*, 2000). In the context of transition from CAMHS to AMHS, the notion of experiencing multiple transitions is particularly pertinent, as the transition from child to adult mental health services is synchronous with a developmental transition, and potentially educational transition. The pattern of complexity acknowledges that many factors can affect the experience, process and outcome for an individual in transition, however this concept is not further described in the works of Meleis and colleagues.

Properties of transitions

Meleis and colleagues propose that essential properties of transition include awareness, engagement, change and difference, time span and critical events. Awareness is defined as the recognition that one is in transition. Engagement is synonymous with involvement in the transition process and the level of engagement will differ on one's awareness (Meleis *et al.*, 2000). Components of change highlighted as important by Meleis and colleagues are the perceived importance of the change and the norms and expectations related to the change. For young people experiencing a service transition from child to adult oriented care, a significant change occurs in

relation to the level of independence and autonomy that the young person will be expected to assume (Singh *et al.*, 2010). Within the theory, change is also related to critical events and disruptions in relationships and routines. The differences associated with transition can lead to unmet expectations and feelings, and can lead to an individual being perceived and perceiving themselves as different.

Transition conditions

Meleis and colleagues proposed that there are a number of conditions, (or facilitators and barriers) to achieving a 'healthy transition'. These conditions can be personal, community or societal. Personal conditions include the meaning that one attributes to the transition process, cultural attitudes, socioeconomic status and participation and knowledge. Meleis and colleagues (2000) emphasise the importance of understanding the meaning of a transition from the point of view of those experiencing it, as this meaning can serve to promote or impede the transition process. Schumacher and Meleis (2010) propose that the individual's interpretation of what the transition means for them has an impact on their ability to carry it out, their experiences of it and the potential consequences on their health. Participation in and knowledge of the transition process can also serve to facilitate or hinder the process (Meleis et al., 2000). Community conditions include resources, social supports and information that can support successful transitions (Im, 2010). Societal conditions are facilitators or barriers relating to societal ideologies and culture (Meleis et al., 2000; Im, 2010). In considering the transition of young people from CAMHS to AMHS, societal and cultural beliefs such as stigmatisation towards mental health may directly impact on a young person's transition, as research suggests that experiencing mental health stigma can inhibit young people accessing support and services (Young Minds, 2012).

Patterns of response

In transition theory, health and perceived wellbeing are general outcomes of transition. Patterns of response consist of progress indicators that move a person towards well-being and outcome indicators that reflect a successful transition (Meleis *et al.*, 2010). Progress indicators include feeling connected, interaction, becoming situated and developing confidence and coping. Of integral importance in the transition from child to adult services is for young people to feel connected to and interact with adult providers and services, developing confidence in areas such as independence and coping and becoming situated in the adult world (Young *et al.*, 2009). Outcome indicators include mastery and fluid integrative identities. Mastery can include making decisions regarding treatment, accessing resources, negotiating the changes in the care systems or self-care (Meleis *et al.*, 2000).

Fluid integrative identity relates to the development of a more flexible sense of identity in the midst of the changes that occur throughout transition. For young people experiencing a move from CAMHS to AMHS, this identity change may include becoming an independent and autonomous adult.

Supportive/Therapeutic Interventions

This component of the theory is an important, yet relatively underdeveloped element. Meleis and colleagues propose that support for transition should involve an assessment of readiness and preparation for transition. Ideally, assessment of readiness requires a comprehensive understanding of an individual's needs and includes all elements of transition conditions (referred to above). Preparation for transition is often in the form of education, and requires sufficient time to ensure that an individual is adequately prepared (Im, 2014; Meleis *et al.*, 2000). Ultimately, the utility of the transition theory presented by Meleis and colleagues (2000) lies in its ability to inform practice. Within the theory, supportive/therapeutic interventions represent what others can do to facilitate a successful transition (Schumacher & Meleis, 2010). Thus, developing interventions to support transition entails a consideration of properties, conditions and indicators of successful transitions and considers these components throughout the process of the transition (e.g. prior to leaving CAMHS, during the transition and in supporting ongoing engagement with AMHS). This theory may therefore demonstrate where support may be implemented throughout the CAMHS to AMHS transition process, to prevent negative consequences and improve a young person's well-being (Schumacher & Meleis, 2010).

1.8. SUMMARY OF PART 1:

Mental health difficulties that present in adolescence are likely to continue into adulthood. At present, mental health services for children and adults are largely delivered separately; therefore, crossing the divide between the two creates challenge at a time where young people may be at most risk of developing, or continuing to suffer with mental health difficulties (McGorry *et al.*, 2013). It is widely recognised that the transition from CAMHS to AMHS can be complex and as a result, a number of governmental policy and good practice documents exist. Despite such guidelines, transitions between CAMHS and AMHS continue to be poorly managed, with many young people experiencing sub-optimal transition (Singh *et al.*, 2010). One way that has attempted to bridge this divide is the introduction of transition services, which aim to meet the needs of this specific population.

To date, research regarding transitions between child and adult mental health services has predominately focussed on procedural challenges and successes from the perspective of professionals and policy makers, with little attention paid to the process of transition from the young person's perspective. In order to identify previous research, and provide up-to-date knowledge regarding young people's experience of transition from CAMHS to AMHS a systematic review was undertaken, and will be discussed below (Part 2).

PART TWO: SYSTEMATIC REVIEW OF THE LITERATURE: YOUNG PEOPLE'S PERSPECTIVES

1.9. OVERVIEW OF SYSTEMATIC REVIEW

A systematic search of the literature base exploring young people's experience of transitions from child to adult mental health service was conducted. A SPICE (setting, perspective, intervention, comparison, outcome) question was used to formulate and focus the literature search process due to its suitability in identifying research studies that use qualitative methodologies (Booth, 2004). For the purpose of this review, categories of 'comparison' and 'outcome' were omitted, as the primary interest of the search was to identify literature that would contribute to knowledge about transition experiences of young people rather than making comparisons of, or evaluating, young people's experiences.

The systematic review question was defined as:

What are young people's experiences of the move from child to adult mental health services?

The review was undertaken in order to present a structured and critical synthesis of existing research aiming to provide up-to-date knowledge of the experiences of young people moving from child to adult mental health services. This section includes an outline of the search process, a description of the studies considered in the review, critical appraisal of the studies and a narrative synthesis of the findings. In addition, implications for future research are discussed.

1.9.1. SEARCH STRATEGY

To identify relevant studies, the following six electronic databases were searched on 14th and 15th February, 2016, and on 24th April, 2016: PsychINFO, Medline, Embase, PubMed, CINAHL and Web of Knowledge.

Chapter One: Introduction

Reference lists of full-text articles retrieved using the above search strategy were hand-searched to identify other relevant studies.

1.9.2. SEARCH TERMS

Subject heading and keyword searches using the relevant words and phrases for each key area were identified, this included the use of synonyms (e.g. adolescent or teenager) and acronyms (e.g. CAMHS and AMHS).

Boolean operators were used to combine different search terms using the words 'AND' or 'OR'. Truncating was used to ensure that all relevant permutations of a word were identified in the search. No date limit was applied.

See Appendix i for all search terms used.

1.9.3. INCLUSION AND EXCLUSION CRITERIA

As discussed above, the purpose of the review was to explore the lived experiences of young people moving from child to adult mental health services. Qualitative studies were most appropriate to meet this aim and were included in the review. All articles were screened against the following criteria:

Inclusion criteria:

- Peer-reviewed qualitative research
 - The review focused on ascertaining the subjective, lived experiences of moving from child to adult mental health services, rather than to assess outcome and therefore the participants' descriptions as situated within their particular context was deemed important
- Experiences or perspectives of young people, adolescents or teenagers
 The review, as well as the current study had its interest with young people's experiences of transition
- Transitions between child and adult mental health services
 In order to capture and select studies that contain relevant data to the research question mental health service transitions were explored.

An initial review of the literature highlighted a paucity of research specifically investigating young people's experiences only (n=4), therefore studies that included both young people's *and* the

experiences of their relatives and/or professionals (n=3) were also included in the review to optimise the inclusion of young people's perspectives. The researcher reviewed and commented on the data referring to young people's views only.

Exclusion criteria:

- Not published in English language
- Case studies, editorials or correspondence
- Unpublished studies / abstract only
- Experiences of parents and/or professionals only

1.9.4. SEARCH PROCESS

The search yielded 1,063 studies, following the removal of duplicates the total decreased to 872. A review of titles and abstracts according to the inclusion and exclusion criteria resulted in 47 articles for further review. The majority of studies evaluated related to transitions in other contexts, for example, generic health care, education or system care and illustrates why many articles were excluded at this stage of the review.

Full text copies of the 47 studies were examined further according to the inclusion and exclusion criteria, resulting in a total of six studies to be reviewed in depth. On searching reference sections of the studies one further study was identified. A total sample of seven studies was included in the final review. The search process is illustrated in Figure 4, overleaf.

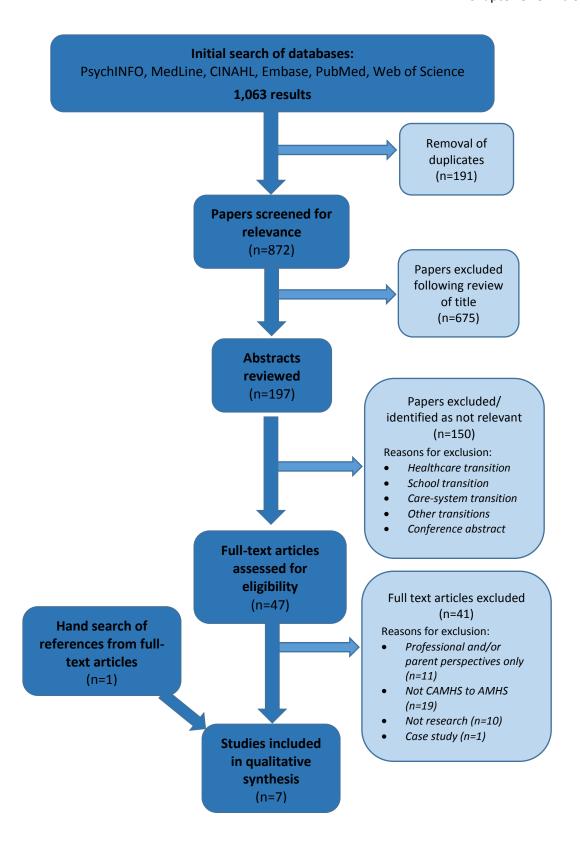


Figure 4: Systematic Search Process

1.10. SUMMARY OF INCLUDED STUDIES

Presented below is a brief narrative account of the included studies to illustrate the design, method and characteristics of participants.

All studies included in the review used qualitative methodologies, with semi-structured interviews as the method of data collection. The most common method of data analysis was Grounded Theory (Dimitropolous *et al.*, 2015; Lindgren *et al.*, 2014; Lindgren *et al.*, 2015). Two studies used thematic analysis (Hovish *et al.*, 2012; Swift *et al.*, 2013). Other methods used were content analysis (Wheatley *et al.*, 2014) and Interpretative Phenomenological Analysis (Burnham Riosa *et al.*, 2015).

Three of the studies were conducted in the UK (Hovish *et al.*, 2012; Swift *et al.*, 2013; Wheatley *et al.*, 2014), two in Sweden (Lindgren *et al.*, 2014; Lindgren *et al.*, 2015) and two in Canada (Burnham Riosa *et al.*, 2015; Dimitropolous *et al.*, 2015). The pattern of location suggests that the results are representative of Western, publically funded healthcare systems, unlike, for example, the USA where services are predominantly paid for at the point of care; thus, findings may not be transferable to other cultures or systems of healthcare provision.

A number of service contexts were also represented in the studies. Dimitropolous *et al.*, (2015) examined young people's transition from child to adult eating disorders services, whereas Wheatley *et al.*, (2013) explored participants' experiences of transition between child and adult secure inpatient services. Swift *et al.*, (2013) specifically examined the experiences of young people with Attention Deficit Hyperactivity Disorder (ADHD) moving between generic mental health services. All other studies sought participants with a range of mental health difficulties moving between generic child and adult mental health services.

The participant samples differed across the studies. Despite all of the studies including young people who had moved or were in the process of moving from child to adult mental health services, one study also examined the experiences of both parents and professionals in addition to young people (Hovish *et al.*, 2012), another study sought the experiences of both young people and relatives (Lindgren *et al.*, 2014), and one study interviewed seven out of ten participants with a parent present (Swift *et al.*, 2013). A total of 61 young people's accounts of transition were represented in the studies, along with the accounts of 19 relatives and nine professionals.

Table 1 provides a detailed descriptive summary of the studies included for review. An outline of the aim, methodology, findings and discussion are provided for each study.

Table 1: Systematic Review: description of included studies

Study	Aim	Method (Design, data collection & analysis)	Participants	Findings	Discussion	Quality score
Swift <i>et al.</i> , (2013) United Kingdom	To explore the experiences of young people with ADHD during transition from CAMHS to AMHS	Qualitative design. Semi-structured interviews exploring young people with ADHD's experience of CAMHS and transition to adult mental health services. Data analysed using thematic analysis. Part of a wider, mixed method project to assess young people's views of transition.	Ten young people aged 17 and 18 years with a diagnosis of ADHD selected purposefully. All participants had been accessing CAMHS clinics in Nottinghamshire. Of the ten participants, two had transitioned to adult mental health services at the time of interview. The remaining eight participants were 'pretransition'. Eight interviews were carried out with a parent/ family member present.	Patients' relationships with their clinician were key factors for a positive experience in both CAMHS and the transition process. Perceived responsibility of care was also pivotal in how the transition process was viewed. Nature and severity of problems and patients' expectations of adult services were contributing factors in the transition process. The need for continued parental support was openly accepted and thought to be required by the majority of young people with ADHD during transition.	Timely preparation, joint working, good clinician relationships and parental support serve to facilitate the process of transition for young people with ADHD. Transitions were more difficult when ADHD was viewed as the main or sole clinical problem. Future exploration of young people's experiences of transition, and their engagement with and experience of adult services is required to provide an overall picture of facilitators to successful transition and integration into adult services.	17/20

	To identify systemic facilitators and barriers of	Qualitative design. Interviews conducted using a structured interview guide.	Fifteen young people aged between 18-21, all had transferred from a specialised paediatric	Lack of consistent procedures to facilitate the transfer led to difficulties navigating care during the transition period. Challenges	Researchers claim this is the first qualitative study focusing on the experiences of young people who have transferred from child to adult	
Dimitropolous <i>et al.,</i> (2015)	transferring young adults (ages 17-21) with eating disorders from paediatric mental health to adult mental health services.	Participants were interview during and after their transfer of care. Data analysed used Grounded Theory methodology.	Eating Disorders Service to an Adult Eating Disorder Service. All participants were female. Twelve had Anorexia Nervosa, three had Bulimia Nervosa.	achieving and maintaining 'recovery' due to the perceived systemic barriers post transfer (e.g. limited availability of preferred treatment options such as outpatient therapy; absence of a formal transfer plan). Recommendations to improve the transfer of care were made by young people. These included: developmental stage rather than age should determine readiness for transition; options for 'adult treatment' should be discussed prior to transfer; child services should provide young people with opportunities to develop practical skills to manage their care independently.	eating disorder services. Young people advocated for better coordination and communication between child and adult mental health providers to bridge the gap between two different systems of care. Importance of adult providers increasing their knowledge about eating disorders and how to balance the young person's need for independence versus ongoing service involvement in supporting behavioural change. Authors suggest future research should examine how the experience of mental health care transition may differ for young people from diverse ethnic and racial groups and from urban vs. rural communities. Future research including young people with eating disorders who may be transferred from primary care settings is also suggested.	13/20

rnham Riosa, <i>et al.</i> , (2015) Canada	To investigate the lived experiences of late adolescents who may be transitioning into adult mental health services.	Mixed methods study design using quantitative measures and qualitative analysis of in-depth interviews analysed using Interpretative Phenomenological Analysis	Ten participants purposefully selected for in-depth interviews, out of 48 participants recruited from an outpatient CAMHS clinic. All participants were 'pretransition' Participants either had a psychiatric diagnosis or demonstrated significant symptoms. Mean age of participants = 17.41 years.	Qualitative data findings only described here: Participants did not appear ready for an institutional transition. Fears of uncertainty and not knowing about adult services contributed to the overall experience of transition. Fears were also related to the transition to adulthood. Participants expressed a desire 'to be heard' and actively involved in the possible service transition. Young people want transition to be gradual; to be informed of the details of the	Services need to attend to transition to adulthood as well as transition to adult services. Formal services for late adolescents that are guided by both child and adult clinicians may be helpful in assisting young people and their families for the transition to adulthood and adult services. Longitudinal research of young people who undergo successful vs. unsuccessful mental health service transition is needed, as understanding the reasons for continuity (or discontinuity) of care is	14/20
Riosa, <i>et</i> Canada	nealth services.	Phenomenological	Participants either had a psychiatric diagnosis or demonstrated significant symptoms. Mean age of	transition to adulthood. Participants expressed a desire 'to be heard' and actively involved in the possible service transition. Young people want transition to be gradual; to be	Longitudinal research of young people who undergo successful vs. unsuccessful mental health service transition is needed, as understanding the reasons for	14/20
				maintained, open communication between child and adult mental health clinicians throughout the transition process.	ongoing mental health difficulties.	

Hovish <i>et al.,</i> (2012) United Kingdom	To describe the experiences of CAMHS users, parents and professionals in relation to the transition between CAMHS and AMHS in the United Kingdom	Qualitative design using semi-structured interviews and thematic analysis to analyse data. Part of a wider study (TRACK) which aimed to examine the process of transition from CAMHS to AMHS, including case note reviews of transition outcomes across four sites (West Midlands and London)	Total of 27 participants. Opportunistic sample comprising of 11 young people, six parents, three CAMHS key-workers and 6 AMHS key-workers. Ten of the young people were interviewed individually. All participants had transitioned from CAMHS to AMHS	Young people's views about transition varied. Informal and gradual preparation, transfer planning meetings, periods of parallel care and consistency in key workers promoted positive experiences of transition. Transfers between AMHS, changes of key worker and waiting to be seen in AMHS were viewed negatively. Other life transitions, including changes in housing, pregnancy, physical illness and the involvement of parents or other services were sometimes powerful extraneous influences on transition experience.	The cumulative effect of multiple transitions is complex and unsettling for many service users. Experience is likely to be more positive if healthcare transition is a gradual process, tailored to the young person's needs. Transfer planning meetings and parallel care was valued by all participants. Highlighting the need for CAMHS and AMHS to work jointly to improve the transition process and enhance outcomes for young people.	14/20
Wheatley <i>et al.</i> , (2013) (United Kingdom)	To gain a fuller account of the experience of young people during transition from secure adolescent mental health services to secure adult mental health services and to add to the knowledge around the transitional process.	Qualitative design using semi-structured interviews which were divided into two parts; one using closed questions to address key factors in the literature and a second part to explore the lived experience of the young person through the transition process. Content analysis approach used to analyse data.	Eight females who had completed transition from adolescent medium secure mental health services to an adult female mental health secure service (medium and low secure) within an 18-month period. All Caucasian origin, single and all but one had forensic history. All detained under the Mental Health Act (1983).	Findings indicated that adolescents are sensitive to the behaviour of others throughout the transition between child and adult secure inpatient services, for example, witnessing aggressive behaviours from other adult patients was perceived as a barrier to feeling safe within the adult service. Young people placed importance on the support from peers and staff in facilitating a positive experience of transition. Young people also expressed a desire to be fully informed and involved in the transition process.	Overall, an increase in positive statements regarding the post-transition experience highlighted that the transition had been viewed positively. Involvement in negotiating the transfer, using preparatory visits, early introduction to adult service staff and peer buddy systems may help to alleviate anxieties regarding the move to adult services.	12/20

Lindgren <i>et al.,</i> (2015) (Sweden)	To explore young adults' experiences of psychiatric care during transition to adulthood	Qualitative design using interviews. Purposive sampling method adopted. Data from interviews analysed using Grounded Theory methodology.	Eleven young people recruited, consisting of seven females and four males. All participant had experience of receiving care at both child and adult mental health services. Participant age ranged between 19 and 26 years.	Young people experienced relationships with AMHS professionals as supportive and unsupportive. Lack of support from professionals throughout the transition process led to feelings of hopelessness and increased the risk of disengagement from services. Young people placed value on the therapeutic relationship to empower them to feel independent in their care and other areas of their life.	The transition process is complex due to the ambivalence of young people being in-between adolescence and adulthood. Support during the process of transition is essential for a successful transition, as lack of support can lead to disengagement from services. Professionals need to facilitate the development of personal resources (such as self-esteem) and provide access to social support. Future research regarding the type of support that young people need to maintain ongoing engagement with adult services was suggested by the authors.	15/20
Lindgren <i>et al.,</i> (2014) (Sweden)	To explore the expectations and experiences of transition from child and adolescent psychiatry to general adult psychiatry as narrated by young adults and relatives	Qualitative Design. Grounded Theory methodology. Semi- structured individual interviews exploring young people and relatives experience of being in child and adolescent mental health services, preparation for transfer, the expectations and experiences of the transition and the experience of being in adult mental health services.	Theoretical sampling method used to recruit young people from two outpatient Child and Adolescent Mental Health Units in Sweden. Three young people who had transitioned to AMHS (two females, one male) and six relatives were interviewed.	Young people identified the need for support throughout the transition process in order to manage the change of services, in line with their developmental needs. Young people did not feel mature enough to take responsibility for their own care, despite 'coming of age'. Young people struggled to balance a desire to take responsibility with a fear of having to become independent. A lack of information regarding adult services led to participants feeling anxious and uncertain about what services would be offered in AMHS.	Highlighted the need for professionals to focus on both the situational and developmental transition from child to adulthood. A well-planned transition process through co-operation between child and adult services and families is needed to facilitate the young adult's ability to establish a caring relationship and encourage continuity of care, without which, the young adult is likely to fall into a 'caring gap'.	18/20

1.11. QUALITY OF RESEARCH

A critical appraisal of the quality and credibility of research findings was conducted for all studies identified in the systematic search. A variety of checklists have been developed as a bench mark to assess quality in qualitative research, for example, Consolidated Criteria for Reporting Qualitative Research Checklist (COREQ, Tong *et al.*, 2007); Critical Appraisal Skills Programme Qualitative Research Checklist (CASP, 2010) and Elliott *et al.*, (1999).

For the current review, the Critical Appraisal Skills Programme Qualitative Research Checklist (CASP, 2010) was used to appraise the studies as it provides a clear checklist and is recommended for use in public health practice (Ciliska *et al.*, 2008). The CASP tool is a 10-item checklist designed to appraise qualitative research reports '...broadly in terms of rigor, credibility and relevance.' (Chenail, 2011, p.237). The CASP (2010) criteria used are presented in Appendix ii.

The checklist contains ten quality indicators; thus the studies were scored for each indicator to give an indication of overall quality. Scoring is suggested as a useful means of comparing and contrasting articles' quality (Chenail, 2011). For each study, the ten items on the checklist were rated with either a score of zero (no reported adherence), one (indicator partially fulfilled) or two (criteria met). Studies were given an overall score between zero and 20. To enhance the reliability of the scores obtained, independent ratings were provided by a peer (Trainee Clinical Psychologist) who also reviewed the studies. Disagreements in ratings were resolved by discussion until a consensus was reached. The quality review for all studies is presented in Table 2, followed by narrative description of the quality of the collated research studies.

Table 2: Systematic Review: Summary of Quality Review

Study Quality Score	Aims Was there a clear statement of the research aims?	Methodology Is a qualitative methodology appropriate?	Design Was research design appropriate to address research aims?	Recruitment Was recruitment strategy appropriate to address the research aims?	Data Collection: Was the data collected in a way that addressed the research issue?	Reflexivity: has the relationship between researcher and participants been adequately considered?	Ethics: Have ethical issues been taken into consideratio n?	Data Analysis Was the data analysis sufficiently rigorous?	Findings is there a clear statement of findings?	Value of research Does the research discuss the contributions of research?
Swift <i>et al.</i> , (2013) 17/20	Clear aim, importance and relevance noted in relation to existing literature (2)	Aim to explore experience of young people with ADHD during transition. (2)	Design using Thematic Analysis reported and rationale given (2)	Recruitment method transparent, no reasons or sampling method identified (1)	Interview method described (including interview questions) and justified. Interviews audio taped and transcribed (2)	Relationship between researcher and participant, including role bias not discussed. (0)	Ethical considerations discussed in terms of informed consent. Ethical approval reported. (2)	Epistemological position of the researchers given. Clear and transparent description of analysis process. Quotes used to illustrate findings (2)	Findings are explicit and discussed in relation to research question. Credibility discussed via triangulation. (2)	Implications for practice identified. Areas for future research considered. (2)

Dimitropolous <i>et al.,</i> (2015) 13/20	Clear aim. Importance and relevance stated. (2)	Sought to provide accounts of young people with eating disorders transferred from child to adult mental health care. (2)	Grounded theory described as method used. No rationale given (1)	Recruitment method reported and justified. Inclusion criteria noted. (2)	No setting reported. Unclear whether inpatient or community services. Interviews used as method of collection, no justification given. Saturation discussed. (1)	Relationship between researcher and participant not discussed (0)	Consent and confidentiali ty discussed. Ethical approval not reported. (1)	Little description of analysis process. Descriptive results given. Few quotes to support findings. (1)	Findings in terms of themes described, yet no theoretical framework derived. Credibility checks notes and triangulation discussed. (1)	Results linked with previous research findings. Clinical recommendations noted. Future research identified (2)
Burnham Riosa <i>et al.</i> , (2015) 14/20	Clear aims and rationale reported following comprehensi ve review of the literature. (2)	Mixed methodology appropriate. Qualitative aspect justified to explore experience of late adolescents who may be transitioning to adult services. (2)	Brief description of IPA given. No justification for use of IPA over other methodolog y noted. (1)	Purposive sample used and rationale given. Process of recruitment is reported. (2)	Interviews method of data collection. No detail of interview location or who facilitated interviews. (1)	Highlights position of one researcher, no detail of bias.	No detail of consent of confidentiali ty given. Ethical approval is reported.	Stages of IPA described. Quotes used to support themes. Detailed description evaluating rigor in study yet no explicit detail. (2)	Findings discussed in relation to research question. Triangulation stated yet no clarity over who analysed data. (1)	Results discussed in relation to existing research. Limitations acknowledged in regards to sample size. Future research areas discussed (2)

Hovish <i>et al.</i> , (2012) 14/20	Clear aims, importance and relevance stated following literature review (2)	Qualitative methodology appropriate as study focussed on experience of CAMHS service users, parents and professionals. (2)	Design not justified. Thematic analysis of interview data via case dossiers. (1)	Clear description of recruitment procedure, opportunisti c sample from larger study (Singh et al., 2010). Difficulties in recruitment reported. (2)	Semi-structured interviews as data collection method. Interview schedule reported No discussion of data saturation (1)	Reflexive approach mentioned but not discussed. No report of researcher role and bias.	Consent discussed, no ethical approval reported.	Brief description of analysis process given. Some note to derivation of themes. No report of researcher bias in analysis. Some quotes to support findings. (1)	Findings are explicit and discussed in relation to research question. Credibility noted, data triangulated by 3x sample groups. (2)	Findings are discussed in relation to existing research. Biases highlighted in terms of generalisability of findings. Future research areas discussed. (2)
Wheatley <i>et al.,</i> (2013). 12/20	Clear aim, importance and relevance stated. (2)	Qualitative methodology discussed and rationale given. To gain fuller account of the lived experience of young people during transition from child to adult secure mental health services. (2)	Nothing discussed about method beyond 'qualitative' and 'content analysis approach'. (1)	No report of selection or recruitment of participants.	Setting reported. Semi-structured interview schedule used with open and closed questions. Data collected in written form. (1)	Relationship between participant and researcher not discussed. (0)	Ethical considerations not discussed. No report of ethical approval.	Clear description of data analysis. Data presented to report findings, including participant quotes. (2)	Findings are clear and discussed in relation to research question. Two analysists used to aid credibility of findings. (2)	Links to existing literature highlighted. Limitations of sample highlighted. Areas for future research discussed. (2)

Lindgren <i>et al.</i> , (2015) 15/20	Clear aim, importance and relevance given following comprehensi ve literature review (2)	Methodology appropriate to explore young adults' experience of psychiatric care during transition to adulthood. (2)	Grounded theory design specified, yet no justification. (1)	Purposive sampling noted, inclusion criteria given. Indepth account of recruitment process, including difficulties faced (2)	Individual interviews used to collect data. Questions used and procedure are reported. (2)	Researcher professional role discussed yet no detail of bias (0)	Ethical issues considered and ethical approval sought and reported.	In depth description of analysis. Theoretical sensitivity noted. Derivation of themes is clear. Minimal quotes used to illustrate findings. (1)	Findings are explicit and discussed in relation to research aims. Credibility not discussed. Limitations of research are noted (1)	Findings discussed in relation to existing literature. Limitations and areas for future research presented. (2)
Lindgren <i>et al.,</i> (2014) 18/20	Clear aim, importance and relevance stated. Focused review of the literature. (2)	Study sought to explore young people and relatives' expectations and experiences of transition (2)	Grounded theory method reported, justification given. (2)	Theoretical sampling used and justified. Recruitment procedure documented (2)	Interview setting reported, individual interviews used to collate data. Detailed description of methods used to inform interview questions (2)	Relationship between researcher and participants not discussed (0)	Informed consent gained from participants. Ethical approval noted.	Clear description of data analysis and how categories formed. Quotes used to support and illustrate findings. (2)	Findings are explicit and discussed in relation to the research questions. Credibility checks noted. (2)	Findings discussed in relation to current practice and existing literature. Limitations are discussed. (2)

1.11.1. NARRATIVE QUALITY REVIEW

The quality framework of CASP was used to critically appraise the seven studies identified as relevant to the research question. As Table 2 depicts, the quality of the research across studies varied. No studies achieved 'quality excellence' as represented by the maximum score of 20. Only two studies can be said to be of 'good-to-high' quality, with a score of 17 and above (Lindgren *et al.*, 2014; Swift *et al.*, 2013). The remaining studies are considered as 'medium quality standard', with scores of 15 (Lindgren *et al.*, 2015), 14 (Burnham Riosa *et al.*, 2015; Hovish *et al.*, 2012) 13 (Dimitropolous *et al.*, 2015) and 12 (Whatley *et al.*, 2013).

1.11.1.1. RESEARCH AIMS, METHODOLOGY AND DESIGN

All studies provided a clear statement of aims for the research, which was justified in terms of relevance to literature and practice. Qualitative methodologies were appropriate in meeting the aims of the studies which broadly sought to elicit and explore young people's experiences of transition from child to adult mental health services. However, the rationale for choosing such methodology was only reported in two studies (Lindgren *et al.*, 2014; Swift *et al.*, 2013). All but one study used a single method qualitative design; Burnham Riosa and colleagues (2015) used mixed methods to capture young people's experiences of transition. As the focus of the systematic review was to synthesise data from qualitative methods, only the qualitative data gathered within Burnham Riosa and colleague's (2015) research is attended to within the quality review and narrative synthesis.

1.11.1.2. RECRUITMENT AND DATA COLLECTION

All but one study provided information regarding the recruitment of participants, although the depth of this information varied. For example, Wheatley *et al.*, (2013) failed to detail how and why participants had been selected and recruited to the study, merely describing the location of recruitment only; whereas others provided more detailed account of the recruitment procedure. For all studies, clinicians acted as gatekeepers for the recruitment of participants. Inclusion and exclusion criteria were reported in only two studies (Dimitropolous *et al.*, 2015; Lindgren *et al.*, 2015).

The reporting of sampling methods also varied, with four studies explicitly reporting the sampling method. Purposive sampling was used in two studies (Burnham Riosa *et al.*, 2015; Lindgren *et al.*,

2015). Hovish and colleagues (2012) used opportunistic sampling in their study, drawn from a sample that were already involved in a multi-method, multi-site study (TRACK, Singh *et al.*, 2010). Theoretical sampling was reported by Lindgren *et al.*, (2014). Such sampling techniques were deemed appropriate by the researchers to allow for an over representation of the topic under enquiry, allowing the researchers to get close to the participants' experiences of the topic being studied, but does mean that the results may not be representative of the wider population of young people who are experiencing a transition from CAMHS to AMHS. Further, self-selection of participants may itself present a limitation, as those who did not elect to participate may have had a different experience of the transition process.

Limitations also arise from a sampling bias which occurs as a consequence of clinicians managing the recruitment process. Whilst it is recognised that it would be unethical for researchers to make the initial approach to young people, it may be suggested that clinicians may have selected participants whose experiences may have been particularly positive *or* negative, thus perspectives of such young people may be biased towards either extreme. Additionally, clinician's availability and motivation to aid recruitment may have limited the number and range of young people recruited to the studies.

All studies were deemed to have sufficient numbers of participants for their adopted methodology, although only one of the papers provides details on saturation (Dimitropolous *et al.*, 2015). Small sample sizes were highlighted by the researchers as a limitation in all of the studies, however, given that the stated intentions of the research were to give a voice to young people rather than to present generalisable conclusions, sample sizes across all studies were deemed appropriate.

All of the studies utilised interviews as the method of data collection. The process and type of data collected was transparent in all studies. As highlighted previously, some of the studies sought the views of parents/carers and professionals in addition to young people (Hovish *et al.*, 2012; Lindgren *et al.*, 2014; Swift *et al.*, 2013). Some interviews within Swift and colleagues' (2013) study were conducted with parents present, therefore the views expressed by young people may be likely to have been influenced to some degree by the presence of parents/carers during the interviews.

1.11.1.3. REFLEXIVITY

Researcher reflexivity was an aspect of quality that was lacking in all of the studies reviewed. The findings of all studies would be made sincerer with the inclusion of self-reflexive accounts. Whilst reporting of the researcher's position was evident in two of the studies (Burnham Riosa *et al.*, 2015; Lindgren *et al.*, 2015) no detail or consideration of the researcher's subjective values or biases that

this may have created was noted. Therefore, the credibility of findings from all studies is brought into question.

1.11.1.4. ETHICAL CONSIDERATIONS

The ethical approval granted from either university or local ethics committees was noted in four studies (Burnham Riosa *et al.*, 2015; Lindgren *et al.*, 2014; Lindgren *et al.*, 2015; Swift *et al.*, 2013).

Despite the absence of reported ethical approval, considerations concerning informed consent were reported by Hovish and colleagues (2012), and consent and confidentiality by Dimitropolous and colleagues (2015). Wheatley and colleagues (2013) failed to report any considerations or implementation of ethical standards in addition to a lack of reported ethical approval.

1.11.1.5. DATA ANALYSIS

Descriptions of data analysis were clear and detailed in five of the studies (Burnham Riosa *et al.*, 2015; Lindgren *et al.*, 2014; Lindgren *et al.*, 2015; Swift *et al.*, 2013; Wheatley *et al.*, 2013). Quotes from participants were used to support findings; however the amount of quotes used to illustrate themes varied. Fewer quotes were used by Dimitropolous *et al.*, (2015), Hovish *et al.*, (2012) and Lindgren *et al.*, (2015) therefore the lack of 'thick' description of quotes brings the credibility of their findings into question. Triangulation and credibility checks were discussed in several of the studies; this was in relation to the use of multiple sources of information and use of more than one researcher completing the analysis.

1.11.1.6. FINDINGS AND OUTCOMES

Despite reporting the use of Grounded Theory methodology to analyse the data, Dimitropolous and colleagues (2015) did not appear to report or describe a theory derived from their data, rather, a more descriptive account of the findings is conveyed. In addition, the content analysis approach adopted by Wheatley and colleagues (2013) may have limited the depth of meaning that could be generated from participants' narratives, as a descriptive rather than an interpretative account was presented in the write up of their study.

All papers were judged by the researcher to have contributed unique and valuable findings to the limited literature base. Some studies offered rich data to specialist service areas where little is known, for example, transition between child and adult eating disorder services (Dimitropolous *et al.*, 2015); transition experiences of those with ADHD, (Swift *et al.*, 2013); and experience of the

transition between child and adult secure services (Wheatley *et al.*, 2012). All of the studies reported their findings in relation to the original aims of the research and related outcomes to the literature included in their introductions. Some of the studies also drew upon policy and service provision in order to discuss the clinical relevance of the studies.

1.11.1.7. SUMMARY OF QUALITY REVIEW

For the majority of the studies reviewed, the authors provided clear descriptions of the method of recruitment, data collection and analysis. However, some studies lack a reported justification of the chosen methodology, and further, transparency of the attempts to enhance credibility and rigour were limited. Therefore, further research is required in this area in order to contribute to a high quality evidence base. With the limitations and quality scores highlighted above in mind, a narrative synthesis of themes derived from the studies will be presented.

1.12. NARRATIVE SYNTHESIS

The aim of the systematic review was to synthesise research on young people's experiences of the transition from child to adult mental health services. A narrative account of the key themes derived from all studies is presented below and have been tabulated for ease of reading in Table 3.

Theme Study	Practical and procedural processes	Being involved and informed	Expectations and feelings	Requiring support	Importance of therapeutic relationships
Swift et al., (2013)	✓	✓	✓	✓	✓
Dimitropolous et al., (2015)	✓	✓			
Burnham Riosa et al., (2015)	✓	✓	✓	✓	✓
Hovish et al., (2012)	✓	✓		✓	✓
Wheatley et al., (2014)	✓	✓	✓	✓	
Lindgren et al., (2015)	✓	✓	✓	✓	✓
Lindgren et al., (2014)	✓	✓	✓	✓	✓

Table 3: Narrative Synthesis: occurrence of themes across studies

1.12.1. PRACTICAL AND PROCEDURAL PROCESSES

All of the studies included in the review highlighted both positive and negative experiences of the practical and procedural processes in the transition of from CAMHS to AMHS. Participants in several studies emphasised a number of practical elements that were conducive to successful transition. One such element included having at least one transition planning meeting, which was viewed as a key component in having a positive transition (Hovish *et al.*, 2012). Having regularly booked meetings and developing a treatment plan to aid continuity of care were also seen as contributing to having a successful transition experience (Lindgren *et al.*, 2014; Lindgren *et al.*, 2015). Further, meeting a clinician from the adult service and being able to visit the service prior to transfer were also seen as beneficial factors in facilitating a successful transition (Wheatley *et al.*, 2013).

However, many studies cited a number of barriers to successful transition. Participants commented on the disparity of services received, with little or no support in AMHS in contrast to the level of support received from CAMHS (Dimitropolous et al., 2015). This was further compounded by service thresholds that limited the availability of support to some young people, as some young people found that they had no ongoing support upon leaving CAMHS (Swift et al., 2013; Lindgren et al., 2014; Lindgren et al., 2015). Additionally, several young people found themselves in a 'caring gap' (Lindgren et al., 2014 p.3) with long waiting times between leaving CAMHS and entering AMHS, which was seen to impact negatively on well-being (Hovish et al., 2012; Dimitropolous et al., 2015). A lack of flexibility around the timing of transitions also left some young people experiencing the transition as abrupt as they were unable to choose when they were ready to leave CAMHS (Burnham Riosa et al., 2015; Lindgren et al., 2014). Further difficulties in the transition process included a lack of early preparation, which led young people to feel concerned about who they might be seeing when they got to AMHS (Lindgren et al., 2014; Lindgren et al., 2015). Interestingly, participants in Lindgren and colleague's (2014) study, attributed a good transition to 'luck', rather than a wellplanned process (p.5). Finally, the differences in the culture of care between CAMHS and AMHS was also commented upon in several studies (Lindgren et al., 2014; Wheatley et al., 2013), for example, the AMHS culture of having a more individualised and autonomous approach to care caused anxiety for some young people as they were being expected to make contact with adult services themselves, with little family involvement. This was in contrast with CAMHS where parents/families are normally very involved.

1.12.2. Being informed and involved

Young people being informed and involved in the transition process was highlighted as an important aspect of successful transition in many of the studies, and this links to practical and procedural processes outlined above. Many participants discussed a desire to be fully involved in the transition process, yet this was not always the case (Swift *et al.*, 2013). For example, Dimitropolous and colleagues (2015) found that some of the participants in their study had been excluded from conversations about why they were being transferred to adult care and what would be offered. Some young people in Wheatley and colleague's (2013) study reflected that their transition experience may have been enhanced if they had been given adequate and timely information regarding the transition. Similarly, many participants in Burnham Riosa and colleague's (2015) study expressed a desire to be involved in the planning of the transition and their ongoing care needs, as this would result in their feeling empowered to become an active participant rather than a passive recipient of the services that they received post transition. Ultimately, being informed about adult services prior to transfer, and having involvement in meetings and decisions about transfer contributed to feelings of certainty and control for young people (Lindgren *et al.*, 2014; Lindgren *et al.*, 2015)

1.12.3. EXPECTATIONS AND FEELINGS AROUND TRANSITION

Many participants felt apprehensive about the move to AMHS, which included mixed feelings of anxiety and excitement in anticipation of moving to a new service (Wheatley *et al.*, 2013). For some young people the prospect of service transition was viewed positively, with excitement about the possibilities of building new relationships with others (Wheatley *et al.*, 2013), 'having a new start' and gaining more support in contrast to what had been received from CAMHS (Burnham Riosa *et al.*, 2015, p. 462). Some young people talked about anticipating being viewed as an adult in AMHS and this fostered feelings of excitement (Burnham Riosa *et al.*, 2015).

For some participants the transition from CAMHS to AMHS was compounded by the transition to adulthood and many participants described feeling overwhelmed by having to negotiate multiple simultaneous transitions, which they described as both frightening and enjoyable. For example, participants in Lindgren and colleague's (2015) study reflected that whilst the thought of being responsible for their own life was worrying, it also brought feelings of relief and empowerment. Young people commented that they felt 'in between' childhood and adulthood; that they were no longer children, but not yet adults (Burnham Riosa *et al.*, 2015; Lindgren *et al.*, 2014). For many, this included a change in the amount of parental involvement in their care, which left some young

people uncertain and concerned about the level of responsibility they were going to have to take for themselves (Swift *et al.*, 2013).

Feelings of abandonment were also prevalent in some studies, with young people feeling exposed and dumped following discharge from CAMHS, particularly when transition was experienced as abrupt (Lindgren *et al.*, 2014; Swift *et al.*, 2013). Further, some felt unsafe and neglected after transferring to AMHS (Lindgren *et al.*, 2015). This appeared to link with feelings that young people were expected to be responsible for their own care yet not feeling ready to, which led to some young people feeling alone, frightened and concerned about the prospect of having to make decisions autonomously (Lindgren *et al.*, 2014; Lindgren *et al.*, 2015; Swift *et al.*, 2013).

Many young people feared what might happen when they moved on to AMHS, with a lack of information and preparation leaving them feeling uncertain and uncomfortable (Lindgren *et al.*, 2014). For some participants, anticipation of the future was linked to a negative outlook, for example, young people interviewed by Burnham Riosa and colleagues (2015) stated that they had expected the professionals in adult services to be *'cold, distant and firm'* (p.463). Similarly, participants in the studies conducted by Lindgren and colleagues (2015) and Swift and colleagues (2013) expected that they would not receive the same level of support as they had received in CAMHS. Such anticipated lack of support gave participants feelings of hopelessness and decreased motivation to continue care (Lindgren *et al.*, 2015).

1.12.4. REQUIRING SUPPORT

A main theme that emerged from many of the studies was the level of support that young people felt that they required before, during and after transition. This included not only support from family, but support from services to address needs during the move. A central theme in the study by Lindgren and colleagues (2015) was the need for support as a prerequisite for the transition to adulthood and motivation to continue to engage with services. Young people in this study highlighted that professionals need to acknowledge that the young person may not be fully independent as they reach AMHS. Lindgren and colleagues (2015) also proposed that supportive environments, including a comfortable physical environment and support from others (such as relatives and education) are further facilitative factors in a young person's positive transition to adult services, adulthood and independence. Others suggested that support from peers helped in the process of transition; being with others who have gone through a similar experience was helpful for participants in Wheatley and colleagues (2013) study.

For many young people, support was highlighted as important for managing the changing culture of care. This included being supported by clinicians to be able to talk openly about their feelings (Lindgren *et al.*, 2015); support from parents to access services in the initial stages of transfer (Swift *et al.*, 2013); and involvement of a key worker from CAMHS to accompany the young person to their first AMHS appointment (Hovish *et al.*, 2012). Furthermore, an important factor for participants in Burnham Riosa and colleague's (2015) study was a need for individualised support, described as a product of forming positive relationships with professionals.

1.12.5. IMPORTANCE OF THERAPEUTIC RELATIONSHIPS

Almost all studies recognised the importance and strength of therapeutic relationships (in both CAMHS and AMHS) as being integral to experiencing transitions as either positive or negative. Hovish and colleagues (2012) found that continuity of therapeutic relationships with key workers contributed to young people feeling prepared and supported throughout the transition process. Similarly, participants in Lindgren and colleague's (2015) study reported that the relationship between the young person and AMHS professional had been essential in developing motivation to manage their own care, in line with the expectations of the AMHS service. Clinician qualities were often reported to a pivotal part of the transition process. For example, developing relationships with CAMHS clinicians who were seen as 'nice, understanding, supportive and informative, non-judgemental and good listeners' (Swift et al., 2013, p. 79) was associated with a positive experience of transition. For many young people, feeling safe and secure in CAMHS had come as a result of close therapeutic relationships, yet at the point of transfer these relationships needed to be left behind and new relationships with AMHS professionals need to be developed. As such, young people expressed a desire to not have to terminate relationships with CAMHS in fear that trusting relationships would be difficult to develop in AMHS (Lindgren et al., 2014).

1.13. SUMMARY OF PART TWO: SYSTEMATIC REVIEW

The seven studies included in this systematic review provide some insight into how transitions are experienced from the perspectives of young people. All studies highlighted a number of factors which appear to influence young people's experiences of the transition from child to adult mental health services. Such factors include practical and procedural processes that impede transitions (e.g. service thresholds, poor planning) and those that facilitate transition (e.g. having adequate and timely information regarding transfer and ongoing services). The studies reviewed highlight that being fully informed and involved in the transition process is important to young people, as was the therapeutic relationship they had with staff in CAMHS and AMHS. Furthermore, young people

expressed a desire for professionals to view them as both independent *and* dependent (i.e. requiring support) during transition. Many studies highlighted that transition between services can be experienced as both exciting and anxiety provoking, and as such, highlights a need for timely and individualised support to assist the young person as they make the transition from adolescence to adulthood in addition to the transition between one service and another.

Limitations of the systematic review are acknowledged. Whilst maximising the amount of data that could be derived from young people's accounts of transition, the inclusion of studies with mixed samples may have introduced a limitation to this review. For example, three out of seven of the studies reviewed included data derived from interviews with parents and clinicians in addition to young people (Hovish *et al.*, 2012; Lindgren *et al.*, 2014; Swift *et al.*, 2013). Data from each participant group was often mixed within the write up and themes derived from young people exclusively were at times difficult to establish; thus findings highlighted in this review may not be solely attributable to young people's perspectives. Furthermore, participants across studies varied in terms of whether they had yet made the transition to AMHS, with some studies interviewing participants prior to transition (Burnham Riosa *et al.*, 2015), post-transition (Dimitropolous *et al.*, 2015; Hovish *et al.*, 2012; Lindgren *et al.*, 2014; Wheatley *et al.*, 2013) or both (Swift *et al.*, 2013). Therefore, the findings may not be representative of the full transition process.

1.13.1. IMPLICATIONS FOR FUTURE RESEARCH

Despite the above limitations, the findings discussed in the review provide a useful starting point from which to begin to understand the experiences of young people as they move from child to adult mental health services. The systematic review yielded only a total of seven qualitative studies that addressed the research question and met the inclusion and exclusion criteria. The evident recency of studies in this review demonstrates that exploring young people's experiences of the transition from CAMHS to AMHS is a current issue worthy of research. Of the seven studies in the review, only three are relevant to the UK. Furthermore, findings from two of the three studies conducted in the UK relate to a specific speciality (e.g. transition between inpatient secure services, Wheatley *et al.*, 2013) or specific service user group (e.g. young people with ADHD, Swift *et al.*, 2014) and thus only represent a small proportion of young people's experiences.

Overall, many studies in this review tended to focus on practical aspects of transition with less attention paid to the lived experience of moving from one service to another and as such, did not employ theoretical frameworks in order to guide interpretation of findings. Thus, a paucity of

literature remains. To increase understanding of the lived experience of young people who transition from CAMHS to AMHS further research is needed.

PART THREE: RATIONALE AND AIMS FOR CURRENT RESEARCH

1.14. RATIONALE FOR CURRENT RESEARCH

Transition between CAMHS and AMHS occurs simultaneously with developmental change when a young person moves from adolescence into adulthood, a time at which young people are at enhanced risk of psychosocial difficulties (Patton & Viner, 2007). Current evidence strongly suggests that mental health problems that are present in adolescence are likely to remain into adulthood. Therefore, it is likely that many who are in receipt of care from CAMHS remain in need of care from AMHS. Young people with mental health difficulties represent a particularly vulnerable group in which a smooth transition is crucial, to ensure that a young person's needs continue to be met (McGrath, 2010; SCIE, 2011). Research has revealed that consequences of poor transitions include broken relationships with health and social care practitioners, disengagement with services and deteriorating mental health (Young Minds, 2006; Singh, 2009; Singh *et al.*, 2010).

The current research base exploring transition has largely focused on the perspectives of practitioners and policy makers. For example, tracking how many individuals have completed transition successfully, and has focused on organisational and service factors acting as barriers to effective transition of care between CAMHS and AMHS (e.g. McNicholas *et al.*, 2015; Paul *et al.*, 2013; Singh *et al.*, 2010). Despite the wealth of policy and guidance regarding service transition, a systematic review of the literature highlighted a paucity of research exploring the lived experiences of young people who transition from child to adult mental health services. At present, there appears to be limited research exploring mental health transition undertaken within the UK and moreover, an absence of research conducted within Wales.

Research has found that young people feel that being listened to; being taken seriously; receiving flexible services; and having a continuity of care constitutes a 'good transition' (National Advisory Council, 2009). Nonetheless, research has found that up to a third of young people are 'lost from services' during transition, and a further third experience an interruption in their care (Singh, 2009). Transitional services are aimed at improving the transition experience for young people. By conducting research to find out how young people experience the move from CAMHS to AMHS with support from a Transition Service, professionals may be better able to understand factors that can contribute to a successful experience of transition.

Accordingly, the focus of the current research is to increase knowledge about the transition process from the perspectives of young people. Thus, if CAMHS and AMHS professionals have a better understanding of the experiences of young people with mental health difficulties as they move through the transition from child to adult services, services could be sensitively targeted to the needs of this population, thereby improving both transition experiences and long term mental health outcomes.

1.15. RESEARCH AIMS AND OBJECTIVES:

The exploration of young people's perspectives reflects those that are unique and important to consider, compared with those of service providers (on which the majority of the limited research undertaken in the UK is based) as they are the primary recipients of care. Current policy, legislation and guidance recognises that there is a need to incorporate the views of young people in service planning and delivery in order to better meet the needs of young people in their transition from CAMHS to AMHS (e.g. DOH, 2006; NAW, 2001; WG, 2013). Accordingly, this study aims to provide a platform for young people to share their experience of moving from CAMHS to AMHS with support from a Transition Service. By exploring young people's experiences of receiving support during transition, the current study aims to address some of the gaps in the existing research.

The use of a qualitative methodology will allow for exploration of a phenomenon where little is known. The broad aims of the study are to:

- Explore how young people experience and make sense of the transition process. This may
 include their experience of any challenges/barriers and facilitative factors; communication
 within and between services and professionals; and suggestions of how the process of
 transition may have been executed differently;
- Explore young people's thoughts and feelings as they were approaching the end of their involvement in CAMHS and as they enter AMHS;
- Explore young people's experiences of support that they receive during and following the move to AMHS;
- Explore young people's reflections on the process of transition and its impact on their lives, e.g. in their level of independence, use of services, relationships with professionals; and
- Gather information regarding the experience of being supported by a Transition Service.

2. METHODOLOGY

2.1 OVERVIEW OF CHAPTER

This chapter will detail how the research study was developed and conducted. An outline of the study design will be presented, along with a rationale for the use of the chosen qualitative methodology, Interpretative Phenomenological Analysis (IPA). The process of recruitment, ethical considerations and a detailed description of data collection and analysis procedures will also be presented. Furthermore, this chapter will include a description of individuals who participated in the study.

2.2 DESIGN

This study aimed to focus on understanding individual's experiences, for this reason a qualitative methodological design was selected. This study utilised semi-structured interviews with young people who had made the transition from CAMHS to AMHS with support from a third-sector Transition Service (TS). The purpose of the interview was two-fold. Firstly, to explore the young persons' experiences of the transition. Secondly, to capture the participants' experiences of being supported throughout the transition process (see Interview Schedule, Appendix xi). In particular, the study aimed to explore:

- how young people experience and make sense of the transition process;
- young people's thoughts and feelings as they were approaching the end of their involvement in CAMHS and as they entered AMHS;
- young people's experience of the support that they received from the TS during and following the move to AMHS; and
- young people's reflections on the process of transition and its impact on their lives.

2.2.1 RATIONALE FOR USING A QUALITATIVE METHODOLOGY

The objective of qualitative research methods is to describe and understand experiences and not predict them (Willig, 2013). Researchers employing qualitative methods are interested in how the individual experiences the world and as a result the research is led by the participant. This allows participants to raise and discuss topics not anticipated by the researcher. Qualitative research methods aim to construct meaning around how individuals understand and make sense of events by drawing upon information about how individuals experience them (Willig, 2013, Barker *et al.*, 2008).

Qualitative methodology was determined as the most appropriate method for this study as the researcher was interested in the experiences of young people who had made the transition from CAMHS to AMHS. The aim of the research was to understand the personal meanings of participant's experiences, rather than measure the frequency with which they occur. Thus, qualitative methods enabled a deeper understanding of the phenomena in its own right, than would have been obtained using quantitative methods (Barker *et al.*, 2008; Elliott & Timulak, 2005).

Semi-structured interviews are a common method of data collection in qualitative studies. Smith and Osborn (2003) argue that semi-structured interviews are possibly the best way for data to be collected in studies using IPA. Semi-structured interviews were thus utilised for this study as they produce richer, fuller, more genuine and more realistic information on the interviewee's own terms (Smith & Osborn, 2003; Coolican, 2009).

For this study, qualitative data were collated and analysed in accordance with Interpretative Phenomenological Analysis (IPA) methodology. The interpretative process within IPA enabled the data to be organised into coherent emergent themes that were intended to capture the personal meaning of the young people's experiences as described in their interviews. A brief discussion regarding the philosophical underpinnings and rationale for the use of IPA is outlined below.

2.2.2 Interpretative Phenomenological Analysis (IPA)

IPA is a qualitative research methodology committed to examining how people make sense of their life experiences. It has theoretical groundings in phenomenological, idiographic and interpretative perspectives and has been developed as a '...distinctive approach to conducting qualitative research in psychology.' (Brocki & Wearden, 2006 p. 87).

Phenomenology is the philosophical study of 'being' and is concerned with how the world is perceived through human experience (Smith, 2008). An individual's account of a particular experience thereby becomes the phenomenon (Willig, 2013; Smith *et al.*, 2009). The idiographic nature of IPA concerns itself with the particular rather that the general (Smith *et al.*, 2009; Larkin & Thompson, 2012). As such, IPA looks at the particular in order to understand individual experiences. It is concerned with knowing in detail '...what the experience for this person is like, what sense this particular person is making of what is happening to them.' (Smith *et al.*, 2009, p. 3). IPA research can be used to explore individual's personal perspectives by starting with detailed examination of each case prior to exploring convergence and divergence of narratives across cases (Smith *et al.*, 2009).

IPA also has an interpretative (or hermeneutic) phenomenological epistemology, with an interest in understanding an individual's relatedness to the world through their meaning-making (Larkin & Thompson, 2012). Within IPA interpretation occurs at two levels, known as a 'double hermeneutic' (Smith & Osborn, 2003, p. 35). Firstly, there is the participant's interpretation of their experience, and secondly the researcher's interpretation of the participant's experience. This requires the researcher to engage fully with the experience whilst acknowledging their own beliefs and values. (See section 2.2.5 for an account of the researcher's position).

2.2.3 RATIONALE FOR USING IPA IN THIS RESEARCH

For this research study, IPA methodology was favoured over other qualitative methods, such as Grounded Theory (Glaser, 1998). Grounded Theory aims to develop a theoretical framework for understanding a phenomenon. The current research did not intend to define or explain the process of transition from child to adult services in a theoretical nature, rather to explore individual's experiences of the phenomenon in order to illuminate a greater understanding of the experience. IPA methods allowed the researcher to gain a detailed understanding of the lived experience with an open mind, rather than requiring the researcher to commence the study with predetermined ideas about the nature of the experience (Smith & Osborn, 2003).

IPA helps to provide new and differing perspectives on a phenomenon by learning from those who are experiencing it, rather than learning from or being biased by theories or predetermined notions in existing research. The idiographic nature of IPA therefore fits with the objective of this research, to investigate in detail the lived experiences of a small group of individuals, rather than generalising notions for larger populations (Smith & Osborn, 2003).

Furthermore, IPA aims to give a voice to the views of participants and it is argued that this approach fits well with current NHS agenda which promotes service user involvement (Reid *et al.*, 2005; DoH, 2010).

2.2.4 ENSURING SCIENTIFIC QUALITY AND RIGOUR IN QUALITATIVE RESEARCH

Qualitative methods have become increasingly utilised in recent years within education and health research, and increasingly so in psychology. Standards of good research practice in qualitative research have also emerged, including those developed by Elliott, Fischer and Rennie (1999) and Yardley (2008). Elliott and colleagues (1999) developed guidelines with three main functions: a) to

legitimise qualitative research, ensuring it is methodologically rigorous; b) to promote more valid scientific reviews of qualitative research; and c) to encourage researchers to examine their research in a reflective manner, during both the design and write up stages of research. The quality of the current research study was assessed in relation to the guidelines proposed by Elliott *et al.*, (1999) and are discussed below. Guidelines suggested by other authors (e.g. Yardley, 2008 and Ahern, 1999) were also incorporated within the following sections to ensure breadth of perspectives and greater assurance of quality.

2.2.4.1 OWNING ONE'S PERSPECTIVE

Researchers should make explicit their assumptions, anticipations, values, theoretical orientations and interests. This enables the reader to interpret the data and the understanding that has been made of such. To address this, the researcher has written a reflexive bracketing statement of their position (Ahern, 1999), see 2.2.5 below. Furthermore, the researcher sought regular supervision and kept a reflective journal throughout the process which tracked the researcher's assumptions, thoughts and feelings throughout the research process. This allowed the researcher's position to remain transparent throughout the study. (See Appendix iii for an extract from the researcher's reflective journal).

2.2.4.2 SITUATING THE SAMPLE

Guidelines stipulate that the researcher should describe research participants and their life circumstances in order to assist the reader in judging the range of participants, identify similarities and differences between participants and to assess the relevance of the findings (Smith *et al.*, 2009). The context from which the participants were drawn is detailed in Section 2.5.2. A description of participants, including demographic details is given in Section 2.5.4.

2.2.4.3 GROUNDING IN EXAMPLES

Elliott and colleagues (1999) suggest that examples of the data should be used to illustrate the analytic procedures undertaken and the subsequent understanding that has been developed. This enables the reader to appraise the fit between the data and the researcher's understanding of them and demonstrates transparency in the research process (Yardley, 2008). An example of the analysis process is provided in Appendix iv, which provides an extract from an annotated transcript. Furthermore, themes identified during analysis are illustrated by the inclusion of participant's verbatim quotes in the write up of this study.

2.2.4.4 Providing Credibility Checks

Researchers should check the credibility of their work by referring to other's interpretations of the data or re-analysing the data using a different method of analysis (Elliott *et al.,* 1999). In order to address this, the researcher met with both academic and clinical supervisors at several stages of the analysis process to seek additional perspectives on the development of themes.

2.2.4.5 COHERENCE

Guidelines suggest that researchers should aim to represent their findings in a way that achieves coherence and integration, whilst retaining nuances in the data. The coherence and integration of the study results were checked by both supervisors. Diagrams illustrating how themes are related and a narrative description of themes are presented in the results and discussion chapters to ensure coherence.

2.2.4.6 ACCOMPLISHING GENERAL VERSUS SPECIFIC RESEARCH TASKS

There should be clarity of whether a general understanding of the phenomenon is intended or a specific instance or case is to be understood. The aim of the current study was not to generalise, but to explore, in detail, the specific experience of young people who had transitioned from child to adult mental health services with support from a third-sector organisation in South Wales. IPA methodology was used as it allows data to be analysed systematically and comprehensively. The limitations of such methodology are acknowledged in the Chapter Four.

2.2.4.7 RESONANCE WITH THE READER

Elliott and colleagues (1999) suggest that findings should be presented in such a way that allows the reader to connect with the interpretation. Presentation of findings should also provide the reader with a deeper understanding of the phenomena being explored. Resonance with the reader may also be enhanced through an awareness of related literature, so that the reader may draw upon other theories to develop the research interpretations (Yardley, 2008). Resonation was addressed through the review of relevant literature discussed in Chapter One. Resonance was also checked by both supervisors through supervision and the production of draft chapters.

2.2.5 ACKNOWLEDGING THE RESEARCHER'S POSITION

Reflexivity is a key concern for qualitative researchers and is increasingly becoming part of the research process (Brocki & Weardon, 2006; Smith *et al.*, 2009; Yardley, 2008). Defined by Finlay (2006) reflexivity is an '...immediate, dynamic and continuing self-reflection' (p. 262) with the aim of critically analysing the research process. According to Willig (2013) there are two types of reflexivity: personal and epistemological reflexivity. The former involves in ways in which the researchers '...values, experiences, interests, beliefs, wider aims in life and social identities have shaped the research' (Willig, 2013, p.10). Conversely, epistemological reflexivity requires the researcher to '...reflect upon the assumptions made in the course of the research' (Willig, 2013, p.10).

Within IPA there is explicit recognition of the researcher's interpretative role and the potential impact of the researcher's beliefs and assumptions on the research (Smith *et al.*, 2009). For this reason, the researcher kept a reflective journal throughout the research process (Appendix iii). This meant that the process of analysis from the researcher's perspective became transparent and was available for external observation. The following position statement outlines the potential influences on and of the researcher, and was developed via the process of reflexive bracketing (Ahern, 1999).

2.2.5.1 RESEARCHER'S POSITION STATEMENT

The researcher writes from the position of a married, thirty-two-year-old British middle-class female Trainee Clinical Psychologist. The researcher did not know any of the participants prior to conducting the study. Participants were made aware of the researcher's trainee status and understood that the research was a partial requirement of their Doctoral studies.

Prior to training, the researcher had limited experience of working with young people both in a CAMHS and AMHS context. It was during training placements within CAMHS and AMHS that the researcher had experienced the tensions between young people and adult services with not very positive results. It caused a great deal of anxiety, frustration and confusion for the young people concerned and in her experiences, only few had experienced an optimal transition process. These experiences were the driving force behind the researcher's interest in this study.

In addition, the researcher has felt powerless as a practitioner to raise their concerns in supervision, particularly regarding the arbitrary divide between services based upon age. The researcher was left wondering how the transition process had truly impacted on the young people, specifically in regards to how they felt as a young person moving from a more family-orientated culture in CAMHS to adopting a more autonomous role AMHS. The researcher felt that the study would provide an

opportunity for young people to express their views and concerns about transition from CAMHS to AMHS. Therefore, to be able to conduct this study and give young people a voice appealed to the researcher intuitively.

Throughout the course of the study, the researcher had expected to hear stories of transition that had been difficult. The researcher wondered how much the young people had been involved in discussions about the transition, how much preparation for the transition they had received and how well integrated into AMHS they had felt. The researcher was aware of their own potential biases and experiences and tried to remain neutral with a focus on asking open questions throughout the interviews. The researcher was also aware that the subject matter could be emotionally distressing for some of the young people. Ways to manage these situations appropriately and professionally were discussed with the research supervisors. Debriefing packs were developed and a space to seek support with either the researcher or a member of the transition service was ensured following each interview.

The researcher used supervision with both the academic and clinical research supervisors to acknowledge her position throughout the research. The researcher reflected that she was also approaching a transition; coming to the end of her training role and beginning to enter her career. Akin to the transition from adolescence to adulthood, the researcher was aware of the implicit expectation to have achieved a level of mastery, in this case, to be able to adapt to the role of autonomous practitioner. This was met with feelings of anxiety, which may have limited the invariability of her reflective capacity. Nonetheless, the researcher was able to reflect on these issues through supervision, in order to maintain a balanced and open-minded approach.

2.3 ETHICAL CONSIDERATIONS

2.3.1 GAINING ETHICAL APPROVAL

The study gained full ethical approval from Cardiff University School of Psychology Research Ethics Committee prior to commencing recruitment and data collection. A copy of the approval letter can be found in Appendix v. As participants were recruited via a third-sector TS approval for the study was also gained from the third-sector organisation's Research Ethics Committee and a copy of the approval letter can be found in Appendix vi.

2.3.2 INFORMED CONSENT

In line with the Health and Care Professions Council (HCPC) Guidance (HCPC, 2012) and the British Psychological Society (BPS, 2009) the researcher sought and obtained consent from all young people who participated in the study. An information sheet (Appendix vii) outlining the details and rationale for the study was given to potential participants by the manager of the TS, to help potential participants make an informed decision as to whether or not to participate in the study. The researcher was not privy to any contact details of potential participants until they had indicated their interest in finding out more about the project using an opt-in form (Appendix viii) attached to the information sheet. Following the completion of the opt-in form interested participants received further information about the project when initial contact from the researcher was made. The information sheet was given to participants by the researcher when they attended for interview and time was given for participants to ask any further questions about the study. Participants signed a consent form (Appendix ix) to acknowledge their agreement to engage in the study. The consent form confirmed that participants had read and understood the information sheet, that participation was entirely voluntary and that withdrawal from the study would not impact on services they received.

2.3.3 CONFIDENTIALITY AND ANONYMITY

In accordance with BPS (2009) and HCPC (2012) Code of Ethics and Professional Standards, the researcher ensured that confidentiality was maintained throughout the research process. While the limits of confidentiality were acknowledged, every effort was made to ensure that confidentiality was maintained. Thus, if a concern was raised by a young person regarding risk of harm to either the young person being interviewed or another, steps were in place to ensure their safety. These steps were in line with the TS risk management protocol and procedure which included notifying the TS manager in the first instance. The researcher informed participants of the limits of confidentiality prior to conducing the interview. This was explicitly stated in the information sheet, on the consent form and verbally prior to commencing the interview.

The researcher assigned a pseudonym to each participant and this pseudonym was used throughout the research process. Only the researcher knew participant's real names and the corresponding pseudonym. Contact information and other identifiable information, such as the completed consent form, were stored separately from the data in a secure cabinet that only the researcher had access to.

Digital recordings of interviews were transcribed verbatim by the researcher and destroyed following transcription. All identifiable information needed for the write up of the research, including any names, for example, of places, was also changed to further ensure anonymity.

2.3.4 PARTICIPANT WELL-BEING

It was not anticipated that interviews should raise potentially emotive or distressing issues for the young person. Despite this, the researcher considered the well-being of all participants at every stage of the process. The researcher ensured that appropriate avenues of support were available to participants should an interview result in participant distress. Participants were offered the opportunity to have a member of the TS (who was known to them) available at the time of the interview. The TS support worker did not sit in during the interview, rather they were available at the interview location should the young person become distressed and require support. Participants were informed that the interview could be stopped or postponed if they became distressed or did not want to continue for any reason. The TS support worker was also available directly following the interview and subsequently should the young person require support at a later time. No participants used the TS worker support at the time of interview and no participants became obviously distressed during interview.

Time for debriefing with either the researcher or the TS support worker was ensured at the end of the interview. All participants were given a debrief information sheet outlining the researcher's contact details and other contacts for further support or information following the interview (Appendix x).

2.4 MATERIALS

The following section details the materials that were developed and used in the study. All materials mentioned below were reviewed by a service user with links to the South Wales Clinical Psychology Doctoral Programme, to ensure that they would be suitable for use with the target population. The service user was a young person (aged between 18-25) who had direct experience of using both CAMHS and AMHS.

Chapter Two: Methodology

2.4.1 Participant Information Sheet

A participant information sheet (Appendix vii) was designed to provide potential participants with information in order to assist them in making an informed decision as to whether they would like to participate in the study or not.

The information sheet provided the following information:

- The purpose of the study
- Information about the procedure of the study and what participation would involve
- Information about confidentiality, anonymity and the right to withdraw
- Information regarding how data would be collected, analysed and stored.

The Information sheet also included an 'opt-in' form for individuals to indicate whether or not they would like to learn more about the study, an envelope was also attached so that individuals could keep their response private.

2.4.2 CONSENT FORM

A consent form (Appendix ix) was developed in line with Cardiff University School of Psychology Research Ethics Committee guidelines to enable the researcher to gain written informed consent from participants. The consent form included:

- Confirmation that the participant had read and understood the information sheet
- Confirmation that the participant had opportunity to ask the researcher questions
- Consent to take part in a one-off interview
- Confirmation that the participant understood that they could withdraw from the study without needing to give an explanation
- Consent for the interview to be audio-recorded
- Consent for anonymised direct quotations and the write up of this to be made publically available through publication in a research journal and as a summary report

2.4.3 SEMI-STRUCTURED INTERVIEW SCHEDULE

The interview schedule aimed to explore young peoples' experiences of the transition from CAMHS to AMHS and the support that they had received from the TS. The interview schedule was developed using guidance from the literature (Smith & Osborn, 2003; Smith *et al.*, 2009) which suggests that

Chapter Two: Methodology

the researcher should think broadly of the range of issues to be covered during the interview and

then place them into an appropriate structure. The topics covered in the interview were:

Experience of CAMHS and AMHS

• The process of transition, including planning and support

• Support from the TS

The researcher generated appropriate questions and prompts. Willig (2013) suggests that the

interview schedule should include a relatively small number of open-ended questions. Furthermore,

Smith and colleagues (2009) suggest that questions should avoid jargon or technical language and be

neutral rather than leading.

The researcher developed the final interview schedule in line with the above guidance and based on

a review of the literature on transition in mental health services, the researchers own curiosities and

discussions with the Service User and Carer Involvement Co-ordinator and Research Director from

the South Wales Clinical Psychology Doctoral Programme. The schedule can be found in Appendix xi.

2.5 PARTICIPANTS

2.5.1 SAMPLE

IPA aims to describe in detail the perceptions and understanding of a particular group under

investigation, rather than making more general claims (Smith & Osborn, 2003). Due to its strongly

idiographic focus, IPA requires that cases are examined individually in detail prior to conducting a

cross-case analysis (Smith et al., 2009). To allow for such detailed case analysis IPA is typically

associated with a concentrated focus on a small sample; as Larkin and Thompson (2012) claim, it is

quality rather than quantity of data that allows for insightful analysis. Smith and colleagues (2009)

suggest that between 4-10 participants is adequate for analysis of data at doctoral level. Thus, the

present study sample of seven young people was considered sufficient to gain meaningful results.

Within IPA, it is usual for researchers to undertake purposive sampling in order to find a fairly

homogenous sample, for whom the research question is meaningful (Smith et al., 2009). All

participants were young people who had transitioned from CAMHS to AMHS and had been

supported by a third-sector TS.

62

2.5.2 SERVICE CONTEXT

Participants were recruited from a third-sector organisation TS in South Wales which supports young people aged over 16 with a diagnosed mental health difficulty. Referrals to the TS are received from CAMHS and the TS is typically accessed at a point when transitional planning between services is formulated. Transition support workers aim to attend transition meetings (with CAMHS and AMHS) in order to meet with young people and develop an agreed transition support plan. Such plans include support to access employment, education and training opportunities whilst simultaneously supporting physical, psychological and social functioning throughout the transition process. The TS provides a 12-week programme which includes one-to-one support to collaboratively develop and follow the transition support plan. Additionally, young people can access therapeutic groups which aim to develop appropriate coping skills to enable young people to better manage their mental health. Social groups are also offered to young people to provide activities and practical and social support.

2.5.3 Inclusion Criteria

Participants were suitable for inclusion in the study if they were:

- aged 18+;
- had completed the transition from CAMHS to AMHS in the previous three years (i.e. young people who had previously accessed CAMHS and had been seen in AMHS); and
- able to participate in an interview of approximately 60 minutes

2.5.4 DESCRIPTION OF PARTICIPANTS

Fourteen of 26 young people attending the TS met the inclusion criteria for the study and were given information about the project by the TS manager. Of the 14, nine responded to say that they would be willing to participate in the study. Two young people were unable to be contacted by the researcher within the time frame for recruitment (December 2015 – February 2016) and did not take part in the research. The final sample of seven young people is described in Table 4, overleaf.

Participant Pseudonym	Age (years)	Age first seen in CAMHS	Duration in AMHS
Anna	18	17	9 months
Ben	20	17	1 month (no longer engaged with AMHS)
Connie	18	15	8 months
Della	18	14	3 months
Emma	18	17	6 months
Fran	19	16	10 months (no longer engaged with AMHS)
Gareth	19	12	13 months

Table 4: Participant Details

Due to the limited number of young people who fit the inclusion criteria, the researcher has minimised the possibility of identification. Therefore, only basic demographic information and background information is described to contextualise the information gleaned from interviews and to inform the qualitative analysis. All participants were aged between 18 and 20 years (mean age 18.5 years). At the time of interview all of the participants had transitioned from child to adult mental health services within the last two years, and had accessed adult services at least once during that time. Five participants were female and two were male. Six participants were White British. One participant was European and had lived in the UK for just under 18 months at the time of the interview. All participants were living in an urban area of South Wales and four participants lived with their parents. A number of reasons for accessing mental health services were reported, these included: self-harming behaviours, social anxiety, eating disorder, ADHD and post-traumatic stress disorder. Two of the seven participants had disengaged from AMHS following transfer, whilst all other participants were still in receipt of support from AMHS at the time of interview.

All participants had accessed support from the TS. Anna, Ben, Della, Emma and Fran met with a TS support worker at their initial transition planning meeting. Connie and Gareth were referred to the TS after transition planning had taken place. All participants had developed a transition support plan with the TS and had either completed or were engaged in a 12-week programme of support with the TS at the time of the interview.

2.6 PROCEDURE

2.6.1 RECRUITMENT

Following ethical approval, the researcher approached a third-sector TS as the target for recruitment. The researcher met with the TS Manager and a number of support staff to explain the research in detail. A copy of the research proposal and all accompanying documentation including participant information sheets, consent forms and debrief forms were given. The service manager agreed to assist in identifying potential participants who met the inclusion criteria, based upon their knowledge of the young people in the service. The service manager also agreed to disseminate information about the project, via the information sheets, to all those who fulfilled the inclusion criteria.

Young people who were given the information sheet were required to complete an opt-in form (Appendix viii) indicating whether or not they would like to know more about the study. Individuals who indicated that they would like to know more were required to provide their contact details and indicate the best way for the researcher to contact them (i.e. phone, letter, email). Thus, the researcher had no contact with potential participants at this stage of the study to ensure that independent and non-coerced decisions about participation could be made.

The researcher contacted those who had 'opted in' by telephone in order to further explain the details of the study and answer any questions. Following this, when potential participants agreed to take part in the study, a convenient date, time and location for interview was arranged. Interviews took place either in participants' homes or in meeting/therapy rooms across various sites of the third-sector organisation.

2.6.2 INTERVIEW PROCEDURE

Participants took part in a one-off semi-structured interview which lasted approximately one hour. At the outset, participants were reminded of the study aims and shown the participant information sheet. The researcher reminded participants of the limits of confidentiality and that participation in the study was entirely voluntary. The researcher discussed the consent form with the participant and each item was carefully covered to ensure that informed consent was gained. The start of the interview also afforded the researcher time to build rapport with the participant and to help put them at ease (Smith *et al.*, 2009). The interview was conducted in a flexible manner, using open ended questions and appropriate prompts in order to encourage participants to elaborate on statements or words they used (Smith & Eatough, 2007).

On completion of the interview the researcher thanked participants and gave opportunity for participants to comment on the research process and ask any further questions. All participants were given a debrief sheet and asked if they would like to receive a summary report of the research findings.

Each interview was recorded using a digital recorder to enable later transcription and analysis. Interviews varied in length from between 35 and 75 minutes. Following each interview, data from the digital recorder was transferred to a password protected file in order for transcription to take place. Recordings were deleted following transcription. Interviews were transcribed by the researcher and the transcript document file was saved under the participant's pseudonym and password protected.

2.7 DATA ANALYSIS

Data were analysed according to IPA methodology, using a structured framework proposed by Smith and Osborn (2003) and Smith and colleagues (2009). Smith (2004) argues against using such framework prescriptively, and recommends its use as a suggestion to be adapted. It was decided that the framework would be used in a non-directive way as a starting point for analysis. A summary of the stages of analysis used in the study are outlined below.

During collection, transcription and analysis of the data the researcher kept a record of the process and reflections on any changing ideas and assumptions made.

2.7.1 STAGE 1: READING, RE-READING AND NOTING

In keeping with IPA's idiographic commitment, each interview was first analysed in-depth individually (Smith *et al.*, 2009). The researcher listened to each recording and read the transcripts several times in order to become immersed in the narratives. This was to ensure that the researcher was able to develop a sense of meaning. Initial annotations were documented in the left-hand margin of the transcripts. Such notes included comments on use of language and content descriptions of what the researcher considered interesting or significant within the transcript, for example, use of metaphor or hesitations.

2.7.2 STAGE 2: DEVELOPING EMERGING THEMES

Analysis moved from a focus on the transcript to a deeper exploration, documenting emerging themes in the right margin of the transcript. This was to capture the essential quality of what was noted originally in the left margin. Emerging themes remained close to what participants said, but were expressed at a theoretical level. An example of an annotated transcript is provided in Appendix iv.

2.7.3 STAGE 3: SEARCHING FOR CONNECTIONS ACROSS EMERGENT THEMES

With the specific research questions in mind a list of emergent themes was devised and examined, looking for connections. Themes were written onto separate sheets of paper and those that were related conceptually or had shared meanings were grouped (or clustered) together and labelled as subordinate themes. Labels captured the essence of the subordinate themes yet still made sense in relation to the original data. At this stage, the researcher frequently oscillated between the whole transcript and particular parts to ensure a good fit between the text and the interpretation. Some emerging themes were discarded at this stage due to a lack of supporting evidence within the text.

2.7.4 STAGE 4: SUMMARISING THEMES IN A TABLE

The researcher constructed a summary table to present subordinate themes together with quotes and line locations to illustrate each of the themes. Following this stage of analysis, the researcher met with the supervisors to discuss and check credibility of the identified subordinate themes in the context of original data.

2.7.5 STAGE 5: MOVING TO THE NEXT CASE

The same process was repeated for the other six transcripts. Here, the importance of treating the next case in its own terms is emphasised by Smith and colleagues (2009). As far as possible, the researcher bracketed the ideas from the analysis of previous case(s) using the reflective journal, whilst working on the next so that new ideas could be noted on subsequent analyses. This allowed the idiographic approach inherent in IPA to continue.

2.7.6 Stage 6: Identifying patterns across cases

The researcher finally looked for patterns across cases to identify areas of convergence and divergence between the cases. Following this, a list of recurrent subordinate themes was created. Subordinate themes were clustered further to create superordinate themes. Such themes reflected both idiosyncratic accounts and shared experiences and were labelled with the participant's own words. The frequency in which a theme was supported across cases was used as an indicator of the importance of a theme. A table to show the frequency of subordinate themes across transcripts is shown in Appendix xii. To ensure quality throughout the analytic process the researcher met with the research supervisors to check the credibility of the superordinate and subordinate themes. Following the data analysis, a literature review was conducted to consider how the findings relate to existing literature.

2.8 DISSEMINATION OF RESULTS

All participants were provided with the contact details of the researcher and made aware that they may request a Research Summary Report outlining the main findings of the study upon its completion. Following analysis, the resulting themes were shared in a one-off meeting with the TS in order to provide critical yet sensitive feedback where appropriate. Feedback obtained from the TS was affirmative and resulted in no changes to the identified themes.

3. RESULTS

3.1 OVERVIEW OF CHAPTER

This chapter presents the themes that emerged following an Interpretative Phenomenological Analysis of data collected via interviews with seven young people. The intention of the interviews was twofold; firstly, to explore the lived experiences of the participants' transition from CAMHS to AMHS and secondly, to capture the participants' experience of being supported through the transition by a third-sector organisation Transition Service (TS). Overall, the analysis yielded three levels of themes: superordinate; subordinate; and emerging themes, which will be discussed in detail. For clarity within the write up, each superordinate theme will appear in **BOLD CAPITAL** and subordinate themes in **bold lowercase**. Emerging themes derived from the young people's narratives within each subordinate theme will be underlined.

To highlight and support the themes, verbatim extracts from the interviews have been included and are written in *italics* with participant name and line numbers to reference. This is in accordance with Elliott and colleagues' (1999) recommendation that quotations be used to allow a detailed scrutiny of the analysis. Square brackets '[]' are used within the text where the researcher has added information (e.g. to explain what the participant was referring to). Additionally, three full stops '...' are used to indicate when text has been edited to shorten quotations. All identifying information has been removed or changed, and the pseudonyms used in Chapter Two have been maintained to protect anonymity of participants.

3.2 OVERVIEW OF THEMES

Four superordinate themes were derived from the data, each comprising three subordinate themes:

- Within the first superordinate theme BEING A YOUNG PERSON WITH MENTAL HEALTH
 DIFFICULTIES, the experience of being in a validating environment and gaining support from
 CAMHS, yet feeling stigmatised and powerless are presented.
- The second superordinate theme THE PROCESS AND IMMEDIATE IMPACT OF CHANGE
 encapsulates the expectations and pressures that were experienced approaching and
 following transfer from CAMHS and includes feelings associated with uncertainty.

The third superordinate theme LIFE AFTER CAMHS outlines the challenges and successes of
moving into AMHS, including the negotiation of new relationships and adjusting to the
changes associated with being seen in AMHS.

• The final superordinate theme **BRIDGING THE GAP** details the participant's experiences of the TS in supporting young people throughout their transition journey.

Table 5 overleaf summarises the Superordinate, Subordinate and Emerging themes.

It is recognised that the themes identified are one possible account of the experience of moving from child to adult mental health services with support from a TS. They do not cover all aspects of the participants' experiences and were selected due to their relevance to the research aims. It is acknowledged that they are a subjective interpretation and that other researchers may have focussed on different aspects of the accounts. Whilst many of the themes were common to the seven participants, there were areas of divergence and difference, some of which are commented upon.

Superordinate Theme	Subordinate Theme	Emerging Themes
Being a young person with Mental Health Difficulties	"You're mental"	Feeling stigmatised Sense of shame Needing to protect others A hidden self
	"It's OK to not be OK"	Being in a validating environment
	"What about what I want?"	Powerless Disempowerment Not listened to
The Process and Immediate Impact of Change	"You don't know how it is"	Uncertainty and confusion Outlook
	"They think something magic happens"	Manage expectations Readiness to move on
	"Tossed out on my own"	Loss and Rejection
Life after CAMHS	"In the deep end"	Discomfort Seriously let down Sense of abandonment
	"You're supposed to care"	Desire to build a therapeutic relationship Inequality in the therapeutic relationship Superficial rather than genuine care
	"I feel like an adult"	Treated like an adult in AMHS Adjust to new ways of being Increased responsibility
Bridging the Gap	"Having someone there"	Need to be held and contained Positive relationships
	"Taking hold of your own care"	Developing a sense of agency Lack of pressure
	"All in it together"	Belonging

Table 5: Summary of Superordinate, Subordinate and Emergent Themes

3.3 SUPERORDINATE THEME ONE: BEING A YOUNG PERSON WITH MENTAL HEALTH DIFFICULTIES

From the data collected, it became clear that there were several important issues that concerned the participants, which although not specifically related to the transition process, appeared to have a continuing impact on their lived experienced of transition. In order to talk about moving from CAMHS to AMHS, the participants found it important to initially talk about their experiences in the context of receiving support from CAMHS. The superordinate theme BEING A YOUNG PERSON WITH MENTAL HEALTH DIFFICULTIES encapsulates the feelings of young people as they first came to access CAMHS, and their experiences following the receipt of services. This theme includes the strong influence of other people in the participants' perceptions of themselves. This included negative self-perceptions as a result of stigmatising treatment from others, and conversely, feeling better about themselves and their difficulties in response to feeling validated. Three subordinate themes will be discussed: "You're mental", "It's OK to not be OK" and "What about what I want?"

3.3.1 "YOU'RE MENTAL"

A key experience for many of the participants was <u>feeling stigmatised</u> for having mental health difficulties. For some, this was experienced at the point of seeking help in primary care; prior to input from CAMHS. Often, participants had been given the message that their difficulties were such that they needed specialist help that could not be delivered by the GP. Many participants reflected that this had left them feeling that there was a sense of urgency in getting support:

"I went to the GP and almost immediately he said 'you need to go and see someone in CAMHS'" (Emma, 4-5)

"You're in the GP's office and you mention anything mental health and they're like, CAMHS, go please! Go to CAMHS!" (Fran, 151-153)

"The doctor [GP] asked for it... and they referred me straight to CAMHS, like, a specialist CAMHS. I needed more intensive support" (Connie, 55-57)

Some participants appeared to internalise the perceived stigma by referring to themselves as "a little bit crazy" (Fran, 59) and "I was messed up" (Emma, 37). Likewise, in his reflections of being referred to CAMHS, Ben commented how he had perceived himself as "mental":

"And so I got referred to CAMHS, and I remember thinking 'oh no, you're mental...send you to CAMHS'" (Ben 8-10)

Furthermore, as illustrated by Ben, a sense of stigmatisation from the GP led to feelings of both worry and frustration:

"[The doctor] made it seem like there was something seriously wrong with me, and I'm like ok, so, I know it's not normal behaviour, but like, come on! Gimme a break! I felt more, definitely, way more stigmatised in that appointment" (Ben, 517-519)

Likewise, for Fran, the sense that specialist help was needed provoked a feeling of anxiety that there was something seriously wrong:

"He [GP] was like, you need to...talk to them [CAMHS], you know, we can't help you. But you know, it really didn't help because I was already scared of my situation... I was a bit like 'oh my god I really should be [scared]'" (Fran, 155-158)

It seemed that having mental health difficulties had also led Della to experience stigma from others, which in turn, had affected aspects of her life. Della described how she had been "kicked out" of school due to perceived risks that she posed to others:

"...I felt disowned kind of thing. Not only did I feel offended, I felt like no one cared enough to give me an education, just because. I felt like I was discriminated against for having mental health issues" (Della, 43-45)

Some participants talked about feeling a <u>sense of shame</u> about their mental health difficulties and, as a result, did not want their family and friends to know about their difficulties, as Connie explained:

"I don't tell anybody about it... 'Cause I think there is such a stigma about it" (Connie, 587-588)

Similarly, Ben spoke about feeling that he had to withhold information relating to his mental health difficulties from his father:

"It was hard because I had to hide the appointments from him and stuff like that and, [pause] my dad didn't know anything that was going on" (Ben 90-92).

When Ben did eventually tell his father about his problems, it was met with a stark, negative and invalidating response:

"...[He said]'Why do you have an appointment in mental health services?' And I'm like 'because I need mental services.' And he was like 'why? what's wrong with you?' And... then it all came out... then he told me I was gonna die alone and whatever" (Ben, 98-101)

A further theme emerging from participant's accounts involved a sense of <u>needing to protect others</u> from sharing the burden of their mental health difficulties.

"I was so nervous to tell her [mother], because I thought I'm ruining this, like it'll destroy her. She thinks I'm fine, everyone thinks I'm fine, I don't want to break that" (Fran 138-140)

"...it's quite difficult because I don't want to talk [about mental health difficulties] ... You want to keep everything for yourself. I don't want to make her [mother] upset... I don't want to make her feel bad for me or to worry about me or my feelings, if I am sad" (Anna, 301-304)

Ben also spoke about his reluctance in letting others know how he was feeling. He explained:

"I don't like upsetting people, so if I talk about my problems I feel like I am upsetting somebody else" (Ben, 48-49)

Despite being seen in CAMHS, several young people also commented upon how they had initially preferred to not talk about their difficulties to mental health professionals and maintain <u>a hidden self</u>. For example, Anna reflected on how she had been resistant to talk about herself to CAMHS practitioners:

"It wasn't nice. I didn't tell the truth, because I still don't want people to know about me, yeah, I just, I don't want people to know" (Anna, 320-324)

Likewise, Della and Fran spoke about how they had initially concealed elements of themselves and their difficulties from the CAMHS team:

"Half the time I told lies and said that I was fine and they believed that" (Della, 113).

"I'd been living a bit of a lie and kind of, because I'd had problems. [I'd] had ups and downs and been to CAMHS back and for a little bit... I was sort of living as if I was in a really good place and that I was absolutely fine" (Fran 130-133)

For Fran, hiding her difficulties from professionals meant that she could "move on" (Fran, 137) with her life. As a result, Fran had initially been discharged from CAMHS after several months. Yet upon reflection, Fran commented that it "probably wasn't the best thing to do" (Fran, 113), as she had been re-referred to CAMHS some months later.

3.3.2 "IT'S OK TO NOT BE OK"

This subordinate theme describes participants' accounts of the service that they received in CAMHS. Throughout the narratives it became evident that being seen in CAMHS was a positive experience for some because of being in a validating environment; a place where "It's OK to not be OK".

Participants described CAMHS as "safe" (Della, 281), "nurturing" (Fran, 586), "comfortable" (Emma, 76; Fran, 638), and "accepting" (Ben, 511).

"[CAMHS] was a comfortable place to be... A reasonably nice place to sit. If you have to sit and wait for an appointment it's a quite warm, it's got books. It's a lot more welcoming [than AMHS]" (Fran, 638-641)

It appeared that at the time of referral to CAMHS many of the participants had little knowledge of what attending CAMHS would be like. This seemed to cause the young people to initially feel apprehensive, however, these feelings appeared to shift to positivity once they had a better understanding of what to expect:

"In my first appointment I was really wary of my surroundings. And the person I was seeing I was wary of them. But after like, half an hour or so, it was like chilled." (Ben, 69-71)

"I was really worried at first, but they weren't intimidating when you went in there. They were like 'how are you?' and were just like 'you can talk about whatever you wanna talk about. If you wanna focus on one thing for today that's fine. If you don't wanna talk about past things that have happened that's fine.'" (Emma 70-75)

Anna indicated that being accepted into CAMHS had been a profound experience, evident in her powerful statement:

"It was kinda life changing I guess...'Cause obviously I knew that was the first step to actually getting better. I needed to do it." (Anna 11-13)

For many of the participants it seemed that being accepted into CAMHS brought feelings of validation and relief. For example, Fran commented that attending CAMHS for some time had provided her with a space where she could be authentic. This appeared in contrast to her earlier statement about hiding aspects of herself from professionals:

"Well like it was almost like I had a space where I was allowed to be... It was the only place I could be an absolute twat. [laughs] Sorry to use the word, but it [being in CAMHS] would just be to not have to worry about other people's feelings" (Fran, 35-39)

Fran later commented that having the opportunity to be herself was something she felt was justified.

"I deserved to not be perfect in one area of my life... I could definitely just sit there [in CAMHS] and be my own little bit of crazy, in a good way and just be like: OK, I can just do whatever here" (Fran 52- 61)

Gareth also described how CAMHS could be a place where he felt comfortable to talk about his difficulties, without pressure or judgment:

"Well, just the way I've got someone to talk to that's not family... I do struggle to talk to people. 'Cause the only person that I did talk to was my Nan... That was the only person really I would [talk to] ... And there's not really anyone else that I can talk to. But then, at least I could try talking to the [people at] CAMHS, and show how I feel... And I can't be judged" (Gareth, 127-129)

Additionally, several participants described how being accepted into CAMHS had led to them feeling that their difficulties were genuine, which appeared to bring about a sense of acceptance and validation:

"[Being in CAMHS] sort of made it feel like it's [mental health difficulties] a lot more common than people are led to believe, like depression and anxiety and stuff like that. It's a lot more common than people make it seem. And things like self-harm and things like that are also more common than I thought... So it was all like an accepting environment in CAMHS" (Ben 508-511)

"I did feel like I was at least getting validation that something was wrong. So I was still allowed to be not ok...it was a space where I was, it was ok to not be ok" (Fran 331-334)

Furthermore, regularly attending CAMHS appeared instrumental in leading Fran to develop confidence and optimism that she would be able to recover from her mental health difficulties. She reported:

"The fact that I was going the fact that it validated my issues, to me almost made me go 'no, this is a real thing; what I'm going through is real. And that means that it's a real problem which means it's got a real solution. Which means I will be able to fix it and it will be able to be fixed'. It just made me think we can work with this" (Fran 660-665)

3.3.3 "WHAT ABOUT WHAT I WANT?"

A further salient theme that emerged from the young people's narratives regarded perceiving themselves at times as a <u>powerless</u> young person in receipt of mental health services, this appeared to be in relation to making decisions about the care and support that the young people were receiving.

A sense of powerlessness was apparent in Fran and Emma's accounts of interactions with clinicians when they were first referred to CAMHS, which appeared to result in them taking a passive role in their care. Fran described how she had been seen by a psychiatrist during initial appointments, but

soon after her support had been switched to a nurse. In the following extract, Fran's use of the word "lumbered" is interpreted as depicting both hopelessness and dissatisfaction that she was seeing someone without relevant skills and experience. Despite reflecting on how this made her feel, it did not seem that Fran had been able to discuss it with the CAMHS team at the time, which is evident in her passive statement at the end of the extract:

"I ended up being lumbered with Fred [CAMHS nurse] when actually I think still needed to be seeing someone, like a psychiatrist or a psychologist because I still felt like I was in a place where that was necessary. But you sort of just do what you do, don't you?" (Fran, 82-87)

In her reflections, Emma also portrayed how she had felt powerless when trying to explain to CAMHS the difficulties that she had been experiencing. She reported how she had been referred to CAMHS by her GP, but that CAMHS had not taken her "seriously enough" (Emma, 35) and was subsequently discharged back to the GP.

"I'd been [to CAMHS] twice. The first time I went there they saw me once...I saw the person once, didn't see him for about 6 weeks and then when I went he called me back and then he was like 'yeah you're not ill enough, just read some positivity books and you'll be fine'" (Emma, 15-26)

The following extract illustrates how not being taken seriously had impacted on Emma and how the power imbalance between her and the clinician had resulted in her taking a passive stance, she reflected:

"It was a bit heart-breaking to be honest... I don't feel like I'm well enough to be set off [discharged], but I just accepted it" (Emma 28-30)

Emma reported that following this experience, it had taken almost a year to return to her GP to explain that she was still experiencing mental health difficulties.

Having a lack of choice and control was also evident in participant's accounts. For example, a sense of <u>disempowerment</u> was experienced by Della, who felt resentment towards the system in CAMHS making decisions without consulting her:

"There's lots of arguing and people talking over each other 'well I don't think Della should do this' and I'm like, what about what I want?" (Della, 202-207)

Gareth also reflected how he had been given little choice over what kind of support he would have preferred whilst seen in CAMHS. Gareth explained how he had been aware that other young people

had received one to one therapy, yet he had only been offered group support and felt he should be more involved in decisions about the support he would receive.

"They could have said 'would you prefer group or one on one?', but they never asked that question" (Gareth, 241-242)

Furthermore, in recalling his appointments with CAMHS, Gareth reflected on how the clinician had seemed to disregard any views that he had. Instead, it seemed that Gareth felt that he had little option but to comply with taking medication:

"I was put on tablets... I didn't even wanna be in with the psychiatrist. She just really would speak about things that had happened, what's happening. She didn't ask how I am, what's improving or what's not improving; how I'm getting on with or feeling about the tablets" (Gareth 50-55)

This experience was echoed by Fran, who reported how she too had become a passive recipient of medication:

"I did start medication, but I didn't feel a change. I mean I still take medication but I don't really, I don't know how much it does, I don't really know. But, you just keep taking it don't you, because they tell you, because it's just what you do" (Fran 174-178)

Della also explained how regular changes in medication had made her feel depersonalised:

"[The Doctor] lowered my dose [of medication] and put me on another medication... then changed it again to [another medication] ... It kind of felt like [I was] a test subject, more or less" (Della, 98-103)

"I felt angry, you know like. Well I've been on them [tablets] so long. What's wrong with them now?... I felt like I was going through all the changes of medication and I felt like a human test" (Della, 252-255)

Connie, like other participants, described feeling disempowered and defeated when challenging professionals. The experience of how CAMHS "treat you like a child" (Fran, 831) was paralleled by feeling unheard and powerless. Connie commented how she had felt hurt and not listened to by professionals: "...they say I've got a say but actually I don't" (Connie, 327)

The following accounts of discussions between Connie and clinicians seemed to illustrate a sense of defeat:

"I said that it [CBT] didn't work because I've done it before. And she [CAMHS professional] said 'you haven't done it'.... I said 'I have'... And she was like 'I've looked in your notes and you

haven't done it'. I was like 'I have done it, I've spent like 6 months trying to do it and it didn't work'. She wouldn't listen to me" (Connie, 253-256)

"I said it [to change medication] in CAMHS. I'd been saying it for the past, probably, last year that I was with them [CAMHS]. I asked for it [medication] to be changed... and they were like 'no, we're not touching your medication, were not touching it at all. 'Cause you're going to be going to adult [services] in a year and we don't want to start messing about with it'" (Connie, 288-302)

For Connie, these experiences seemed to elicit a sense of hope that she may have more power and control over her own care when she went to AMHS:

"So I was just a bit like well, this is a bit useless. I've got no say in anything. So I thought that when I go to adults I'll be able to change it [medication]" (Connie, 315-316)

Ben was an exception to this theme. The account of his experience of discussing the transition to AMHS put him as central to the decision to continue to access mental health services. Ben seemed empowered by this:

"I was like, the situation with CAMHS is gonna end and I need somewhere to go from there...

We [Ben and CAMHS Nurse] discussed it and I was like... 'I'll stay in mental health services just in case', you know. But as it were, I went into Transition Service as well, just in case... I still found [managing his mental health] difficult and so I decided to go to adult mental health [services] and so she [CAMHS nurse] made the referral" (Ben, 235-238)

3.4 SUPERORDINATE THEME TWO: THE PROCESS AND IMMEDIATE IMPACT OF CHANGE

The superordinate theme **THE PROCESS AND IMMEDIATE IMPACT OF CHANGE** captures the thoughts and feelings that young people experienced as they were approaching the end of CAMHS and beginning to transition to AMHS. Within this theme are three subordinate themes **"You don't know how it is"**, **"They think something magic happens"** and **"Tossed out on my own"**.

3.4.1 "YOU DON'T KNOW HOW IT IS"

The subordinate theme "You don't know how it is" captures the thoughts and feelings of young people as they anticipated the move from CAMHS to AMHS. It appeared that at the point of initial

discussions regarding onward referral to AMHS many of the young people had limited or no knowledge of what AMHS would be like, or indeed, how AMHS might be able support them and their ongoing needs. For participants, this experience had engendered <u>uncertainty and confusion</u> which in turn, appeared to provoke ambivalent feelings of both fear and anxiety *and* hope and excitement.

Fear and anxiety featured strongly in almost all of the participants' narratives when asked about their thoughts about moving on to AMHS. Some anxieties concerned meeting a new clinician and not being certain that the quality of care would be as good as they had found in CAMHS:

"I was stressed and nervous, like how is it there? What will they be like? What is going to happen?" (Anna, 164)

"I think my anxiety levels were really high...um...! felt like I had to start again. Like, in a good way I suppose, I felt like I had started a new chapter and I didn't know whether it was gonna be a good chapter or a bad chapter" (Della, 348-351)

"It was quite a worry really because I didn't have long left in CAMHS and I was not in a great place...I didn't really know what would come in adult services so I wasn't really sure" (Fran, 20-24)

"It's confusing and makes you nervous like...because you don't know how it [AMHS] is, how it might be" (Connie, 254)

"I was ok, a little bit nervous 'cause I was scared that if I had, if I really need the help would they [AMHS] really, would someone really be there to help?" (Emma, 119-121)

Uncertainty and fear regarding the differences between CAMHS and AMHS were also evident in Connie's powerful use of metaphor, describing herself as a "little fish in a massive pond" in the following account:

"It was just it was, it was difficult not knowing what I was going to...'Cause it's just kind of like throwing a little fish in a massive pond, which is... I don't know where I am going... I think that [not knowing] was the scariest part.... It was like the worst part [of the transition] for me" (Connie, 468-472)

Some participants described how they had been prepared for transition, for example, Anna, Emma and Fran described how they had met with professionals from AMHS prior to leaving CAMHS. In the following account it is clear that Emma had not been informed that her CAMHS clinician had arranged a meeting with AMHS to discuss the transfer and this initially provoked feelings of anxiety, before subsequently feeling at ease:

"I didn't know who they [AMHS professional] were... They didn't tell me at first. They [CAMHS clinician] just sat them [AMHS professional] in the room with me. And I was like 'what's this

about?' and she [CAMHS clinician] was like, 'this here is the person you're gonna be meeting with'. And he [AMHS professional] introduced himself... Then it was just fine after that. But it was just initially quite scary. Meeting people for the first time and not really knowing who they are and what they were doing was quite scary" (Emma 135-141)

For some, having the opportunity to meet with someone from AMHS did not help to alleviate their feelings of <u>uncertainty and confusion</u>, particularly when the meeting was perceived as poorly organised. This was captured in Fran's vague recall of a meeting that had taken place:

"There was a meeting... or at least some sort of phone call, I don't know... I wasn't in a meeting with them. Oh no I did have one actually... It was someone who worked for them [AMHS team]. It wasn't.... a mental health or a psychiatrist doctor... I'm not really sure... I don't know who she [AMHS clinician] was.... There was no continuity in it. It was very disjointed and I don't really know what [was] going on" (Fran, 349-354)

Connie also explained how she had met someone from AMHS prior to transfer, yet the person she had met was not the person that she would be seeing in AMHS:

"It was a nurse, um but it wasn't somebody I see now. But I don't have an assigned nurse now or anything. I just have a doctor that I see every 6 months... I think it would have been better if I had sort of like a set [AMHS professional] who I was going to and knew what they were gonna do" (Connie, 445-452)

Similarly, being curious and seeking reassurance and being given information by professionals around the transition process did not appear to alleviate worries. Anna recalled:

"I remember when they started to describe the difference between CAMHS and adult [services]. It was like a big shock because I feel like I am going someplace where people have got real traumas" (Anna, 106-109)

"I still didn't know what was going to happen; how it might be [in AMHS]. So I asked [what AMHS would be like] and even when they told me that it is fine... still, I was nervous" (Anna, 147-149)

Having little or inadequate information and preparation prior to moving to AMHS led some participants to formulate their own ideas, or <u>outlook</u> in terms of what AMHS would be like. For some, this appeared to create a negative outlook. For example, Della anticipated that AMHS would be a negative experience:

"I had no idea... I thought I was going to go from having a really good doctor to finding a really bad doctor" (Della, 307-308)

"I was expecting like a really nasty person to be my doctor, um someone that seemed really strict... My expectations were doom and gloom, I guess." (Della, 343-346)

Emma reflected on her early experiences of not being accepted in to CAMHS and how this impacted on her expectation of support in AMHS. It appeared this early experience led to concerns that AMHS would not be as caring or supportive:

"I thought he [AMHS professional] was gonna think all my problems are like childish, not like adult problems. I suppose I was a bit worried he was gonna say you're not ill enough, like the others [CAMHS] did" (Emma, 144-147)

"It just was more, like I am gonna be serious enough? Is it gonna be worth them [AMHS] taking [me] on. 'Cause I know that obviously there are adults that are maybe more serious than me... I was really nervous about [whether AMHS would accept the referral]" (Emma, 167-172)

A divergent view was expressed by three participants. Connie, Gareth and Fran reported how occasionally they had felt dissatisfied with the input they received from CAMHS. This appeared to lead to a hopeful and positive outlook regarding the move to AMHS:

"I thought let's try and be positive, maybe it'll be better [in AMHS]. Maybe something will get done. I thought I'd have more of a say... I thought I'd be able to have my medication changed" (Connie, 483-484)

"I was looking forward to it [moving to AMHS] ... 'Cause all I wanna do is go see what else, the help I can get, and the people I can meet. I was ok with it" (Gareth, 109-110)

"I was expecting [to have] more [support] from adult services. I was kind of looking forward to that...I might get something a little bit different, it might be really good for me to have a fresh perspective on me and have somebody fresh" (Fran, 341-344)

"...I was expecting to see somebody more, well, somebody better than Fred [CAMHS nurse] for a start! That's what I was excited about. That I'll see someone who isn't maybe, well I don't care if they are highly qualified, just better; they wanna be there. They are a bit more interested." (Fran 374-378)

For Ben, a positive outlook appeared to be linked to a view that he needed continuing support:

"I knew I still needed help. I went into AMHS with that kind of perspective, ah you just need to help me get better" (Ben, 462)

It appeared that some participant's outlook had also been influenced by information that they had received from professionals in CAMHS. Anna reflected how she had worried about going to AMHS, and that she been told that AMHS would be a safe place:

"They [AMHS professionals] told me that I don't have to worry, it's a nice place, it's quiet. You are safe...If you don't like [AMHS], you can say to the doctor if you don't want to go [to AMHS]" (Anna, 116-117)

However, several participants reported that they believed, or were told by clinicians in CAMHS that AMHS would not provide the same level of support. This made the prospect of transition particularly anxiety provoking, as articulated by Connie and Fran, amongst others:

Connie: "I was saying to start off with, that I don't want to go to the adults, I don't want to be with adults, 'cause I knew what it was like"

Interviewer: "How did you know what it would be like?"

Connie: "One of my [CAMHS] nurses told me what it [AMHS] was going to be like and she didn't give me much hope" (Connie, 419-421)

"Basically saying that adult services would be more difficult... I guess not as good. As in less support. There's less sort of out there [in AMHS]. So it's more difficult to get the support" (Fran, 240-242)

"I read it as it sounding like [CAMHS were saying] 'adult services, that's just the abyss'" (Fran 252)

3.4.2 "THEY THINK SOMETHING MAGIC HAPPENS"

"They think something magic happens" is the second subordinate theme within "THE PROCESS AND IMMEDIATE IMPACT OF CHANGE" and captures the reflections of young people as they were nearing the end of involvement with CAMHS.

When asked to reflect upon how they had felt approaching the end of CAMHS involvement, many young people commented on having to <u>manage expectations</u> set by themselves and others leading up to the transfer of care. Woven throughout several of the young people's accounts was a perceived pressure to master tasks and achieve a level of responsibility commensurate with the young person's (and others') conceptualisation of what it meant to be an adult. For example, feeling pressure to become "...a person who can take control of their emotions" (Della, 79).

Fran felt that there had been a pressure and expectation from CAMHS to be ready and well enough by the time she had reached 18, so that she would not have to be seen in AMHS:

"It kinda just always came up, it was always like that thing [CAMHS professionals would say] 'so we need to think about what we're gonna do'. Maybe not every week, but you know, every

other week, every third week... You know, 'what are the plans gonna be for when you're not coming to CAMHS?'" (Fran, 229-233)

"I did think it was kind of like they were saying you know, if you can be like fine by the time you turn 18, then you won't have to [go to AMHS] ... And it was like putting a time pressure on [recovery]. That is really the last thing you need to do" (Fran 242-247)

Della described how she had felt pressure from others, which resulted in her becoming resistant to taking on responsibilities as an adult. She reflected:

"When I was turning 18 they expected me to manage my money, pay bills, feed myself and dress, clean, things like that. And they are things I suffer with daily... It makes me not want to manage my money and clean and stuff like that because I feel like I'm under a lot of pressure to do that. All of a sudden on your 18th birthday [there is an expectation that] you can do all that" (Della, 443-448)

"It's a big responsibility...it's a big responsibility to be an adult, and what they expect of you" (Della, 457-458)

This view was echoed by Connie, whose use of language appeared to convey a sense of frustration with the view that she became an adult once she turned 18:

"I think they think something magic happens when you turn 18...The thing is with mental health services they are so stupid, they can't just say you're 18, go to adult [services], you're in charge of it, because you're not" (Connie, 253-255)

"I remember feeling it's just it's stupid. Like I swear they think that as soon as you'll turn 18, there's like a magic wand and you're an adult, and you're not. It doesn't mean anything" (Connie, 360-362)

An emerging theme captured within the subordinate theme "they think something magic happens" was the concept of <u>readiness to move on</u>. Some participants held the view that were not ready to navigate the perceived increase in maturity associated with transition to adulthood and adult mental health services. The readiness to transfer to adult services seemed to be grounded in participants' personal sense of maturity and self-confidence:

"It was like they were expecting me to be a really skilled person and to manage [looking] after myself. I felt like I wasn't ready, wasn't ready to go from CAMHS to AMHS" (Della, 405-406)

Similarly, Connie reflected on how she was not ready to move to independence:

"Nothing changes. You're in the same mental state as you were when you were 15....17....17 and 364 days. You're still the same" (Connie, 275-277)

"they [parents] had to take complete charge of me for everything, and at 18 now I'm in charge of that, but I'm not ready to be in charge of it" (Connie, 366-367)

Having conversations with the CAMHS professional regarding the transition to AMHS also appeared to lead Fran to feel destabilised, and subsequently resistant to consider the move to AMHS when she had not felt ready:

"I turned 17 in November... By January they [CAMHS] were like 'so, you're going to be leaving'...and I was like 'STOP! I know, just help me where I am for a minute... I need the support now!" (Fran, 117-121)

Della explained how she had felt that she would need to 'grow up' when she got to AMHS, however, she reflected on how she had needed more help to enable her to feel ready to move AMHS:

"It makes me quite angry and sad... It makes me feel like well how can I grow up when I don't have the support that I need?... Like how can I grow up when all of the skills that I've needed for the past few years of being with CAMHS and things like that, I never got" (Della, 400-403)

Conversely, a resistance to move was not experienced by Emma. Her narrative conveyed a personal readiness to change:

Emma: "I was ready to [transition to AMHS] I think. I felt ready"

Interviewer: "How did you know you were ready?"

Emma: "I don't know; I just know I was ready. It's weird, I just know" (Emma, 157-159)

Furthermore, Emma's appraisal of the move appeared to lead her to experience the transition to AMHS as positive:

"I just suppose I was happy about it and not negative, 'cause if you're gonna be negative about it then it won't be a good thing" (Emma, 164-165)

"I feel like if you're ready enough [to move to AMHS]... Even if you're not ready, you just need to let it happen and just go with it. 'Cause once you get to the different service [AMHS] you just, kinda well, you know, this is the service I needed rather than what I was getting in the other place [CAMHS]. It's just better" (Emma, 232-236)

3.4.3 "TOSSED OUT ON MY OWN"

The final subordinate theme "Tossed out on my own" captures the participants' thoughts and feelings as they were leaving CAMHS. Emerging from many of the young people's narratives were feelings of loss and rejection.

A sense of loss was discernible in some participant's accounts. As highlighted in the subordinate theme "It's OK to not be OK", the time in CAMHS was generally seen as a positive experience where the young people had established a sense of validation, security and had developed relationships with staff. To some, the move to AMHS marked a loss of these factors.

Ben spoke positively of his relationship with the CAMHS nurse and conveyed a sense of loss at the ending of this relationship:

"It was really sad, 'cause I'd had such a good experience in CAMHS, and I felt like that must have been rare... The [CAMHS] nurse I was seeing was sad as well. 'Cause she enjoyed my appointments because I was sort of chilled with being there.... It was quite sad even though I'd only be there a year. I'd built a good relationship [with the CAMHS nurse]" (Ben, 243-247)

Ben also spoke about how moving away from CAMHS had generated a feeling of a loss of safety:

"I felt secure in CAMHS and then the realisation came that I wasn't going to be staying" (Ben 621-623)

For Connie, sense of loss appeared to be centred around the level of input that she would receive in AMHS:

"I was upset to leave CAMHS. I didn't want to leave...I think I cried to my mum afterwards, 'cause I was just like, what now? I was more upset about the fact that I was moving from an intensive team to like a general team" (Connie, 449-452)

Two participants commented on the involvement that their parents had in their care when they were in CAMHS. For them, the move to AMHS signified a loss of their parent's involvement.

"It makes me feel like they are taking away, trying to take away that big part. She's [mother] like a team member to me... I feel like they are trying to take away my team member, to single me out... To make me talk about how I feel and things like that" (Della, 281-283)

"Initially I was so dependent upon my parents. They had to take complete charge of me for everything. And at 18, now I'm in charge. They can't be involved as much" (Connie, 366-367)

A salient theme accompanying the feeling of loss appeared to relate to experiencing rejection leading up to and following discharge of care from CAMHS. Whilst many young people described being aware of their inevitable departure from CAMHS, transfer had been experienced as abrupt. Within the following narratives, Ben and Della's use of the words 'dumped' and 'tossed out' seemed to reflect their experience of rejection:

"Yeah and it was like I'd been dumped. I understand it's not CAMHS' fault. It's something they have [to do]. They have to stop their service for over 18s" (Ben, 469-470)

"I felt like I'd been like tossed out on my own, kind of thing" (Della, 311)

Furthermore, Fran recalled she had felt pushed out of CAMHS when she was nearing the upper age limit for services:

"The second you turn 17 they start sort of paving your way out... Like [CAMHS were saying] 'get ready to go, 'cause...we need to prepare you'" (Fran, 21-22)

3.5 SUPERORDINATE THEME THREE: LIFE AFTER CAMHS

The superordinate theme LIFE AFTER CAMHS encompasses the lived experience of all participants once they had transferred from CAMHS to AMHS. This superordinate theme includes three subordinate themes: "In the deep end", "You're supposed to care" and "I feel like an adult" capturing the challenges, successes and opportunities that young people faced as they moved away from CAMHS.

3.5.1 "IN THE DEEP END"

The first subordinate theme "In the deep end" relates to the experiences that several participants had as they were first seen in AMHS. This theme describes the participant's responses to the abrupt change of context; capturing their reflections on the differences in the physical environment and treatment ethos encountered as they attended adult services.

A prominent theme that emerged throughout participants' narratives was <u>discomfort</u>. Many of the young people remarked how differences in the milieu and physical environment had led them to feel as if they were "going into a different world" (Della, 319). CAMHS were often described as "warm" (Fran, 630), "comfortable" (Emma, 76) and "nurturing" (Fran, 586). In contrast, the environment of adult services was described as "a lot more clinical" (Fran, 587), "uncomfortable" (Ben, 527) and "unwelcoming" (Della, 319).

In describing his experience of being seen in AMHS, Ben took time to recall the detail of his first appointment. Within his narrative feelings of discomfort and wariness of the physical environment were apparent:

"...when I got there... It was really hard to find the entrance... The entrance [to AMHS] was sort of a dark bricked up door.... I was like 'what? That doesn't sound dodgy at all'. I didn't have the best impression... Obviously I guess there has to be some form of privacy [in AMHS] but the doors were black and we had to ring a buzzer... It was all shady" (Ben, 308-315)

It appeared that this first impression was influential in Ben's opinion of AMHS, as he later explained that he had been reluctant to go back to the AMHS clinic following his initial appointment.

Della's account describing the adult community mental health team premises appears to mirror the negative impression that Ben had experienced. Della explained that the CAMHS environment had been more "welcoming" (Della, 320) which was in contrast to how she had perceived the environment in AMHS:

"...if you go into [AMHS] centre, it's kind of really daunting. It's dark and gloomy" (Della, 432-433)

Della also explained how she had felt scared and intimidated by the other service users in the physical environment:

"First of all they didn't tell us it was gonna be next to the addictions [service], which I don't think was a good idea. We had to walk past the addictions centre... It was a bit nerve-wracking sometimes.... [In AMHS] there's lots of males and females and they look quite scary looking... I think the [AMHS] centres should be nicer" (Della, 325-330)

Fran also commented upon the difference between the CAMHS and AMHS environment. The following account appears to depict a sense of stigma and unease:

"It's a really horrible little building and it's like on a really manky road and there's just rubbish everywhere. I'm not turning up to a nurturing place [AMHS]...Everything is cold...It backs up that stereotype of like, you know, mental hospitals, old mental hospitals...Like in horror films, they're always depicted as really dirty. That's how I felt it was like. This [AMHS] feels really not a nice place to be... Kind of like they send you in the deep end a little bit" (Fran, 587-591)

For Fran, it appeared that the physical environment had not only created a sense of discomfort, but also led to her to feel unsafe and less likely to engage with the AMHS professional:

"I went to adult services and thought, well, I want to spend as little time here as I possibly can, thanks. It's not a space you want to be in...It's not a space you're particularly comfortable in... And it wasn't a space I particularly wanted to open up in either... I walked in and didn't feel like they wanted me there at all... I just felt quite like unwelcome...I thought well this isn't a space that I feel ok to not be ok" (Fran 641-648)

Throughout the interviews many participants appeared to draw comparisons between CAMHS and AMHS. Some participants reported that they had felt disappointed and "seriously let down" (Ben, 334) as they found they were no longer getting the equivalent level of support as they had received in CAMHS.

Connie explained how following the transfer of care to AMHS she was now having six-monthly appointments, For Connie, a dearth of regular appointments had resulted in her feeling that she had been left with nothing:

"I knew it wasn't gonna be like every week, I knew it wasn't gonna be every two weeks, but I thought there would be more [appointments] there [AMHS] than what there actually is. I was quite shocked when I've got nothing" (Connie, 488-490)

Many participants highlighted the impact that an absence of regular support would have on their recovery. For example, Gareth explained how less frequent appointments may lead some people to experience a decline in their mental health:

"It's a bit daft really. 'Cause if I was bad, like really suicidal and then I had to wait a month, then something bad could happen in a month. Something can happen in a day but, I just think that's daft that's all. Because you could get worse" (Gareth, 153-155)

For Connie, the lack of continued support had an effect on her ongoing well-being:

"I was doing ok [in CAMHS], but now I feel it's [mental health] going up and down a lot more, following transition... I think I've had a lot more down days, and down months and down weeks um, since going to adults" (Connie, 587-599)

A further emerging theme relating to "In the deep end" was a <u>sense of abandonment</u> apparent when participants spoke about the type of support that they were now receiving from AMHS. This seemed to be in response to the change in treatment ethos. In the following extracts, feelings of abandonment are perceived due to a difference in the regularity of appointments the young people received in AMHS:

"They were just sort of like...'we'll book one in for three or four months'. I couldn't believe it. I was like 'sorry?'... It was like I'd just been dropped off the end of a pier!" (Fran, 390-393)

"It feels a bit more lonelier...But I'm is still getting used to it. 'Cause I'm going from all that support [in CAMHS] to once a month [in AMHS]" (Della, 387-390)

"Now I am left months and months and months. I know like I've got an appointment to see my doctor in January, but I know when I go it's gonna be the same five minutes as it was like 6 months ago... It's just so much stress, and you've got no support if you do relapse" (Connie, 366-369)

Fran also explained how a reduction in the frequency of appointments offered by AMHS meant that some young people could be lost to services:

"If I was having weekly or every other week appointments, then that would mean that there's someone who cares... and who is keeping an eye on you. 'Cause I could just go off, I could have just gone off the radar... And their [AMHS] reaction to that would be to discharge me [laughs]. Not to find out what was wrong" (Fran, 557-562)

Della also highlighted how the contrast in the levels of support provided by AMHS had resulted in her feeling that she has to manage alone:

"Like before you're 18 you're expected not to know how to manage money and how to manage your emotions whereas all of a sudden you have to know these things. And there is nobody to sit there and go 'well we can help you do this, and help you with that' like there was in CAMHS" (Della, 470-473)

This view was echoed by Connie, who alluded to the potential destabilising impact of the level of support offered:

"Like I have no support with adults. It is the worst service. It is horrific... I've always said this; they wonder why the suicide rate is so high for young people... It's stupid... I've gone from an intensive therapy team, like the clue is in the name, to no support whatsoever. Like absolutely nothing" (Connie, 223-226)

"I think there is just such as gap in the services for people with my difficulties. It's just a really bad all round service from start to finish. And they wonder why you see in the press like so many people are struggling and it's just absolutely ridiculous" (Connie, 339-342)

3.5.2 "YOU'RE SUPPOSED TO CARE"

The second subordinate theme "You're supposed to care" illuminates the participants' experience of negotiating new therapeutic relationships with AMHS professionals.

For Ben, Fran and Connie, the transfer from CAMHS to AMHS also represented a change from being seen by a professional with a nursing background (CAMHS) to a Psychiatrist (AMHS). Initially, all three participants appeared to enter AMHS with a <u>desire to build a therapeutic relationship</u>. The following extracts illustrate how they had approached their first appointments with a sense of positivity and motivation to form a relationship with the AMHS professional:

"I'd gone in there [AMHS] all sort of like raring to go and ready to sort of like I did with the nurse [in CAMHS], to sort of ready to build a sort of a new relationship" (Ben, 299-301)

"I stayed in there for the full length of the appointment trying to sort of find some kind of way to work with her" (Ben 368-369)

"I just went into the appointment like, I'll get on with you, animated. You know, like, engaging" (Ben, 524-525)

"I was quite looking forward to my first meeting, so I went in there... I sat down, I was really articulate, I was really friendly, I was like yeah, smiling" (Fran, 387-389)

"I thought there might be sort of like a, like a nurse that would, like I could build up a relationship with and speak to her about how I am and you know, how I'm feeling" (Connie, 485-486)

However, Fran, Ben and Connie experienced negative responses which were defined by a perceived <u>inequality in the therapeutic relationship</u>. Fran appeared to value having a more informal relationship with professionals in CAMHS, where she experienced engaging with professionals on a first-name basis. Within Fran's story, it emerged that an artificial barrier was created between Fran and the AMHS doctor due to their apparent reticence about revealing their name. This barrier appeared to impact on Fran's motivation to engage with the doctor in a genuine way:

"Nearing the end I said 'sorry, what was your name again?'. She was like 'Dr so and so'. I was like, ok, you're supposed to be someone I can talk to, I can't open up about anything to somebody who tells me their name is 'Dr [Surname]'... I'm here to talk about deeply personal issues and I don't even know your name... I just found it really alienating" (Fran 400-422)

"It [AMHS] just makes you feel closed off, I don't feel like I was in a safe place. I don't feel like I'm in a place where I want to confide in anyone at all" (Fran, 450-452)

For Ben, an imbalance in the relationship appeared to have been created in response to not feeling listened to by the Psychiatrist. Ben's use of the metaphor "being shot down" seemed to illustrate how he had felt disparaged by the Psychiatrist during his first appointment:

"After the first sort of 15 minutes talking about my past and my triggers... She [AMHS professional] said 'so, tell me about your life?' I was like 'woah lady, what do you think I was doing?'...And then like having to talk about all those things again and just to sort of be shot down while I was already on the floor" (Ben 329-331)

Furthermore, the use of the following metaphor in Ben's narrative exemplifies the power imbalance that he perceived. Ben described this experience as "debilitating" (Ben, 298) as his attempts to engage with the Psychiatrist in AMHS had been unsuccessful:

"[The] lady [Psychiatrist] comes in with some huge concrete wall, metaphorically speaking, and I was like 'oooh'. All I had was a tiny pick axe" (Ben 302-303)

A sense that the Psychiatrist was disinterested and had little time for Connie was apparent in her narrative describing her first appointment in AMHS:

"[There is] obviously no point in her being there like whatsoever. Like I went to an appointment, it was supposed to be at 11 o'clock. I came out of college for it and I didn't see her till about quarter to twelve. Nobody went into the room, nobody came out. I went in, for like 5 minutes, and she asked me all the same questions she did before, got everything wrong, and she had my notes in front of her as well" (Connie, 237-241)

The experiences described by participants suggested that they felt they had received <u>superficial</u> rather than genuine care.

Within Fran's narrative was the impression that the psychiatrist had been insincere:

"You just think, you're [psychiatrist] not really here for me are you?... And I know they're not and it is a job, but it's a job, you know, in a care role and you're supposed to care. You're supposed to give a damn" (Fran 220-223)

"And suddenly it was just so...made me like the last thing I wanna do is talk about anything real. It was like 'I'm fine', you know. It just really turned me off the idea of wanting to share anything with this person. Just on that, I'd already gotten a bit of a feeling about her... I felt she was very distant" (Fran, 427-431)

Similarly, Ben felt that the care he received in AMHS had been impersonal:

"She was just really disrespectful and didn't sort of want anything to do with me, I guess" (Ben, 351-352)

"After me explaining my life, and telling her why I was in CAMHS and stuff and my bad habits and she was like, ah 'why are you here?" (Ben, 375-376)

Connie described how appointments she had attended in AMHS had been rushed, leaving her to feel that the doctor had not been interested in her:

"I don't feel I was seen. I met a doctor. [The doctor] went over all the stuff which is already in my notes, which she had in front of her. [I] saw her a second time. She [the doctor] wasn't interested and got everything wrong, [I saw the doctor] for five minutes. She made me wait for half hour. It was a waste of time" (Connie, 463-466)

3.5.3 "I FEEL LIKE AN ADULT"

The third subordinate theme emerging from the data encapsulates some participant's reflections on the apparent shift from being a child to being an adult. "I feel like an adult" illuminates the personal

changes that co-occurred with moving to AMHS. Such changes include making decisions for themselves and feeling that they were becoming more independent.

For some, the personal changes that occurred came as a result of being seen in AMHS. For example, Gareth and Emma described how being treated like an adult in AMHS had lead them to feel "like an adult" (Emma, 239):

"I felt like an adult then [in CAMHS] but I probably feel more of an adult now. I'm taking my problems on seriously now which is different, so I don't, I don't really know how to explain it" (Emma 239-240)

"I like being treated like an adult anyway. It works out good for me, maybe others would say they don't feel too much like an adult, but I did when I seen the adult [services]" (Gareth, 386-387)

Some participants described how professionals in AMHS now viewed them as adults and as a result they were having to <u>adjust to new ways of being</u>, such as being involved in decision making. Gareth described how he was now able to make decisions about whether he wanted to take medication:

"Well in the adult service, it's like tablets ain't being thrown at me. Well, they [tablets] are but they're not as much as they would down there [CAMHS]... But then in adult services, they're sort of talking to me first before making any sort of [decision], anything given to me like" (Gareth, 356-357)

Anna also described how in AMHS she is able to make decisions about whether she takes medication and what she wants discuss, this is in contrast to CAMHS where she had sometimes felt pressured:

"In adult they don't ask you too much...They don't put pressure on you to talk too much, or give you medication. If I want to take [medication] we talk about it and it's up to me. And I know I have to take it because this is for me, it's important for my health and my life" (Anna, 92-94)

When asked if being seen in AMHS had impacted on participant's sense of self, some participants described how there had been a shift to take on <u>increased responsibility</u> for their recovery, for example, taking medication and engaging in therapy:

"I've gotta go off my own back to get them [medication]. Which I think is better anyway, 'cause it's not like I'm being forced to. All I gotta do is pick the phone up and I can ring them [AMHS] to talk about it" (Gareth, 221-223)

"I just goes on my own now, so if I feel like I wanna say something I feel like I can say a bit more like, and if I don't wanna say anything then I don't, it's my choice" (Gareth, 184-185)

"I've gotta sort of sort things out myself now, not rely on everyone else now" (Gareth, 283-284

For Anna, having a choice about whether to share her feelings with others also defined an increased responsibility for her own recovery and sense of independence:

"Because I can talk about my life when I want, and when somebody doesn't ask you too much you feel like you are independent, it's your life, you can have that choice" (Anna, 281-282)

For Della, being in AMHS and being encouraged to do things for herself led to a change in selfidentity. The following view of herself is in contrast to how she had felt upon leaving CAMHS, where she had felt resistant to take responsibility for her own care:

"I feel like I have to manage a lot more on my own which is true, and I am managing, because I am now 18 and an adult." (Della, 388-389)

"[CAMHS] did a lot for you. In AMHS, because you're expected to be an adult and manage yourself, you kind of have to do some things for yourself and I'm doing it. Like the breathing exercises that they give you, you've gotta do that in your own time. It's like homework that I do." (Della, 479-481).

Emma explained how in CAMHS she had felt that her problems had been less significant. However, upon meeting with the psychiatrist in AMHS she reported being told to "man up" (Emma, 382). Emma appeared to value a more direct approach, which led her to accept and better understand her difficulties:

"I never took it [mental health] seriously. But he [AMHS professional] would always look at me and go 'it's not funny, what you're going through is serious and you need to actually sit down and accept that fact you're an adult now and deal with these things... You need to grow up a bit and just accept them [mental health difficulties] and let me teach you how to deal with it'... It was a bit of a shock, no one has ever been that blunt to me before. But I think it was kind of the kick that I needed, to just kind of get on.... And to get better" (Emma, 250-259)

Some participants described how the lack of input from AMHS had been a facilitative factor in their journey to independence. For example, Fran described how, due to a lack of regular support from AMHS, she had been forced to find her own way of coping:

"Had I been having regular meetings with adult [services] I'm sure I could have got there faster. I could have been able to open up and discuss things a lot sooner. But as it turns out I've just had to let, you know... do it for myself" (Fran, 621-624)

Furthermore, Ben described feeling independent prior to entering AMHS, and therefore did not feel that being seen in AMHS had led him to experience a change in his level of independence and responsibility for his own care:

"Generally speaking from being 16 in high school to now, has all been sort of very independent. And I control everything and I sort of make my own appointments and I talk to people myself... 'Cause I'm one of those people like, if you want something done properly you gotta do it yourself" (Ben, 492-496)

Gareth also reflected that whilst AMHS had been a factor in taking on more responsibility for himself, a shift to increased responsibility had also been a result of changes in his personal life:

"Well I've got kids now, I've got my partner as well, I'm not living on my own. I can't just keep being the way I am so I have to sort of sort myself out like" (Gareth, 172-173)

3.6 SUPERORDINATE THEME FOUR: BRIDGING THE GAP

The final superordinate theme **BRIDGING THE GAP** captures participant's reflections on the support that they received from the TS. All of the participants reflected on how the involvement from the TS had been offered to them in order to assist with the transition from CAMHS to AMHS. When asked to reflect upon the experience of the support that received from the TS, Connie reflected on the importance and value of having additional support at the time of transition:

"I understand that it's a really really difficult thing to transition between services...'Cause it's not like a broken leg, you can't just put it in a plaster cast and it'll be fine in 6 weeks. It's a lot more than that, you need to have more support" (Connie, 546-548)

Participants described key aspects of the TS that were valued, these included "having someone there" throughout the process, for example, having involvement from the TS support worker whilst still attending CAMHS and having the support of the TS support worker at initial AMHS appointments; working collaboratively with a TS support worker to enable the young people to develop a support plan and begin "taking hold of your own care"; and in attending social support groups held by the TS where the participants described how they and other young people are "all in it together".

3.6.1 "HAVING SOMEONE THERE"

Several participants emphasised their reliance on the TS for enabling them to manage the transition on both an emotional and practical level. It appeared that the existence of the TS support enabled the young people to feel safe during a period of uncertainty. Many of the young people talked about how they felt reassured knowing that someone from the TS would remain involved during the transition, and would be monitoring them:

"Someone was keeping an eye... Knowing that I could call on them. And knowing that there was the option of that" (Fran 821)

"Having someone there, since going to adults is what I needed, and it's good to have someone there" (Connie, 678-679)

"Yeah first time I ever met [with] the adult [services] I was with [TS support worker]. And when she seen me crying she said 'don't worry I will come with you to your first appointment...Don't worry if you are not comfortable, I will come if you want'... It's so nice to have somebody there to take care of you" (Anna, 369-372)

"I knew I would be able to have someone to check in on me before I see adult mental health. And I had that one to one meeting every, it was every week when I first went there, yeah. It was every week" (Ben 612-613)

A salient theme that emerged from several of the participants accounts was the <u>need to be held and contained</u> in order to feel safe and certain throughout the transition process. This is understandable given the uncertainty and confusion around the process of transition, highlighted earlier in the interviews.

"I needed somebody to keep myself grounded, instead of floating in all these services" (Ben 617-619)

Having involvement from a TS support worker meant that for the young people there would be an element of continuity during change. Ben reflected how he and the CAMHS nurse had felt the involvement of the TS had brought about a sense of comfort to them both when considering the support that he might need during the move:

"I was like, the situation with CAMHS is gonna end and I needed somewhere to go from there. I think we both felt comfortable that I was going to be with Transition Service and see where it went with adult mental health" (Ben 262-264)

For many participants it also appeared that an important function of the TS support was to fill the void that existed during the time between leaving CAMHS and entering AMHS. For example, Della and Connie reflected on how the TS had been the only source of support during the move:

"I found that during that period of time they [TS] were the only people that were there" (Della, 164-165)

"[TS support worker] got me through it and I'm grateful for [TS support worker]. 'Cause if I didn't have her then I wouldn't have anyone" (Della, 577-578)

"I've really been struggling recently with food and the thoughts and everything. And there is just nothing there for me [in AMHS], absolutely nothing...like the Transition Service is like the closest work I've had since [leaving CAMHS]" (Connie 364-367)

"I think it really is a brilliant service and it just feels like you've got some support there when everything else has gone" (Connie, 612-613)

Furthermore, Emma explained how having someone there has been instrumental in making her transition experience positive:

"I think it made a difference, definitely it was more positive. I feel like if I didn't have that [support] there it would have been a much worse transition to adult services...I wouldn't have had someone... Not a back-up but someone just there for me while this other person [AMHS professional] was waiting to see me" (Emma, 361-365)

Fran also reflected that despite feeling that she may not have necessarily needed additional support to transition from child to adult mental health services, having support from the TS lead her to experience the transition as less disruptive:

"I could have managed it [the transition] without [the TS], but it made it a lot easier with. You know, and it made it a lot sort of, everything, yeah, everything a bit less of a big deal" (Fran 770-772)

A further theme that emerged relating to "Having someone there" is the <u>positive relationships</u> that young people had built with the TS support workers. Many of the participants commented favourably on the relationship between them and the transition support worker. Participants became animated when describing their TS support worker:

"I built a relationship with the woman [TS support worker]. She was so lovely and kind and helpful, it was so good to have someone else to talk to" (Anna, 398-399)

"They were amazing, honestly, I'm not just saying that. I honestly like, I loved my support worker" (Emma, 322-323)

Della explained how having similarities with the support worker fostered a positive relationship:

"[TS support worker] was confident and talkative, so then I felt more confident and more talkative and um, we began to know each other a bit more, and it helps when we have lots of stuff in common as well" (Della, 504-507)

Moreover, Fran explained how the relationship with the transition support worker had been markedly different from relationships with professionals. Fran appeared to value being validated by the TS support worker:

"And the person I worked with [TS support worker], I gained a lot more talking to her than I did the [AMHS] psychiatrist, because she's just a normal person. And she wasn't patronising me. We were just discussing things and she was simply just using human empathy" (Fran 696-700)

"She [TS support worker] was really interested in helping me, and interested in helping me to improve my situation, or whatever it was you know...It was a person who actually gave a crap. Again, sounds quite brash, but you know, someone who actually cares and I think that's half the battle won then really" (Fran 721-725)

3.6.2 "TAKING HOLD OF YOUR OWN CARE"

The subordinate theme "**Taking hold of your own care**" encapsulates the participant's reflections on the how the TS encouraged and supported them to be involved in making decisions about the support they received. This led many of the young people to feel that they were empowered to take hold of their own care and were <u>developing a sense of agency.</u>

"They [TS support worker] kind of let you slowly get used to taking hold of your own care... They did a really good job of that in the [TS]. 'Let's help you. I'll aid you in any way you need but I'm not going to tell you to do anything', you know" (Fran, 850)

"It was really good that they [TS support worker] said 'what can we give you? What can we help you with?' Not, 'you need to do this', it was like 'how can we help?... I don't feel pressured at all, I feel like I can ask for help, not be told I need help" (Fran 786-801)

"Making my own decisions [about support] is a lot better, its given the onus more on me" (Connie, 642)

"[TS support worker] asked us [social group] 'what kind of activities do you want to do?' and 'what do you like?'. They gave us a choice, like for example 'do you want this, do you want that or do you wanna go out?'. It was good because I chose to do something with my life and I feel excited and I enjoy it" (Anna, 353-356)

Working in collaboration with someone appeared to be a novel experience for many of the participants. This was in contrast to feeling both powerless in CAMHS and needing to be autonomous in AMHS. For example, Della's expectation was that the TS would become another layer in the system that would make decisions for her:

"My expectation was like 'ah great, more people who are going to like moan and bitch about how I should live my life'. But it was a complete [change]. It was more about my own choices and about what I want to do" (Della, 547-549)

Having choice about how what support and help Della would need had been a new experience for her:

"It was a bit strange and exciting knowing that I was involved in something new [making decisions] for me I guess" (Della, 533)

The concept of a <u>lack of pressure</u> from the TS was evident in all participant's accounts, which may have signified a contrast from the perceived pressures from AMHS:

"I don't feel pressured at all. I feel like I can ask for help, not be told that I need help. Treating you like a grown up, an adult. You know, adult services treat you like an adult in the sense of 'meh, whatever'. Whereas they [TS] treated you in the sense of 'we care and we wanna help but we want to give, you know, we are not gonna tell you what to do" (Fran, 798-802)

"I was involved...they gave me the sort of outline of what they do by protocol...They said you can either go straight into like group work if you can't do all of that. Or you can do a one to one with one of our mentors and stuff like that. There was no pressure to do anything" (Ben 584-588)

"I don't feel like I'm pressured into anything, nothing at all really" (Gareth, 313-314)

"You have to do and say what you want, no one puts pressure on you" (Anna, 417-418)

Furthermore, Fran and Gareth valued having paced and individualised support, which had been in contrast to how they had felt supported by mental health services:

"You know, treating you as a mature human being who has their own mind and their own decisions to make and you know, I did feel that they [TS service] were very good like that...[The TS were] not patronising, being fully supportive but at my pace and as I wanted it. Not sort of, there was nothing pushing" (Fran, 802-808)

"I think things have been taken slow, not everything just thrown at me like that...[not] having to just answer loads of questions like in adults [services]" (Gareth 317-321)

Chapter Three: Results

3.6.3 "ALL IN IT TOGETHER"

The final aspect of the TS valued by many participants was social support, highlighted in the subordinate theme "All in it together". The opportunity to meet with other young people was shared by many as positive and one in which the young people felt a sense of <u>belonging</u>. The importance for the participants to feel a connection with others who had similar experiences to them clearly emerged from the data.

For Fran, the peer groups that she had been involved in as part of the TS were felt, at times, to be more valued than the therapeutic interventions, such as art therapy, also offered by the TS:

"...the most important part of it [TS] is not about the art therapy, it's about the comradery. It's about the support group. It's about the network that you can broaden" (Fran 711-712)

Similarly, for Anna, building friendships with other young people in the TS has been very important and an aspect that is absent from support offered by AMHS. Anna described how having peer support had enabled her to develop a new sense of confidence:

"When I am at adult [services], they just talk to me. They didn't provide me with people. And with [TS] I have social group and friends, more people to see and more people to talk to" (Anna, 412-413)

"Having their [peers] support. Step by step it's building my confidence. All of them help me to build my confidence" (Anna, 402-404)

Many participants described how they felt validated by having other young people around them who were going through similar experiences. The participants' narratives conveyed a sense of relatedness, which also led them to feel less isolated:

"It was nice, it was like again, it's that comradery...That sort of all in it together" (Fran, 758)

"We can do this [transition], I'm not the only person going through this...You know, there's so many of us!" (Fran 773-774)

"I do feel a lot better knowing that there's adults that suffer with the same thing [mental health difficulties]" (Della, 466)

"It was just really good to meet other people... You don't know much about them but you know that they're going through stuff. You know they're in transitions for a reason...They [peers] are someone who is gonna understand everything that you are going through" (Emma, 341-347)

Finally, for Ben, the social support that he received through the TS was markedly different from other support that he had in other areas of his life. Belonging to a group of young people who also had mental health difficulties was experienced as therapeutic, evident in his account below:

"Just being around like-minded people I guess. 'Cause none of my friends like outside, like my friends from college, they didn't really, they weren't on my level... And it was really just nice to be around people who sort of have similar experience. Some [have] not so similar experiences... I suppose it's sort of cathartic really, being around people who understand" (Ben 631-635)

3.7 SUMMARY OF RESULTS:

The overall aim of this study was to explore young peoples' experiences of the transition from CAMHS to AMHS with support from a TS. The semi-structured interviews elicited rich, in-depth data and IPA was utilised to make sense of participants' narratives. Four superordinate themes were derived from the data analysis:

- Being a young person with mental health difficulties
- The process and immediate impact of change
- Life after CAMHS
- Bridging the gap

The first three superordinate themes focused on the young peoples' experiences of being a young person in receipt of CAMHS support, the process of transition from CAMHS to AMHS and the experience of ongoing support received from AMHS. The final superordinate theme encapsulated the participants' experiences of having support from the TS and included key aspects of the TS that young people valued. Each of the superordinate themes consisted of further subordinate and emerging themes.

In summary, it appeared that for the young people in this study the process of transition from CAMHS to AMHS was often confusing and uncertain, which was compounded by their own sense of readiness to become an adult. Many participants experienced unanticipated changes in the level of support that they received in AMHS which were in contrast to the level of support that they had received in CAMHS. This resulted in some participants feeling that they had been let down by services. Further differences between CAMHS and AMHS were highlighted throughout the participants' narratives and included feelings related to changes in the physical environment and relationships with professionals.

For all participants, the TS was integral to ensuring that there was continuity in the transition process. It appeared that having the TS support afforded them the opportunity to become empowered to develop a sense of agency. Moreover, participants highlighted the value of being integrated into a peer group with the support of the TS.

These results will be discussed in more detail and in relation to existing literature and theory in Chapter Four.

4. DISCUSSION

4.1 OVERVIEW OF CHAPTER

This chapter contains a summary of findings and a discussion of these in relation to the relevant existing literature and theoretical perspectives. Potential service and clinical implications of the results will be outlined, followed by a discussion of the methodological strengths and limitations of this study. Finally, ideas and recommendations for future research will be discussed.

4.2 Interpretation of Results

The main aims of this research were to explore the experiences of young people who had transitioned from CAMHS to AMHS and to explore the experience of being supported through the transition process by a Transition Service (TS). Four superordinate themes emerged from the data analysis: BEING A YOUNG PERSON WITH MENTAL HEALTH DIFFICULTIES; THE PROCESS AND IMMEDIATE IMPACT OF CHANGE; LIFE AFTER CAMHS; and BRIDGING THE GAP. Each superordinate theme and the subordinate themes contained within them will be discussed in relation to existing literature. In line with the presentation of themes in Chapter Three, superordinate themes discussed here will appear in BOLD CAPITAL and subordinate themes will appear in bold lowercase.

IPA and other qualitative approaches often lead to new and unexpected themes that emerge during interviews and analysis (Smith *et al.*, 2009); thus some of the literature introduced below will be new to the reader. As highlighted in Chapter One, the literature base regarding young peoples' perspectives of the transition from CAMHS to AMHS is limited in its application to understanding transition from a theoretical viewpoint, therefore there will be an exploration into the extent to which the findings fit with the transition theory proposed by Meleis *et al.*, (2000).

4.2.1 SUPERORDINATE THEME 1: BEING A YOUNG PERSON WITH MENTAL HEALTH PROBLEMS

The first superordinate theme **BEING A YOUNG PERSON WITH MENTAL HEALTH DIFFICULTIES** captured the participants' experiences of living with mental health difficulties, and of receiving support from CAMHS.

Some participants in this study expressed that they had felt stigmatised by others for having mental health difficulties. Furthermore, these participants appeared to apply a negative stereotype to themselves, which was captured in the theme "You're mental". The effects of stigma of mental health are known to negatively affect individuals and can result in intense feelings of shame, social exclusion and low self-esteem (Gale, 2007). Calear and colleagues (2011) reported that young people's perceived stigma from others was worse than personal stigma which they bestowed upon themselves. Indeed, experiencing stigma from others led some participants in this study to feel shame and conceal aspects of themselves from their family, peers and CAMHS professionals. Research has shown that acquiring a label associated with having a mental health difficulty can be viewed as having negative connotations (Pinto-Foltz *et al.*, 2011; Elkington *et al.*, 2013); thus potentially explaining why young people in this study had initially been reluctant to reveal their difficulties to others.

As developmental theories posit, a key task in the transition from adolescence to adulthood is the formation of a sense of self or identity (Erikson, 1980; Arnett, 2000). In line with Arnett's (2000) theory of emerging adulthood, Schwartz and colleagues (2013) suggest that developing a sense of identity is more challenging to navigate due to a prolonged transition to adulthood. Furthermore, membership of CAMHS or AMHS, whether perceived as positive or negative may influence a young person's developing identity. Research has shown that experiencing stigma, and the internalisation of stigma may lead to the formation of a 'spoiled identity' (Goldman, 1963, cited in Gale, 2007). Having a spoiled identity or negative view of self may, in turn, have implications for young people and their ongoing engagement with adult mental health services, as perceived stigma is highlighted as one barrier to young people seeking help (Gulliver *et al.*, 2010; Young Minds, 2012).

Interestingly, the experience of being seen and supported by CAMHS appeared to outweigh the young people's concerns regarding stigmatisation from others. Many young people within the current study expressed relief in receiving a diagnosis, which led them to feel validated in regards to having a mental health difficulty and appeared to encourage them to continue to access help. Participants described CAMHS as a safe and nurturing environment where they felt "**OK to not be OK**" which was in contrast to how they reported they were presenting in other areas of their lives. For some participants, feeling safe and validated in CAMHS had also come as a consequence of a positive therapeutic relationship with the CAMHS professional. These findings are consistent with earlier research by Lindgren and colleagues (2014) who found that young people feel safe and secure in CAMHS due to close caring relationships.

The subordinate theme "What about what I want?" captured participants' experiences feelings of powerlessness in relation to the treatment received in CAMHS. Many participants expressed feeling disempowered due to a lack of involvement in decision making regarding their care. As a result, some of the participants in this study appeared to acquiesce with treatment, which posed a threat to their developing autonomy and independence. Many young people described accepting medication despite voicing that they had a desire to change, or indeed, did not want to be placed on medication. These findings support earlier research by Coyne and colleagues (2015) who found that many adolescents seen in CAMHS report limited involvement in care decisions despite requesting inclusion in decision making. Having choices and engaging in shared decisions is important to individuals using mental health services and has been found to improve engagement with services and aiding recovery (Coyne et al., 2015; Laugharne & Preibe, 2006). Current guidelines, such as those developed by NICE (2016) recommend that person-centred approaches should be used to ensure that young people are supported to make decisions about their own care. Being empowered to make decisions in CAMHS may provide young people with the opportunity to develop autonomy and independence which in turn, may prepare young people for the change in treatment approach when they move to AMHS (Dimitropolous et al., 2015).

4.2.2 SUPERORDINATE THEME 2: THE PROCESS AND IMMEDIATE IMPACT OF CHANGE

The superordinate theme **THE PROCESS AND IMMEDIATE IMPACT OF CHANGE** describes participants' experiences and feelings about the process and timing of transition. This theme captured participants' reflections of the time leading up to the end of their involvement with CAMHS and beginning to transition to AMHS. The prospect of transition from CAMHS to AMHS was associated with feelings of fear and anxiety for most participants. This was captured in the subordinate theme "**You don't know how it is"**. Several factors appeared to contribute to anxieties about the transition. These included a lack of knowledge of what AMHS would be like and what support the young person would receive, indeed, some participants simply did not know what to expect in AMHS. Similar findings are acknowledged in studies conducted by Hovish and colleagues (2012), Lindgren and colleagues (2014), and Swift and colleagues (2013), where an absence of information and formal transition planning led young people to feel uncertain and confused about the ongoing transfer of care to adult services.

Being prepared and having knowledge, which includes a need to be involved and informed in transition planning, are highlighted as facilitative factors for a healthy transition, outlined in Meleis and colleague's (2000) transition theory. Within this study, participants who reported an absence of

adequate information or transition planning described a more negative experience of transition. This is consistent with findings from studies of young people's perspectives of transitional care in physical health and mental health (Dimitropolous *et al.*, 2015; Hovish *et al.*, 2012; Shaw *et al.*, 2004). The findings are also in line with the recommendations from policies and guidelines on transition (e.g. DoH 2008; NICE, 2016) which emphasise the importance of a planned and co-ordinated transition process.

Having at least one transition planning meeting has been identified as a component of 'optimal transition' (Hovish *et al.*, 2012; Singh *et al.*, 2010). For some participants in this study, meeting with a professional from AMHS was part of the preparation process and in some part, relieved some of the anxieties that the young person was experiencing. However, these meetings were not always appropriately planned. For example, one participant said that they had not been informed that a professional from AMHS would be present at their CAMHS appointment. Moreover, the AMHS professional that a young person met was not always the person they would be seeing in AMHS, which caused participants to feel uneasy about the ongoing transfer.

This study reflected that young people's appraisal of the transition prior to transfer to adult services serves to both help and hinder them in managing the process. An individual's appraisal of a transition has been found crucial in determining how an individual will proceed with a transition (Meleis *et al.*, 2000). Participants in this study appraised the transition to AMHS in varied ways. In their reflections on leaving CAMHS, some participants viewed the transition as stressful which led to a resistance in moving on to AMHS despite ongoing needs. Conversely, some participants described how negative experiences of CAMHS fostered a sense of hope and optimism for what could be offered in AMHS, which resulted in a positive appraisal of the impending transition. Preconceptions about what AMHS would be like contributed to the young person's outlook of transition to AMHS. For many, these preconceptions were generally negative, and were influenced by information that they had received from professionals in CAMHS. In response, some participants seemed to become increasing disinclined to feel ready and willing to move to AMHS. These findings are consistent with literature outlined in Chapter One which indicates that due to poor communication between services, CAMHS professionals often have misconceptions about what AMHS can offer (Singh *et al.*, 2010).

Participants reported that age-based criteria were used to determine the timing of transition, particularly upon turning 18, when the young person would need to take a more autonomous role in their care. This resulted in some participant's feeling pressured to meet expectations of others (and

themselves) regarding tasks that they should have mastered at the point of transition, illustrated in the theme "they think something magic happens". The transition theory proposed by Meleis and colleagues (2000) highlights the importance of the individual's meaning of transition. The socially constructed view of adulthood, that is, achieving a level of autonomy and independence on reaching the age of 18, may have influenced the participants' views that they had to achieve a level of independence in terms of their functioning. Some participants reflected that they had not felt ready to transition to adult services as they had not achieved a level of independence, such as being able to manage their emotions. The results showed that some participants are therefore approaching adulthood with ambivalence, grounded in a personal sense of maturity and self-confidence. Such findings are concurrent with Arnett's (2000) theory of emerging adulthood which suggests that the period of transition to adulthood is prolonged for many young people. The readiness to transfer to AMHS was therefore compounded by the expectation that young people had achieved a level of maturity commensurate with taking responsibility for their own care when they reached the age of 18. This led some participants to adopt a stance of resistance, and a lack of desire to embrace change.

Several participants reflected that they had felt "tossed out on my own" upon leaving CAMHS, particularly when transition was experienced as abrupt. This appeared to lead participants to feel rejected and abandoned by services, and essentially become forced to continue to manage their own care needs independently. The need for more flexibility in the criteria for ending support with CAMHS and accessing AMHS (such as that based upon age) was highlighted by participants. The experiences of participants in this study are in contrast to the approaches delineated within government policies and guidelines (e.g. DoH 2014; WAG, 2005a) which advocate that the transition from child to adult services should be viewed as a flexible process, determined by individual need rather than age. These findings are also present in previous literature reviewed in Chapter One (e.g. Burnham Riosa *et al.*, 2015; Lindgren *et al.*, 2014)

4.2.3 SUPERORDINATE THEME 3: LIFE AFTER CAMHS

The third superordinate theme **LIFE AFTER CAMHS** offers a framework for understanding how participants experienced the differences between CAMHS and AMHS. The accounts of participants indicated that there were a number of factors that presented a barrier to their involvement with, and increased the risk of disengagement from AMHS.

Many of the participants in this study drew comparisons on the level and type of support received from CAMHS to the level of support that they were now receiving in AMHS. Many participants were

both surprised and disappointed with contrasts in the service culture and environmental context between CAMHS and AMHS. Such contrasts led many participants to feel that they had been thrown "In the deep end". A salient theme that emerged from participants' accounts was the discomfort that they experienced in relation to the physical setting of AMHS. Participants commented on the physical surroundings as dark, gloomy and shady, which exemplified their reluctance to return to AMHS settings. Similar findings have been reported in the literature. Buston (2002) explored young people's views and experiences of mental health services and found that young people viewed adult mental health settings as clinical and dirty, leaving them feeling dissatisfied with the services they received. Similarly, Lindgren and colleagues (2015) found that young people's experience of a homelier physical environment in CAMHS led young people feeling supported, whereas a more clinical setting with a lack of stimuli in AMHS led young people to feel uncomfortable and dehumanised. The findings from this study and earlier research suggest that the impact of the physical environment appears be important to young people and influences their willingness to engage with adult services.

Furthermore, a shift in the provision of regular appointments from CAMHS to less frequent appointments offered in AMHS appeared to lead to a disruption in care, and was experienced by participants as a negative aspect of their transition. For many participants, the lack of regular support led to feelings of abandonment and was regarded by many participants as a risk factor for deterioration in their mental health. These findings concur with participants' accounts in Hovish and colleagues (2012) study, which found that a disruption in care between CAMHS and AMHS negatively impacted on young people's well-being. Such findings demonstrate the potential need for additional support for individuals during the transition process, in order to enable them to seek support and manage their ongoing recovery.

Within this study, the interpersonal characteristics of professionals in AMHS and their practices and attitudes were key issues reported by some participants as more important than other service aspects. The importance placed upon establishing a therapeutic relationship with professionals at AMHS was highlighted by participants as a factor in the success of the transition to adult services and is illustrated in the subordinate theme "You're supposed to care". Literature suggests that professionals' personal qualities, attributes or traits may facilitate the development of a positive therapeutic relationship (Ackerman & Hilsenroth, 2003) which in turn, is linked to the maintenance of engagement with services. Indeed, 'feeling connected' and 'interacting' are indicators of a 'healthy transition' in Meleis and colleagues' (2000) theory of transition. One threat identified with the formation of relationships with AMHS professionals was the absence of a developmentally

sensitive approach. Within the literature, professionals' qualities such as being rigid, tense, aloof and distracted have been suggested as barriers to developing a therapeutic alliance (Davies *et al.*, 2009). Some participants highlighted that the AMHS professionals had not been sensitive to their motivation to build a therapeutic relationship. In particular, one participant commented that the formal manner of the mental health professional in AMHS had been an influential factor in disengagement from services. The findings from this study mirror those found in Buston's (2000) study exploring young people's experiences of mental health services, which concluded that a formal manner introduced a barrier to developing a meaningful relationship with clinicians.

The perception held by some participants that some AMHS professionals focused on finishing paperwork and carrying out routine clinic activities, rather than on the individual needs of young people were reported as significant sources of frustration and dissatisfaction with AMHS, particularly by two participants who described feeling let down. These experiences resulted in the young people feeling that they had received superficial rather than genuine care. In response, young people did not feel that they had been heard and that professionals were disinterested in them and subsequently contributed to their disengagement with AMHS. These findings support the evidence which highlights the importance of building a positive therapeutic alliance with mental health professionals in order to maintain future engagement with mental health services (Ackerman & Hilsenroth, 2003; Buston, 2002).

The accounts of participants in this study demonstrated a number of personal factors that facilitated the move to independence and taking on more responsibility for their care when they reached AMHS. This was illustrated in the subordinate theme "I feel like an adult". Participants' experiences of AMHS seemed to be influenced by their fluctuating identify formation (Arnett, 2007). For instance, it may be inferred that feeling like an adult prior to transition may have led some participants to feeling misplaced in CAMHS, this in turn resulted in feeling ready to receive care in an adult orientated system prior to discharge from CAMHS. These findings are supported by research by Harper and colleagues (2014) who found that some young people aged 16-18 felt that they no longer 'fit' the culture of care in CAMHS and had a desire to take on more responsibility for their care, in line with their increased maturity.

Specifically, participants in the current study identified the importance of being involved in decision making in AMHS, often regarding medication. In line with previous research, some participants in this study valued the opportunity to have increased control over decisions about their treatment (Dimitropolous *et al.*, 2015), which consequently led them to "...feel like an adult". For the young

people in the current study, there appeared to be a need to change their definition on themselves in line with the service context. Furthermore, participant's appeared to need to consider themselves as adults in order to achieve mastery of the skills associated with becoming an adult, such as increased autonomy (Levinson, 1987). This is in line with Meleis and colleagues (2000) transition theory which postulates that transitions denote a change in identity. However, some participants appeared to struggle with the expectation that they should assume a more autonomous role in treatment and had initially wished others to retain responsibility for decision making. It may be that some participants had achieved developmental maturity to cope with these changes, while others did not. Interestingly, those participants who had initially been resistant to taking on roles and responsibilities associated with being an adult commented on how they had begun to take on such roles by the time they were attending AMHS. Achieving mastery therefore appeared to influence whether the young person had become 'situated' in the 'adult world' (Meleis et al., 2000). This fits with a recommendation that a gradual transition to adult-orientated approaches may be required for young people who have an ambivalent relationship with the concept of being an adult, or delayed development in other domains (Arcelus et al., 2008). In line with developmental theories, a balance between autonomy and direction has been reported as the most successful approach to supporting young people as they enter adulthood and adult services, which maintains the young persons need for guidance and control (Baltes & Silverberg. 1994; Reid et al., 2008).

4.2.4 SUPERORDINATE THEME 4: BRIDGING THE GAP

A number of key aspects of the TS that were valued were highlighted throughout participants' narratives. Many participants agreed that there was a need for additional support to negotiate the move between CAMHS and AMHS. This finding is consistent with participants' accounts in previous research. For example, Lindgren and colleagues (2015) found that participants in their study had highlighted that they needed additional support from services to address their ongoing mental health needs during the move and to increase motivation to continue to engage with services. Arguably, these findings indicate that a shift to independence necessitates dependence on other individuals and services. Participants in the current study described the importance of the TS in "having someone there" to provide stability and continuity during the move between CAMHS and AMHS. It appeared that some participants were seeking safety during the transition process. This finding may be understood in terms of attachment theory, which highlights that in response to threat or distress, individuals seek out attachment figures (Bowlby, 1969). Furthermore, attachment theory highlights the importance of a sense of safety and security as fundamental to a person's ability to explore the world and develop a sense of identity (Bowlby, 1969). For some participants

this was portrayed in their reliance on proximity to the TS support worker. This mirrors previous findings of the tension between continued dependence on others and a desire for independence during this stage of development (Arnett, 2007; Lindgren *et al.*, 2014).

Participants also placed importance on the relationship that they had built with the TS support worker. Specifically, participants reported that working collaboratively with the TS support worker enabled them to develop confidence, empowering them to take responsibility and feel that they were "taking hold of your own care". Indeed, working collaboratively had been a novel experience for several participants. Furthermore, being treated as a 'normal human being' was discussed by the participants as a factor which influenced their engagement with the TS. This appeared to be in contrast to how some people had felt treated by professionals in AMHS. These findings support literature which highlights the importance of young people being treated empathically and respectfully (Burham Risoa et al., 2015) and being viewed as competent in making decisions for themselves (Lindgren et al., 2015). Participants also highlighted that they had not felt pressured by the TS service to meet any expectations; rather the young people were encouraged to develop a sense of agency. It appeared that the relationships built with the TS support workers were conducive to promoting autonomy and fostered well-being in the participants in this study. It may be inferred that the TS support workers were more attuned to the developmental needs of the specific population that they support, as they typically work with those between the ages of 16-25, whereas AMHS professionals adopt a more autonomous view of individuals, as they work with people aged 18-65. The findings from this study mirror the guidance set out by DoH (2011) and NICE (2016) which advocate that transition support should be responsive to, and reflect the preferences and priorities of the young person. Indeed, it may be that as the TS sits outside of statutory services, they are more able to be flexible in accommodating the young persons' wants and needs. These findings also exemplify the tension found within statutory mental health services between providing flexible and person-centred services within the confines of having rigid boundaries regarding age of transfer (Singh et al., 2010).

Participants also emphasised how social peer groups facilitated by the TS were a particularly important and positive aspect of the service that they received. The theme "All in it together" captured participant's feelings of connectedness and belonging to a group who also have mental health difficulties, which in turn, led them to feel more confident and less isolated. These findings are consistent with previous research highlighting that peer support led to a positive experience of transition between inpatient services (Wheatley *et al.*, 2013). Furthermore, these findings are consistent with the literature which claims that peer support promotes hope and belief in the

possibility of recovery, empowerment, increased self-esteem and less self-stigmatisation (Repper & Carter, 2010; Repper, 2013). Additionally, in a review of the existing evidence of peer support among individuals with severe mental illness, Davidson and colleagues (1999) found that peer support groups may improve symptoms, promote larger social networks, and enhance quality of life. Peer support has also been found to be influential in the development of a positive sense of identity (Repper, 2013). According to Davidson and Strauss (1992), if youth with mental health issues do not find positive images that depict their situation or receive encouraging feedback from their peer groups, building or rebuilding a healthy sense of self can become an onerous task. These findings reflect the importance of peer support in the transition process to enable young people to feel 'situated' and develop a positive sense of self.

Overall, it appeared that the services provided by the TS facilitated a balance between independent, self-confident action and positive relationships with others, particularly at a time when many participants felt ambivalence towards assuming an adult role. These factors appeared to be optimal for the young person's psychosocial adjustment and development towards becoming an adult, and assisted some participants to engage with adult mental health services.

4.3 IMPLICATIONS OF THE FINDINGS

The results of this study provide insight into the experiences of young people who transitioned from CAMHS to AMHS with support from the TS. The findings indicated a number of implications for clinical practice and for the role of professionals in supporting young people who are moving from CAMHS to AMHS. Firstly, theoretical implications will be explored.

4.3.1 THEORETICAL IMPLICATIONS

As far as the researcher is aware, the application of transition theory proposed by Meleis and colleagues (2000) has not previously been used to inform the understanding of young peoples' experiences of transition between child and adult mental health services. A number of themes that emerged from the findings appear to fit well with the transition theory proposed by Meleis and colleagues (2000). The model is described in Chapter One, but in brief, Meleis and colleagues propose that there are a number of conditions that facilitate or hinder transition processes towards a healthy outcome. Such conditions can be personal, such as meaning, attitudes, preparation and knowledge about the forthcoming changes (Im, 2010; Meleis *et al.*, 2000). Community and societal conditions are also factors that can facilitate or hinder transitions. Indicators for the progress of a

healthy transition are described as feeling connected, interacting, being situated, and developing confidence and coping skills (Im, 2010; Meleis *et al.*, 2000). Outcome indicators are described as mastery of the skills and behaviours that are needed in the new situation and environment, and, moreover, the reformulation of one's identity.

The ways in which the emerging themes relate directly to the model proposed by Meleis and colleagues has been addressed in the previous section. The transition theory has the potential to inform knowledge and practice related to the co-occurring developmental and service transitions that are evident in the population under study. Indeed, this model emphasises potential facilitators and inhibitors to a successful transition and these may be considered when planning support for young people in transition from CAMHS to AMHS. However, the model is particularly descriptive and generic, and its focus is essentially on the individual's experience of transition without the consideration of relational difficulties that were demonstrated within the present study. Therefore, this theory does not appear to sufficiently address the complexities of the transition experienced by the young people in this study, such as the difficulties in negotiating new therapeutic relationships, and the change and difference in culture and context between child and adult oriented services.

Furthermore, this theory has not been found to inform research or practice related to the transition experienced by this particular population. In the current study the transition theory proposed by Meleis and colleagues (2000) was not utilised in the development of the research aims and process, and not all aspects of transition proposed by this theory have been explored. Further research could usefully extend the application of this theoretical framework to further explore experiences of young people who transition from CAMHS to AMHS. Alternatively, further research may seek to develop a theory of transition from CAMHS to AMHS through the use of qualitative methods such as grounded theory, in order to identify interpersonal or relational factors in the facilitation of a successful transition for this population.

4.3.2 CLINICAL AND SERVICE IMPLICATIONS

The current study provides an understanding of the aspects of young peoples' experiences of the transition from CAMHS to AMHS that they perceive as either challenging or facilitating their ongoing involvement with mental health services and their transition towards adulthood. Furthermore, the findings illustrate aspects of support that are required to enhance the journey from CAMHS to AMHS, specifically, support provided from a TS. The clinical and service implications of these findings will now be discussed.

The findings from this study suggest that participants' experiences of the preparation for transition were mixed. Often young people received minimal or inadequate preparation for the transition from CAMHS to AMHS. The preparation they had experienced seemed to consist of a single conversation or meeting in which they were informed that they would be moving to AMHS. These findings appear to contradict recommendations outlined in existing transition guidelines (e.g. DoH, 2011; NICE, 2016) and research (e.g. Hovish *et al.*, 2012; Singh *et al.*, 2010) which advocate standard practice should include features such as a transition plan and more active involvement with AMHS prior to transition.

Surprisingly, no participants discussed the use of a Care and Treatment Plan (CTP) in the facilitation of the transition process, and where the use of CTP was discussed, many young people were not aware of the document. This finding is alarming, given that a CTP should be in place for all people who access secondary care (WAG, 2010b). The utilisation of a CTP may have served to enhance the young person's involvement in their care and support needs as they moved from CAMHS to AMHS; however, it is acknowledged that a specific question regarding the utility of a CTP did not feature in the interview schedule, therefore this finding is of a tentative nature. Nevertheless, attention should be drawn towards the use of the CTP in aiding young people, CAMHS and AMHS to collaboratively develop an appropriate and individualised support plan in order to assist the transition process. Indeed, in order to facilitate a 'healthy transition' (Meleis *et al.*, 2010) it is recommended that there should be a meeting between the services involved together in order to develop a personalised and collaborative transition plan.

Missing from young people's narratives within this study was the report of a conversation about how the young person felt during the process of transition, particularly in relation to their ambivalence towards becoming an adult. Facilitating conversations about a young person's readiness and appraisal of the transition to adulthood may address some of the personal concerns that a young person has in the process of transition to adult-oriented services. Meeting a professional from AMHS for the first time was often daunting for the participants in this study. Therefore, it may be prudent for CAMHS professionals to support a young person to consider questions that they would like to ask the AMHS professional prior to meeting with them. This process may also help to alleviate some anxieties related to meeting with someone new. Transition preparation could therefore be enhanced by meeting with the relevant AMHS professional (who they will be engaged with in AMHS) whilst still being seen by CAMHS services, and in providing information about AMHS, including a realistic conversation regarding the differences between CAMHS and AMHS. Young people who are

due to move to AMHS should also have opportunity to meet with the AMHS professional at the AMHS setting prior to transfer. This process may serve to facilitate familiarity with the AMHS setting, which was found to be threatening, clinical and unwelcoming by the young people in this study.

The anticipated transition from CAMHS to AMHS was perceived by many participants as stressful. Research suggests that many individuals struggle to process verbally presented information provided by health professionals, particularly at times of stress (Kessels, 2003). Therefore, it may be helpful for services to develop an information leaflet to be given to all young people who are due to move from CAMHS to AMHS, outlining a comprehensive description of the services offered and the roles of professionals' in AMHS. Such a leaflet may further aid young people's involvement in making informed decisions about their ongoing care.

Perhaps the most challenging aspect of the transition from CAMHS to AMHS was the young people's integration into an adult-oriented model of care. This included feelings of discomfort in relation to the physical environment, feeling let down due to a decrease in the frequency of appointments, and also in relation to developing positive therapeutic relationships with AMHS professionals (which is discussed further below). Some participants did not feel 'ready' to be in adult services until they made the transfer to the adult team and many of the young people in this study believed that readiness to transfer to AMHS was grounded in their own sense of maturity, mastery and self-confidence. Preparation work completed in CAMHS to support young people to assume an active role in decision making could therefore promote the development of independence and autonomy which may consequently influence a young person's appraisal of their readiness to leave CAMHS and as they enter AMHS.

The importance placed on the therapeutic relationship was a theme that emerged within many of the superordinate themes derived from participants' narratives. This was illustrated through the young people's accounts of their experiences in CAMHS, AMHS and the TS. The results from this study therefore highlight the importance for all service professionals to be sensitive to the individual's developmental and attachment needs as they approach the end of their involvement with CAMHS and as they approach and build new relationships with AMHS. Professional's manner and practice in AMHS were key aspects of the transition process commented on negatively by participants in this study. Training is central to continuing professional development, and in turn, contributes to effective service delivery (Onyett, 2003). Such training could, for example, be directed towards broadening the expertise of professionals who work with young people in transition, particularly those who are aged over 18 and supported by AMHS. For example, it may be prudent to

teach and/or refresh skills in developing and maintaining positive therapeutic relationships. Furthermore, sharing the literature on emerging adulthood (Arnett 2000; 2004; 2007; Tanner, 2006) could provide clarity for services regarding the confusion that prevails in relation to this stage of development. It offers a shared language to describe the age period from 18-25 which may aid communication between all those who support young people during this developmental period. This may assist in moving services towards a model of understanding which may reduce the anxieties that exist regarding an individual's readiness to transfer. Furthermore, it would enable services to tailor support to the individuals' needs in terms of the stage of their development rather than chronological age. The findings from this study therefore highlight the need for professionals in AMHS to be mindful of the expectations of building therapeutic relationships and the young person's developmental needs when they reach AMHS, and provides a strong argument for more joint working between CAMHS and AMHS professionals (Singh *et al.*, 2010).

It is widely agreed that mental health service transitions occur at a vulnerable time for many young people (DoH, 2008; Lamb *et al.*, 2008; Singh *et al.*, 2010)., Therefore it would seem that access to appropriate support during this period is paramount. Beyond the implications for the individual, the results from this study provide evidence for additional support, such as that provided by the TS, during transition as integral to ensuring that young people experience the transition from CAMHS to AMHS as undisruptive as possible. All of the participants reflected that they had required additional support to manage the transition, thus the TS provided young people with a sense of stability during a period of uncertainty. Furthermore, the support received from the TS appeared to be key in promoting and empowering young people to develop independence within the context of a supportive and nurturing environment. The results demonstrate that the TS was able to provide a flexible and responsive service, which the NHS was unable to provide. In line with the literature discussed in Chapter One, investment in services to support transition could have long term and positive outcomes for the well-being of young people who are in the process of moving from CAMHS to AMHS.

Moreover, this research has strengthened the argument to consider specialist youth mental health models of service for individuals aged 16-25 (Richards & Vostanis, 2004). The development of Early Intervention (EI) services lends support to the success of this notion. Such services may reduce the risks associated with disengagement from services at a crucial developmental stage, and to ensure that transition is not occurring at the same time as other significant life stresses (Hovish *et al.*, 2012). Irrespective of the ethos of the service, a gradual transition, tailored and paced to the needs of the young person, with a flexible structure and approach, is essential.

A notable factor highlighted within this study was the feeling of a general lack of awareness of mental health difficulties amongst those who are in a position to support young people (outside of specific mental health services) such as families, peers and GP services. There would seem to be a strong need for the promotion of positive awareness of mental health amongst the public and primary care services. Services should also maintain awareness of the risk of social isolation as a consequence of having a mental health difficulty (Gale, 2007) and the potential negative impacts on the young person.

Lastly, the findings from this study indicate the importance of attending to social issues and providing young people with opportunities to develop skills needed to surmount the social disruption and stigma associated with having a mental health difficulty. The participants in this study appeared to gain a sense of hope and belonging as a result of being part of a social support group provided by the TS. By being part of a peer support network, many participants were able to avoid the despair of social isolation associated with having a mental health difficulty. This potentially highlights the importance of the commissioning and development of social support groups aimed at the cohort of young people who are moving from CAMHS to AMHS.

4.3.3 THE ROLE OF CLINICAL PSYCHOLOGY

Clinical psychology can play a central role in working with young people to ensure that their developmental and psychosocial needs are better met during transition from CAMHS to AMHS. The current study has highlighted the difficulties that CAMHS and AMHS professionals and young people face during the transition between child and adult services. Clinical psychologists are key professionals that sit within both CAMHS and AMHS multidisciplinary teams and many aspects of a clinical psychologists' training (including a strong background in developmental and psychosocial influences of young people's mental health, research methodology, developing interventions, evaluation and evidence-based practice) arguably places them in a unique position with a skill set to work with young people in both CAMHS and AMHS.

Consultation and supervision of other professionals is a key role of a clinical psychologist within a multidisciplinary team, and can help a team to develop a cohesive approach as well as provide much needed support frameworks for staff. The leadership, teaching, training and consultancy skills of clinical psychologists can be utilised to enhance others' understanding of the developmental and psychosocial needs of young people who are in the process of transition from CAMHS to AMHS and to encourage well-evidenced changes in service delivery. For example, clinical psychologists may be

best placed to facilitate training for AMHS professionals in considering the diverse needs of the young people who are referred to AMHS, and also in teaching creative and diverse approaches to building a therapeutic relationship with young people.

As identified in Chapter One, research pertaining to mental health service transitions concludes that there is a gap between best practice guidelines and service delivery (Singh *et al.*, 2010). To continue enhancing understanding of the transition process, longer-term outcomes need to be explored and evaluated. Clinical psychologists can take a lead role in implementing such evaluations.

4.4 DISSEMINATION OF FINDINGS

A number of plans to disseminate the findings from the research have been made. Firstly, a training event for the local CAMHS network has been planned for Autumn 2016 and will detail the main findings of this research. The event will be facilitated by the researcher, TS manager and a young person (who had participated in the study). Secondly, the researcher has been invited to work alongside the TS in order to liaise with the Welsh Government 'Transition Workstream', part of the wider Together for Children and Young People Strategy. The results from this research are expected to inform elements of a Transition Pathway and specifically a Transition Passport for young people who move from CAMHS to AMHS in Wales.

4.5 STRENGTHS AND LIMITATIONS OF THE STUDY

The aim of this research was to explore the lived experience of young people who have moved from child to adult mental health services with support from a transition service. A review of the relevant literature, presented in Chapter One highlighted a lack of research in this area, specifically in relation to young people's perspectives of the transition, and in receiving formal support during the transition more broadly. Research appears to focus on procedural processes rather than the individual's meaning of the transition experience. Therefore, the current study sought to fill this gap by pursing a qualitative analysis of the experiences of a sample of young people who had transitioned from CAMHS to AMHS with support from a transition service. The quality criteria proposed by Elliott and colleagues (1999) was considered throughout the research process (for details of the criteria see Chapter Two). Therefore, these guidelines (Elliott *et al.*, 1999) and the CASP (2010) criteria will be considered when assessing the methodological strengths and limitations of the current study.

4.5.1 Methodology and Design

Qualitative methodology was deemed appropriate for this study due to the limited available evidence base in the UK regarding young people's experiences of the transition from CAMHS to AMHS, and in particular, those who have received support from a TS. This was a novel area of research and the use of IPA was considered an appropriate method to meet the aims of this study, allowing a rich and detailed understanding of the participants' meaning of their experiences. The use of IPA also allowed insight into the nuances and the complexities of the young peoples' experiences, something which a quantitative method may have missed. The use of IPA also enabled the emergence of themes which had not been considered in the existing literature or considered previously by the researcher. For example, one theme not anticipated by the researcher was the impact of the physical environment at AMHS, on the participants' engagement and satisfaction with services.

The use of IPA methodology allowed the researcher to remain close to the participants' own words and to construct themes using rich, nuanced quotes. Providing quotes to illustrate themes is considered important to allow others to make sense of the data, to generate new ideas (Elliott *et al.*, 1999) and to demonstrate transparency of the research process (Yardley, 2008). The interpretative element of IPA also enabled the participants' narratives to be analysed for their meaning in relation to relevant theory and clinical practice.

The retrospective nature of the research may be considered a limitation of this study. All participants were required to have transitioned from CAMHS to AMHS in the last three years. As such, the range of time since participants had made the transition to AMHS varied, for example, one participant was interviewed almost two years following transition from CAMHS to AMHS. Participants' accounts may therefore have been influenced by potential recall issues and may have been subjected to significant reinterpretation over time (Jobe & Mingay, 1991). Further, such variations in time since transition may limit the extent to which the findings can be generalised due to the variability between the participants. As those who had more recently transitioned to AMHS (within the last three months) may have found it more difficult stand back and reflect on their experiences.

4.5.2 RECRUITMENT AND SAMPLE

The method of recruiting participants might be considered a limitation. The sample comprised participants who were recruited through the TS manager; hence, it is possible that the TS manager may have selected individuals who were less likely to hold critical views and more inclined to reflect

the TS in a positive manner, particularly as findings from the study would be fed back to the TS. However, the pool of potential participants from which the sample was selected was relatively small, and effort was made to contact all participants who met the inclusion criteria for the study (n=14) to invite them to participate in the study.

Additionally, the sample comprised people who were willing to participate in the study. Participants choosing to take part may have held particular positions in relation to the topic which may have motivated them to participate, possibly reflecting a bias in the sample. One such bias may be towards young people who experienced the transition from CAMHS to AMHS negatively. However, the narratives were diverse and reflected findings of previous studies of young peoples' experiences of the transition from CAMHS to AMHS. Hence, whilst it is possible that this may pose a limitation, in general it appears that self-selection bias had not jeopardised the study's findings.

A strength of this study was its participants. The inclusion of young people's perspectives reflects those that are unique and important to consider compared with those of service providers (on which the majority of the limited research undertaken in the UK is based) as they are the primary recipients of care. This allowed for exploration of a phenomenon where little is known.

A significant limitation of this study is the sample size of seven participants.. However, IPA uses small sample in order to reflect the detailed data it aims to gather, with a focus on depth of understanding and the creation of meaning (Smith, 2004). A sample of seven participants fell within the recommended range of four to ten participants for a doctoral study (Smith *et al.*, 2009).

Moreover, the study aimed to investigate the experiences of young people who had been supported by a TS in addition to the experience of moving from child to adult mental health services. To the researcher's knowledge, there is only one TS operating in the area where the research was based, therefore it was considered that seven participants were sufficient for the emergence of common themes amongst the participants' data (Smith & Osborn, 2003). Caution should be given to the generalisability of the findings, as results presented here may only be relevant to the TS service from which participants were drawn. IPA is an idiographic approach that does not seek to find definitive or positivist answers. It is not possible to make claims about the generalisability of these results for the wider population of young people who move from CAMHS to AMHS with support from a TS. Therefore, although others may have had similar experiences, it is necessary to acknowledge that the findings provide an in-depth insight into the salient themes of the participants' experiences in this particular study. It is important therefore to consider the transferability of these findings within this context.

Furthermore, Elliott and colleagues (1999) highlight the importance of situating the sample, this was carried out through providing a description of the participants in Chapter Two. However, a limitation of this study was the restriction of information provided by the researcher about each participant in relation to their quotes which may have limited the understanding of the context of the participants' narratives. However, preserving anonymity of participants was paramount due to the small number of participants that fit the inclusion criteria for this study.

4.5.3 DATA COLLECTION AND ANALYSIS

Data was collected using semi-structured interviews. The use of a semi-structured interview schedule ensured consistency across interviews. Smith *et al.*, (2009) recommends using between 6-10 questions with prompts, this allowed the researcher to establish the area of interest whilst also entering the psychological and social world of the participant (Smith & Eatough, 2007). In this way, participants could direct the interview and had maximum opportunity to tell their own stories and experiences. This provided rich data that might not otherwise have been achieved.

A limitation of the use of a one-off interview is acknowledged. In the interviews conducted some young people were not as articulate and forthcoming as others. Laws (1998) has commented on the importance of allowing enough time to build up trust with young people, however the time constraints associated with carrying out the research did not allow for this.

All young people were interviewed either in their home or at one of the third sector organisations' premises and, although not present during the interview, someone from the TS was available at (or near to) the interview location in order to support the young person before, during and after the interview if required. Three participants chose to be introduced to the researcher by the TS support worker, however the support worker left the room whilst the interviews took place. The presence of a TS support worker during this time may have influenced the participants' accounts, as perhaps they felt restricted in what they could say should a member of the organisation hear. A further consideration is that although every effort was made to provide the young people with reassurance that they would not be identifiable by the transition service, concerns about confidentiality may have resulted in the young people seeking to present a positive view of the service. Participants were aware that they would be assigned a pseudonym and all identifiable information would be removed from the transcripts.

The study used IPA to analyse the data. IPA was thought to be appropriate due to its focus on understanding the lived experience of participants and how they make sense of the phenomenon in question (Smith & Osborn, 2003). It was felt that this was the most appropriate method of analysis because of the study's aims to gain a better understanding of the transition from CAMHS to AMHS from the young person's perspective.

Smith and Osborn (2003) and Smith and Eatough (2007) argued that analysis in IPA can take different interpretive stances: an empathic stance and a questioning / critical stance. It is argued that this study took more of an empathic stance, with the aim of trying to understand lived experience. A different interpretation could have been more removed from the data, asking curious and critical questions. Although either stance is acceptable in IPA, it could be argued that a combination of the two might have yielded a richer interpretation of the results.

The limit of the analysis to an empathic stance rather than going beyond to take a more questioning or critical stance might reflect the researcher's lack of experience using IPA. Smith (2004) argued that inexperienced IPA researchers can sometimes be too cautious with their interpretations. However, he argued that a 'good enough' analysis is acceptable rather than a forced interpretation. With this study, reflections of how the participants made sense of their experience are acknowledged, but perhaps analysis did not go far enough to explore the researcher's interpretation of this. However, it did provide an empathic account of the experiences of participants who have moved from CAMHS to AMHS which can inform practice both at a service and clinical level. In this way it met the phenomenological principle of IPA, by exploring lived experience, if not fully meeting the hermeneutic principle with its interpretation of the data.

4.5.4 ENSURING CREDIBILITY

IPA requires the researcher to engage in a process of sense making and interpretation. Therefore, one's own position and interpretation of the data lends itself to potential biases and hypotheses of the participants' accounts. Although this was accounted for through cross checking analyses with the research supervisors, it cannot guarantee for total elimination of presuppositions, nor can it control for these becoming present during the interviews. Attempts to address the credibility of the research findings were made throughout this study and were ensured by adopting a position of reflexivity during the research process. The researcher made explicit their own position both through a personal statement (Section 2.2.5, Chapter Two) and through keeping a reflective journal (Appendix iii). Credibility of the research findings can be enhanced via the use of member validation

via focus groups with participants to explore the results. However, this study did not use member validation to establish the credibility of the findings due to time restrictions. Every effort was therefore made to be rigorous and transparent in the analytical process, this was achieved through the use of regular supervision with both research supervisors and exploration of the meanings drawn from the data with peers (Trainee Clinical Psychologists) who were also undertaking qualitative research.

4.6 FUTURE RESEARCH

The current study is relatively small and preliminary in nature, however, the findings suggest a number of possibilities for further research. Due to the small sample size, it is not possible to generalise the findings of the current study. Therefore, revisiting this area of investigation using larger sample sizes may further develop our understanding of the transition process as it is experienced by young people within South Wales.

All of the participants in this study were at a different time point in terms of their transition and ongoing engagement with AMHS. The use of a different methodology, such as longitudinal research could allow for a more detailed exploration of young people's outcomes following transition and their ongoing engagement with AMHS and would allow longer term outcomes of transitions to be determined. By conducting interviews shortly following transfer to AMHS and at several time points thereafter, facilitative factors and barriers to remaining engaged with AMHS may be highlighted.

Unlike previous research, this study has not covered the perspectives of parents or professionals. It may be important to explore the attitudes, perceptions and expectations of the wider system around young people to determine the impact that others have on their transition experience. Further investigation into the views held by CAMHS and AMHS professionals and parents or carers in relation to their experiences of transition would help to establish a greater understanding of the transition from CAMHS to AMHS.

Further research into the specific areas mentioned within the findings may also provide further insight into the experiences of moving from child to adult mental health services e.g. the meaning of transition; the importance of developing therapeutic relationships with AMHS professionals; the impact of the physical environment on engagement; and the impact of social support and social environments in terms of ongoing well-being for this particular cohort of young people. The latter may be particularly important for young people who find the transition to AMHS more difficult.

Finally, the replication of this study with young people who are supported to transition from specialist services, such as inpatient CAMHS to AMHS across the UK would help to validate the findings in other settings.

4.7 CONCLUSION

Previous research regarding mental health service transitions has neglected the views of young people and as such, much of the understanding of the experiences of transition from CAMHS to AMHS is largely based on service provider perspectives. The aim of this research was to explore the lived experience of young people who had transitioned from CAMHS to AMHS and who had also received support from a transition service. The young people were able to provide rich accounts of their experiences of service transition from CAMHS to AMHS and their adjustments to receiving support from mental health services as an adult. Overall, the findings emphasise the complex and multiple process of transitioning between child and adult services whilst simultaneously experiencing a developmental transition. In line with developmental theories, the findings suggest that young people are in the process of forming identities, negotiating new relationships and developing autonomy and independence. Furthermore, the findings from this study support the claim that mental health service transitions are often focused on service transfer and can ignore the developmental needs of the individual (Singh, 2009).

For many participants the transition from CAMHS to AMHS was associated with uncertainty and confusion which led to feelings of fear and anxiety. Transitions that were planned and co-ordinated provided the best continuity of care, while an absence of transition planning (including having information or visiting the AMHS premises prior to transfer) was associated with disruptions of care and negative outcomes. Participants voiced their desire to have more involvement in transition planning and decision making.

Differences in the service culture, context and treatment approach between CAMHS and AMHS were explored. Participants experienced a shift in responsibility and autonomy in relation to their care in AMHS. While some participants viewed this change positively, others struggled with the expectation to take more responsibility with their care.

Participants reported both positive and negative outcomes in relation to their transition experience. Positive outcomes included increased insight into their mental health difficulties and increased independence. Negative outcomes were associated with a disruption of care due to a decrease in the level of support and difficulties in establishing therapeutic relationships with AMHS

professionals. Personal readiness and the appraisal of the transition process was deemed an important determinant of outcome.

This study highlights the valuable role that transition services play in enabling young people to navigate the transition from child to adult services, this includes promoting independence through collaborative working whilst providing a nurturing environment from which the young people feel empowered to take on a more autonomous role.

Developing an understanding of how young people experienced the move from CAMHS to AMHS with support from a TS enabled a number of clinical and service recommendations which focus attention to how young people can be best supported through the move from CAMHS to AMHS.

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APPENDICES

APPENDIX I: SEARCH TERMS USED IN SYSTEMATIC REVIEW

Terms in relation to the participant group:

adolescen* adult* youth* teen* child*

young person* young people* young adult* minor*

Terms in relation to setting:

CAMHS AMHS Psychiatric Mental Health

Child Psychiatry

Terms in relation to transition:

transition* transfer* continuity of care move* handover*

Example search from PsycInfo:

- 1. exp Child Psychiatry/
- 2. CAMHS.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 3. (adolescen* or child* or juvenile* or teen* minor* or youth* or "young adult*" or "young person*" or "young people" or "young men" or "young women" or "young male*" or "young female*").mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 4. exp Mental Health/
- 5. ("mental health*" or "psychiatric").mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 6.4 or 5
- 7. 3 and 6
- 8. 1 or 2 or 7
- 9. exp Mental Health/
- 10. (adult* adj3 mental health*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 11. AMHS.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 12.9 or 10 or 11
- 13. (transition* or transfer* or move* or moving or handover*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

- 14. exp "Continuum of Care"/
- 15. "continuity of care".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 16. 13 or 14 or 15
- 17. 8 and 12 and 16

APPENDIX II: CRITICAL APPRAISAL SKILLS PROGRAMME (CASP) QUALITATIVE RESEARCH CHECKLIST

Screening Questions		
1. Was there a clear statement of the aims of the research? HINT: Consider What was the goal of the research? Why it was thought important? Its relevance	Yes	Can't tell No
2. Is a qualitative methodology appropriate?	Yes	Can't tell No
If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants Is qualitative research the right methodology for addressing the research goal?		

Is it worth continuing?



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Detailed questions		
3. Was the research design appropriate to address the aims of the research? HINT: Consider If the researcher has justified the research design (e.g. have they discussed how they decided which	Yes	Can't tell No
(e.g. nave they discussed now they decided which method to use)?		
4. Was the recruitment strategy appropriate to the aims of the research?	Yes	Can't tell No
If the researcher has explained how the participants were selected If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study If there are any discussions around recruitment (e.g. why some people chose not to take part)		

5. Was the data collected in a way that addressed	Yes	Can't tell	No
the research issue?			
If the setting for data collection was justified If it is clear how data were collected (e.g. focus group, semi-structured interview etc.) If the researcher has justified the methods chosen If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)? If methods were modified during the study. If so, has the researcher explained how and why? If the form of data is clear (e.g. tape recordings, video material, notes etc) If the researcher has discussed saturation of data			
6. Has the relationship between researcher and participants been adequately considered? HINT: Consider If the researcher critically examined their own role, potential bias and influence during (a) Formulation of the research questions (b) Data collection, including sample recruitment and choice of location How the researcher responded to events during the study and whether they considered the implications of any changes in the research design	Yes	G □ Can't te	II No

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4

7. Have ethical issues been taken into consideration?	Yes	Can't tell	No
If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) If approval has been sought from the ethics committee			
8. Was the data analysis sufficiently rigorous?	Yes	Can't tell	No
 If there is an in-depth description of the analysis process If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process If sufficient data are presented to support the findings To what extent contradictory data are taken into account Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation 			

9. Is there a clear statement of findings?	Yes	Can't tell	No
HINT: Consider			
 If the findings are explicit If there is adequate discussion of the evidence both for and against the researchers arguments If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst) If the findings are discussed in relation to the original research question 			

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

APPENDIX III: EXTRACT FROM REFLECTIVE JOURNAL

2nd Dec: I have my first interview booked for this evening. I feel nervous and quite anxious as to whether the young person will feel comfortable to share their experiences with me. In my preparatory reading I've become aware of the potential challenges I may face when interviewing young people, and as a novice researcher I'm concerned how this may impact on the project. I need to be mindful of my assumption that young people may be difficult to engage and unwilling to discuss their experience with me... Having just completed my first interview. I'm not sure if I am asking the right things in order to get rich enough data. I noticed how I needed to be mindful of interviewing from the perspective of researcher rather than clinician. This was a little hard at first, as I was trying not to interpret what the young person was saying as we were working through the interview.

3rd Dec: Listening back to this first interview, I am aware that perhaps I am jumping in too quickly with questions, not allowing enough silences. I also noticed that I ask two questions at once, I wonder if this is particularly confusing! I think I'm fearful that the young person will have nothing to say. I will discuss this with Helen and other trainees doing qualitative and see how they have experienced this. I will need to ensure that I approach the next interviews with a more open mind.

18th Dec: I've just returned from my third interview. During the interview today I found myself becoming annoyed at the arbitrary divide that exists between child and adult services based purely on age. This has really made me think about the social construction of what it means to be an adult. There appears to be so much pressure, both within and outside of the young person to have achieved mastery in certain aspects of their lives. It felt that the young person just had to 'grin and bear' it rather than have a say in what they wanted. I found myself getting wound up about the lack of care and support that she had received.

January: (Transcribing) I'm really struck by the way in which the young people are really showing an interest in the project. I am feeling really privileged that these young people are sharing their experiences with me, and I'm feeling that I have a responsibility to do justice to their experience when I come to analyse the data. I am mindful that this might have been the first time that they have ever had a conversation about their experiences of the transition from CAMHS to AMHS, and they have openly shared their experiences with me. However, they are unlikely to ever see me again, which makes me feel a little uneasy. I'm Really struck by the amount of 'growing up' these young people have had to do given the stark differences between care in CAMHS and care in AMHS. I knew it was different but the effect that it has on the YP can be debilitating. I was struck by how Della explained that being forced to do things for herself made her not want to do them. And how grateful she is for the extra support she receives from the TS.

3rd Feb: I've had such a powerful interview today. A really articulate young lady whose recovery journey is remarkable. I was struck by her maturity and ability to reflect on her own development over the past two years, including the point of transition. Again, she commented on the stark differences between CAMHS and AMHS; particularly about the environment and how safe, secure and nurtured CAMHS made her feel despite not particularly liking the staff there. I was really struck by how much the physical environment would have ab impact on the young person's relationships with services. It was clear that she did not feel comfortable in a clinical setting, where the Doctor won't give their first name. This made me reflect on how, as psychologists we generally don't use our title and surname when greeting and meeting with clients. I wonder what impact that has on building the therapeutic relationship

Feb 10th: Just about to start analysis! Finally got the 6th interview done and so its time I got on with it all. I'm feeling a bit overwhelmed and not sure what direction that the analysis will take me in. I'm aware that I need to start doing my literature search soon and worry that if I look into that too much then I might bias my analysis. I am aware that I am thinking more about themes as I've been transcribing. I've got a notebook with them in now so that I store them away from my analysis notes. As I want to do justice to everyone's experiences it is really difficult at times to let go of certain themes that are prevalent for some! I feel I am constantly questioning whether I have sufficiently captured the essence of their individual experiences.

Feb 15th: I've just finished analysing the first interview and it's made me think about how the themes may have developed if I'd started with a different interview transcript. Although I'm bracketing off my thoughts before every interview it's really hard to actually discount what you know, you can't unlearn something! I am hoping that when I show my preliminary results to Helen and Jane they will also be able to see my position of interpretation as one of neutrality! I suppose that's the purpose of the credibility checks.

March 14th: I have been through so many different ways of interpreting these results now. The themes could be grouped together in so many ways – it's getting quite overwhelming. I've spoken to a few peers to talk through my ideas before I see Helen and Jane. It was reassuring that there were similarities between my themes and their ideas, but also made me think about other areas I'd neglected, such as the power imbalance between young people and professionals

March 21st: Met with Helen about the themes today. I was really shocked at how emotive the themes all were as I was reading the quotes back to Helen, and also how I had become so immersed in the data I hadn't really been thinking holistically about how the young people must be feeling. I'm not sure how far away from the young person's words I can truly go without losing their sense making. Is what they say really reflecting their experience as abandonment or loss? Is it fair that I have interpreted it in that way? Helen had some good ideas, particularly about how the young people experienced CAMHS as a validating place in contrast to AMHS. I am thinking of swapping a few of the themes around now. There are so many ways that they could fit together – I hope I'm getting to a point where I can feel a bit more certain about what I have done!

APPENDIX IV: EXAMPLE EXTRACT OF ANALYSIS OF TRANSCRIPT

	99	know, allyou know, body weight and being fat, you know. And it's	
	100	a really common thing, like it shouldn't be but it is. And um, upon	
	101	kind of explaining this and eventually what he came to was and this	
	102	is genuinely what he said was " I think that what you should really	
	103	try and do is just avoid mirrors, like in your life. I was like "are you	disatisfied
. (a. (a.) . (da	104	kidding me? So that's how I'm gonna fix this is to avoid it, ok cool".	
Not feeling helped	105	Like that's the most unhelpful thing I've been told in my life, like how	feeling let down
striving for suppor	106 ∕	is that useful for me? And in fact, that only backs up what you're	
let dain by	107	thinking already oh I shouldn't even look, I'm so awful I shouldn't	not helped > let down
g077.00°,	108	even look. You know it was just absolutely bizarre and I just thought	
dialectic,	109	who is this person that is supposed to be helping me? Because I	seeming safety
unsupported	110	didn't feel like I gained anything from my time with him. Apart from	being a child
safe enough to	111	having a place to be like crazy.	satery to be
(supported).	112	And being a bit crazy, what was that?	sey aumenti
being someody	113	Being able to not have to act as the really nice, mature person that I	no pretending
different.	114	am [laughs] and that I wanted to be but I was less at the time and	
delleast	115	more striving to be. Now I'm kind of adapted to that and I'm good	canbe. immature
being a different	116	but I just needed to be a bit mean actually and the poor guy had to	
being a diffocus purous to "unsas self"	117	take it hugh	espectations gove
	118	And I'm interested in your view of when you were 17 it was just	sately
	119	like they were just	SMAG
feeling not	120	I was there when I was 16, and it did feel like when I turned 17, I	not ready to
ready to go,	121	really felt the turning point there was, cos I turned 17 in November,	move on
rushed to leave,	122	and so by January they were like "so you're gonna be leaving, so	pushed out
	123	you're gonna be leaving, so we're gonna be" and it was like I know,	* 1
taking back,	124	just help me where I am for a minute, stop talking, you know, like, I	wanting to
CONTINOI - MEUP.	125	need the support now. And it was really yeah, really about that and	& be heard
recognition for full that you,	126	then I had Fred probably from, it must have been from, so sort of	4 DE TOSTA
not ready	127	May, May time onwards, or maybe even April.	
to leave.	128	Who decided you were going to go back to CAMHS when you were	
	129	16?	

Mic	130	Um, we well I went to, I'd been living a bit of a lie and kind of,	pretenie-
not hereafue to seek and the man was.	131	because I'd had problems had ups and downs and been to CAMHS	p. 0.
10 50h , wes	132	back and for a little bit and you know I was, sort of living as if I was	
		in a really good place and that I was absolutely fine, and you never	
sname dea	134	need to worry and no need to worry cos I was really good then I	
0,000 100	135	started having much, like a lot more trouble with Ffion, you know,	
feeling out of	136	with her in my head and her having bit more control of me until I	-
CODEING ON OWN	137	was scared enough to tell my mum because I was like, this can't go	Shameabout
hi a point a choosing to tell	138	on anymore, this, you know. And I was so nervous to tell her,	real sey (H)
Pinno	139	because I thought I'm ruining this, like it'll destroy her, she thinks I'm	
nework, award	140	fine, everyone thinks I'm fine, I don't want to break that I don't want	
lething people down	141	to be the victim again. I'm bloody bored of being a victim in this like,	1 dead but
MH WILCHI YOUVE	142	you know, you just, I'm ready to move on but my brain isn't, you	held back by
a lesser person?	143	know there's so much of me that just wants to be fine but I still have	MH.
want to be betto, acceptance	144	some recovering to do and some healing to do. So and I told her and	7
shave, guilt	145	she said the best thing she probably could have said, "Well, I did	readiness
070074,95011	146	always wonder what it would be like to have twins!" [laughs] and I	to get
	147	was like, that just made it so, pressure off, pressure is off, you know.	better - more on
engma?	148	You hadn't told her about Ffion before?	
strong to be ok,	149	No, that was the last thing she didn't know about because I was so	shame,
sname, hiding	149 150	No, that was the last thing she didn't know about because I was so dead set on being fine, you know and so really, you know and umI	shame, hiding real
			shame, hiding real sey
sname, hiding	150	dead set on being fine, you know and so really, you know and umI	shame, hiding real sey
sname, hiding	150 151	dead set on being fine, you know and so really, you know and umI sort of started saying I hadn't been going to school very much and id	shame, hiding real sey:
sname, hi ding ми proolens	150 151 152	dead set on being fine, you know and so really, you know and umI sort of started saying I hadn't been going to school very much and id been ducking out, and [laughs] duh duh duh duh duh. And yeah, so	hiding real
sname, hi ding MH problems remponing The	150 151 152 153	dead set on being fine, you know and so really, you know and umI sort of started saying I hadn't been going to school very much and id been ducking out, and [laughs] duh duh duh duh. And yeah, so we went straight to the GP then. Went to GP and the poor guy	hiding real sey.
MA problems remposing The shama?	150 151 152 153 154	dead set on being fine, you know and so really, you know and umI sort of started saying I hadn't been going to school very much and id been ducking out, and [laughs] duh duh duh duh. And yeah, so we went straight to the GP then. Went to GP and the poor guy looked so sacred [laughs] and you know you just think, it's alright,	hiding real
MA problems reinforcing The stigma? feeling like an alien	150 151 152 153 154 155	dead set on being fine, you know and so really, you know and umI sort of started saying I hadn't been going to school very much and id been ducking out, and [laughs] duh duh duh duh. And yeah, so we went straight to the GP then. Went to GP and the poor guy looked so sacred [laughs] and you know you just think, it's alright, I'm not about to just flip out or anythingthis poor guy was	hiding real sey.
reinforcing The engine? feeling has an alien over fit more	150 151 152 153 154 155 156	dead set on being fine, you know and so really, you know and umI sort of started saying I hadn't been going to school very much and id been ducking out, and [laughs] duh duh duh duh. And yeah, so we went straight to the GP then. Went to GP and the poor guy looked so sacred [laughs] and you know you just think, it's alright, I'm not about to just flip out or anythingthis poor guy was likeyou're in GPs office and you mention anything mental health.	hiding real sey.
reinforcing The stigma? feeling like an alien	150 151 152 153 154 155 156	dead set on being fine, you know and so really, you know and umI sort of started saying I hadn't been going to school very much and id been ducking out, and [laughs] duh duh duh duh. And yeah, so we went straight to the GP then. Went to GP and the poor guy looked so sacred [laughs] and you know you just think, it's alright, I'm not about to just flip out or anythingthis poor guy was likeyou're in GPs office and you mention anything mental health and they're like, CAMHS, go please! Go to CAMHS [laughs]	hiding real sey.
removing The stigma? feeling lake an alien for the more need more need, must be bad.	150 151 152 153 154 155 156 157	dead set on being fine, you know and so really, you know and umI sort of started saying I hadn't been going to school very much and id been ducking out, and [laughs] duh duh duh duh. And yeah, so we went straight to the GP then. Went to GP and the poor guy looked so sacred [laughs] and you know you just think, it's alright, I'm not about to just flip out or anythingthis poor guy was likeyou're in GPs office and you mention anything mental health and they're like, CAMHS, go please! Go to CAMHS [laughs]	Shame & stigm alienated something
reinforcing The stigma? feeling has an alien don't fit min ore need more need, must be bad.	150 151 152 153 154 155 156 157 158	dead set on being fine, you know and so really, you know and umI sort of started saying I hadn't been going to school very much and id been ducking out, and [laughs] duh duh duh duh. And yeah, so we went straight to the GP then. Went to GP and the poor guy looked so sacred [laughs] and you know you just think, it's alright, I'm not about to just flip out or anythingthis poor guy was likeyou're in GPs office and you mention anything mental health and they're like, CAMHS, go please! Go to CAMHS [laughs] How did that feel for you? I did always think that it was quite, straight away, like ok, you need	hiding real sey.
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		229	And if the patient can sit there any think you don't wanna be here	
		230	then you're doing something wrong.	
		231	You said that in the January time they started to say you're 17	
		232	soon, 17 soon you're gonna be leaving, did that sort of thing	
		233	continue with Fred then?	
		234	Yeah he came in with Luke for a while so we could like you know,	
24.41	ined who	235	cross over. Um yeah it was just it kinda just always came up, it was	nuclaira0
₩.	white about	236	always like that thingbut you know, 'so we need to think about	uni out -
fur	we wanting	237	what we're gonna do', maybe not every week but you know, every	you out - rejected
-1 1		238	other week, every third weekyou know what are the plans gonna	19
CM	envielning	239	be for when you're not coming to CAMHS. [laughs] do you get me?	
		240	Did anything happen with those conversations?	
		241	Well one thing they did say, ah no nothing productive. What they did	pressive.
		242	wanna do, we wanna see if we can get you um, coming less and or	serveof
	lung nushed, www.d-	243	get you not coming before you have to go to adult services. I was	urgency to
	point=	244	like, so my recovery is now on a time limit then!	gerbetter.
(VOV)	e covery, it make it,	245	Did they explain why they would be doing that?	111-11
fea	of failure!	246	Um, basically saying that because adult services would be more	Warring!
Sett	nio up-re	247	difficult, umwe're not I guess not as good, as in less support,	espectations
mut	WYVE.	248	there's less sort of out there. So it's more difficult to get the support.	set up by
		249	Um, but I did think, it was kind of like they were saying you know, if	- outloo
Pres	be sometruly	250	you can be like fine by the time you turn 18, then you won't have to,	- Pressure to be
idon	re nov ready	251	like, you can go and you'll beas if oh it's easier if you don't go to	ok-recovered
70 k	coulvel, .	252	adult services at all. And I was like putting a time pressure on that is	0,6 1,660 10.60
	stred unito it.	253	really the last thing that you need to do.	
MM2.	talore—	254	And how did it feel for you?	
reje	cted again	255	I just, I was like I felt that they just kind of lost interest, oh, bit of a	rejected,
an la	1000	256	lost hope, you know, a lost cause just kind of, if you're not gonna be	hopetess
Nepa	hie outhook.	257	finished by the time we're done with you then you just off intoI read	7.00
	ts = nothing	258	it as it sounding like 'adult services, that's just the abyss' you just get	life after "
	re for you.	259	put into that and that bitI was like great, cool. There was no) Crompas
	you need to			pop iso NT
	Preson			DICTORE !
10	t-down by a	MHI	, nor Kady.	

APPENDIX V: CARDIFF UNIVERSITY ETHICS COMMITTEE APPROVAL LETTER

Ethics Feedback - EC.15.07.14.4163R

psychethics

You replied on 06/08/2015 14:57.

Sent: 06 August 2015 11:55 To: Bethan Hayward-Bell

Cc: Jane Onyett (Cardiff and Vale UHB - Psychology Training South Wales) [Jane.Onyett2@wales.nhs.uk]

Dear Bethan,

Apologies for the delay.

The Chair of the Ethics Committee has considered your revised postgraduate project proposal: Moving from Child to Adult Mental Health Services: Young people's experience of a Transition Service (EC.15.07.14.4163R).

The project has now been approved, on condition that your full risk assessment has now been completed and approved.

Please note that if any changes are made to the above project then you must notify the Ethics Committee.

Best wishes.

Natalie

School of Psychology Research Ethics Committee

Cardiff University **Tower Building** 70 Park Place Cardiff CF10 3AT

Tel: +44(0)29 208 70360

Email: psychethics@cardiff.ac.uk

Prifysgol Caerdydd Adeilad y Tŵr 70 Plas y Parc Caerdydd CF10 3AT

Ffôn: +44(0)29 208 70360

E-bost: psychethics@caerdydd.ac.uk

http://psych.cf.ac.uk/aboutus/ethics.html

Ethics Feedback - EC.15.07.14.4163RA



psychethics

Reply all

04/12/2015

Bethan Hayward-Bell; Jane Onyett (Cardiff and Vale UHB - Psychology Training South Wales) < Jane. Onyett2

Inbox

Dear Bethan,

The Ethics Committee has considered the amendment to your PG project:: Moving from Child to Adult Mental Health Services: Young people's experience of a Transition Service (EC.15.07.14.4163RA).

The project has been approved.

Please note that if any changes are made to the above project then you must notify the Ethics Committee.

Best wishes, Mark Jones

APPENDIX VI: THIRD-SECTOR ORGANISATION ETHICS COMMITTEE APPROVAL LETTER

[]	Research Ethics Committee	
(REC)		
Lead Revie	ewer (on behalf of the Committee)	
Your appli	cation has been approved:	
☑ I am sat research gu	isfied that this research proposal conforms to sethical idelines	
request tha	isfied that this research conforms to sethical guidelines. It comments above are addressed before proceeding with your at you do not need to re-submit your application.	We
Your appli	cation has been declined:	
	mission requires significant amendments before it conforms to ethical guidelines. Please refer to advice and comments given abo	ove.
Name:	Sophie Laws	

Assistant Director for Evaluation and Impact

APPENDIX VII: PARTICIPANT INFORMATION SHEET

13.10.15



Position:

Date:





Participant Information Sheet

Moving from Child to Adult Mental Health Services: Young people's experience of a Transition Service

My name is Beth and I am a Trainee Clinical Psychologist on the South Wales Doctorate in Clinical Psychology, Cardiff University.

I would like to invite you to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. If you want to ask any questions or would like further information, then please feel free to get in touch with me via the contact details given at the end of this leaflet.

What is the purpose of this study?

This research study aims to explore the impact and experiences of young people who have moved (transitioned) from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS). This includes finding out about:

- how you made sense of and prepared for moving on from CAMHS;
- any aspects that were helpful or not helpful during the transition;
- your experiences of the support that you received during the move
- your experience of being supported by xxxxxx Transition Service.

Why have I been invited to take part?

You have been invited to participate in this research study because you have been identified as a young person (aged over 18) who has used CAMHS services previously, and has moved on to access Adult Mental Health Services.

You will be invited to talk about your experiences in a one-off interview.

Do I have to take part?

It is entirely up to you to decide whether you wish to take part.

If after reading this information sheet you decide that you do not wish to receive further information or take part in the study, you may inform the researcher by ticking 'No' on the

'Opt-in form' attached to this leaflet. You may return the form by sealing it in the envelope provided and handing it to the Transition Service Team who will then pass it on to me.

If you decide to take part in the interview and then change your mind later you are free to withdraw from the study up until the data analysis begins (this will be four weeks after the interview). If you do not want to take part anymore you do not have to tell me the reason why. If you withdraw from the study, any information that you have given me, including your interview recording, will be destroyed.

A decision to stop or a decision to not take part will not affect any care or support that you receive, now or in the future.

What if I want to take part?

If after reading this information sheet you decide that you would like to take part in this study you will be asked to inform the researcher by ticking 'Yes' on the 'Opt-in form' attached. You may return the form by sealing it in the envelope provided and handing it to the Transition Service Team who will then pass it on to me. Once I have received the 'opt-in form' I will contact you to explain more about the study and to answer any questions you may have. If you are still happy to take part in the study a time and place to meet with you to conduct an interview will be arranged. A Transition Project Worker will be available to accompany you to the interview location. The worker will remain at the interview location and also accompany you from the interview.

What will happen if I agree to take part?

We will meet on one occasion for about one hour.

At first I will talk to you about consent and go through a consent form with you. I will also answer any final questions that you may have. The consent form is a way of making sure that you know what you have agreed to and you will be asked to sign it if you are still happy to continue with an interview. I will then ask you questions about your experience of moving from CAMHS to AMHS. There are no right or wrong answers, you will have full control over what is said and can take a break or stop the interview whenever you need to.

Will the interview be recorded?

With your consent, the interview will be audio-recorded; you may stop the recording at any time during the interview. After the interview, I will type it out word-for-word in a transcript. This will help me to develop a good understanding of your experience and our discussion. The recording of your interview will not be listened to by anyone else and will be destroyed once it has been typed up. Everyone who takes part in the study will be given a code name so only I will know which interview was yours.

Will my taking part in this study be confidential?

Yes. As outlined above, you will be given a code name and so will not be able to be identified by anyone apart from me. All names and other identifiable information (for example, names of places) will be removed or changed.

Recordings and any paper copies (transcripts) of the interviews will be stored in a locked drawer at the university, any electronic copies of transcripts will be password protected in

order to make sure that you remain anonymous. During analysis of the data I may discuss parts of what you have said with my supervisor, but if this happens I will only use your code name. I may also your words (quotes) from the interview in the write up and publication of the study. Again, only your code name will be used and so only I will know that the quote came from you.

If, during our interview, you share information that makes me concerned for your safety or the safety of other people, or if a criminal act that isn't already known about comes to light, I will be required to tell others involved in your care and support (e.g. your Project Worker and/or the Team Manager). I will always let you know if I am going to do this, and will explain why.

What are the benefits of taking part?

It is hoped that young people will welcome the opportunity to talk about their experiences of using a CAMHS service and what it was like for them when it was time to move on/leave the service. We also hope that we will be able to identify any factors that have been helpful or unhelpful so that we may be able to make recommendations for how services and support could be improved for other young people as they move from CAMHS and enter AMHS.

What are the 'down sides' of taking part?

Some people may find it difficult or upsetting to talk about their experiences. If you became upset at any time during the interview we can take a break or, if you prefer, stop the interview. There is no rule to say that you must carry on, you can withdraw from the study, and this will be ok. The Transition Project worker will also remain nearby at the interview location and be available to offer you any further support before, during and after the interview. I will also provide you with a list of organisations which you can take away with you to contact following the interview.

What will happen to the findings of the study?

This study will be written up as a Doctoral thesis and submitted as part of the Doctorate in Clinical Psychology. It is hoped that the study will be written up for publication in a journal and also as a summary report for young people and the xxxxxxxx Transition Service

If you would like a summary of the thesis following completion of the study, please contact me via email (address below)

Who has reviewed this study?

This study has been subject to review by Cardiff University School of Psychology Research Ethics Committee.

What if I have a problem with the study?

If you are unhappy with any aspect of the study or have any concerns, please contact me (Beth Hayward-Bell), Dr Jane Onyett (Clinical Director at the South Wales Doctoral Training Programme for Clinical Psychology) via the contact details below.

If you are still unhappy after speaking to us and want to make a complaint, you can do this by contacting the Cardiff University School of Psychology Ethics Committee:

Secretary of the Ethics Committee, School of Psychology, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT

Tel: 02920 870 360

Email: psychethics@cardiff.ac.uk

Web: http://psych.cg.ac.uk/aboutus/ethics.html

Further information:

If you have any further questions about taking part in the study or require any more information, please do not hesitate to contact me:

Beth Hayward-Bell, Trainee Clinical Psychologist, School of Psychology, Floor 11, Tower Building, 70 Park Place, Cardiff. CF10 3AT. Email: HaywardBH@cardiff.ac.uk

Or my supervisor:

Dr Jane Onyett, Consultant Clinical Psychologist and Clinical Director, School of Psychology, Floor 11, Tower Building, 70 Park Place, Cardiff. CF10 3AT. Email: Jane.Onyett2@wales.nhs.uk

Thank you for considering taking part in this study and for taking the time to read this information sheet

APPENDIX VIII: PARTICIPANT OPT-IN FORM







Participant Opt-In Form

Moving from Child to Adult Mental Health Services: Young people's experience of a Transition Service

Thank you for reading the Participant Information Leaflet. Please may you let me know if you are interested in taking part in the study and are happy for me to contact you by **ticking one** of the following options:

You are reminded that it is entirely up to you whether you wish to take part in this study. A decision to not take part will not affect any care or support that you receive, now or in the future.

Voc	Lam interacted in the	atudy and would like to kno	www.moro Logroo for the
		study and would like to kno Please enter your contact	•
		n more about the study and not need to provide any con	do not wish to be contacted ntact details.
•		ppe provided. You may pas able to pass it on to me.	s the envelope on to the
With thanks	,		
Beth Havwa	rd-Bell, Trainee Clinical	Psychologist	
		· · · · · · · · · · · · · · · · · · ·	
If you have a	answered 'Yes' above,	please provide the followin	ıg:
Your name:	·		-
Address:			
Telephone	number:		
E-mail addr	'ess:		
The best wa	y to contact me is by (p	lease circle):	
	Letter	Telephone	E-mail

APPENDIX IX: PARTICIPANT CONSENT FORM







Participant Consent Form

Agreement to take part in the study:

"Moving from Child to Adult Mental Health Services: Young people's experience of a Transition Service"

Please carefully read the following statements and if you are happy with each statement please **tick each box** and sign at the bottom.

THANK YOU FOR PARTICIPATING IN OUR RESEARCH

This research has been approved by the Cardiff University School of Psychology Research Ethics Committee.

Address: South Wales Clinical Psychology Doctorate Programme, School of Psychology, Cardiff University, Floor
11 Tower Building, 70 Park Place, Cardiff CF10 3AT

APPENDIX X: PARTICIPANT DEBRIEF FORM







Debrief Form

Moving from Child to Adult Mental Health Services: Young people's experience of a Transition Service

Thank you!

Thank you for helping us to understand what it is like for young people who move from CAMHS to AMHS with support from a Transition Service. It is hoped that the information gained will enable us to make recommendations for how services and support could be improved for other young people as they move from CAMHS to AMHS.

Your Information

The information you have given will be kept confidential and be held anonymously (using a code-name and not your real name).

The only time I would need to break confidentiality is if, during the interview, you share information that makes me concerned for your safety, the safety of other people, or a criminal act that isn't already known about comes to light. If this happens I will need to contact other people, this will be your Project Worker or the Transition Service Team Manager. I will let you know if I need to do this.

You are free to withdraw from the study without giving a reason, at any point up until four weeks after the interview, as this will be when data analysis begins.

Any worries

If you have any worries about the study or have any concerns, please contact me (Beth Hayward-Bell) or Dr Jane Onyett (Clinical Director at the South Wales Doctoral Training Programme for Clinical Psychology) via the contact details below.

If you are still unhappy after speaking to us and want to make a complaint, you can do this by contacting the Cardiff University School of Psychology Ethics Committee: Secretary of the Ethics Committee, School of Psychology, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT, by telephone: 02920 870 360; or via email psychethics@cardiff.ac.uk

Support

Overleaf are the contact/web details of various organisations you may like to contact if you would like further support or information.

Thank you again for taking part in the research

Researcher: Beth Hayward-Bell. Email: HaywardBH@cardiff.ac.uk

Supervisor: Dr Jane Onyett. Email: <u>Jane.Onyett2@wales.nhs.uk</u>

Contacts for further support or information

Young Minds

Young Minds is the UK's leading charity committed to improving the emotional well-being and mental health of children and young people. They offer information to young people and children about mental health and emotional well-being. www.youngminds.org.uk

TheSite.org

TheSite.org is an online guide to life for 16-25 year-olds in the UK. It is owned and run by YouthNet, a London-based registered charity which launched in 1995. They provide non-judgmental support and information on everything from sex and exam stress to debt and drugs. Emotional support is available online 24 hours a day. www.thesite.org

Samaritans

Samaritans volunteers listen in confidence to anyone in any type of emotional distress, without judging or telling people what to do.

Tel: 08457 90 90 90 (24 hrs 7 days a week)

www.samaritans.org

Get Connected

Free, confidential telephone and email helpline finding young people the best help whatever the problem. Provides free connections to local or national services, and can text information to callers' mobile phones.

Freephone: 0808 808 4994 (7 days a week 1pm-11pm)

www.getconnected.org.uk

APPENDIX XI: SEMI-STRUCTURED INTERVIEW SCHEDULE

Introduction (not read verbatim)

Thank you for agreeing to meet with me today. As you know, my name is Beth and I am a Trainee Clinical Psychologist. I am conducting a research study exploring the experiences of young people who have moved from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) with support from a Transition Service. As you have had the experience of moving from child to adult services within the last three years I would like to spend some time talking to you about your experience of that move. There are no right or wrong answers; it is your personal experience and feelings that I am interested to hear.

Firstly I will ask about your experience of CAMHS, the move from CAMHS to AMHS and your experience of AMHS. After that we will have some time to talk about the support that you have received from the xxxxxx Transition Service.

If you would rather not answer a question or would like a break at any point just let me know.

Before we start, I would like to talk through the consent form with you to ensure that you understand what taking part in this study will involve and that you are happy to continue with our interview today (each item on the consent form will be discussed with the participant).

I would like to remind you that our conversation will remain confidential. The only time where this would not apply is if you told me something that made me concerned that there was a risk of serious harm to either yourself or to another person. If this happened I would be required to tell others involved in your care, such as your keyworker. However, I will always let you know when and why I was doing this.

During our interview it is important that I listen to you very carefully so I am planning on recording the interview (point to the digital recorder). Only I will hear the tapes, and I will keep them safely locked in a filing cabinet back at the University.

Are you happy for me to record our conversation?

Topic Guides: (prompts in brackets)

CAMHS experience

• Could you tell me the story about how you first came to see someone in CAMHS? (How old were you when you were first seen? Whose decision was it for you to be seen there? Who did you see?)

Could you describe your experiences of CAMHS?
 (What were the best things, what were the worst things? were your family involved?)

Transition process –planning for transition

Thinking about the time <u>before you moved to AMHS</u>....

- How did you come to know that your time in CAMHS would be ending?
 (what were you told and by whom? how far in advance did you know, what was your understanding of the reasons for the move to adult services?)
- How did you feel about leaving CAMHS?
 (how did you feel about the prospect/timing of transition? What did you expect to happen when you left CAMHS?)
- How did you (and others) prepare for the move?
 (Was there anything that was particularly helpful/unhelpful? E.g. Did you have an initial meeting with someone from the adult service? Is there anything that could have been done differently to help you to prepare for the move?)

AMHS experience

Thinking about the time that you moved into adult services...

- How did you feel about being seen in AMHS?
 (What were your expectations? are your family able to be involved? how does that feel?)
- Could you describe your experiences of being in AMHS?
 (How are you being supported? Are there any ways that AMHS has been better/more helpful or less helpful than CAMHS?)

Impact of transition

- Do you feel that the process of moving from CAMHS to AMHS has affected your life in any way?
 (Do you feel it has had any effect on your independence; changed the way you engage in services; changed the understanding of your problems?)
- Thinking back, is there anything that could have been done differently to support you to access AMHS?

The Transition Service

Can you tell me how you came to access the xxxxxx Transitions Service?
 (Who told you about the service? What did you know? Was it clear what the service was offering?)

- Were you involved in setting up the support you receive? (How did that feel for you?)
- Can you tell me about the support that you have received? (What were your expectations/hope/fears? Which aspects of the service have helped you the most? In what way? Which aspects have helped less? In what way?)

Is there anything else you would like to say about your experience of moving from CAMHS to AMHS that we haven't talked about?

Thank you for telling me about your experiences and reflecting on what the move has been like for you. We have now finished the interview, but I have some time if you would like to talk about how you have found the interview experience or if you would like to ask me any more questions.

Additional probing question examples:

Can you tell me more about that? Can you give me an example? What did you think about that? How did you feel about that? What did that mean for you?

APPENDIX XII: FREQUENCY OF SUBORDINATE THEMES WITHIN TRANSCRIPTS (INCLUDING LINE NUMBERS)

Subordinate Theme	Anna	Ben	Connie	Della	Emma	Fran	Gareth
"You're mental"	226, 301-304, 320-324	8-10, 48-49, 90- 92, 98-101, 517- 519	55-57, 587-589	113, 43-45	4-5, 37	11-14, 59, 113, 130-133, 137- 140, 155-158, 151-153	77-78
"It's OK to not be OK"	11-13, 56-59	49-53, 69-71, 508-511	134-135	76, 125-126, 154- 157, 281	11-13, 40-43, 70- 75	35-39, 52-61, 109-111,331-338, 586, 638-641, 660-665	127-129
"What about what I want?"		235-238, 302-304	9-11, 49-51, 253-256, 288- 302, 301-304, 315-316, 327- 328	14, 98-103, 104- 107, 145-147, 202-207, 252- 255, 264	15-26, 28-30, 35, 214-216,	82-87, 174-178, 831	50-55, 73, 130, 241-242, 353-355
"You don't know how it is"	106-109, 113- 114, 116-117, 147-149, 151- 152, 157-158, 164, 254	126-127, 191- 193, 276-277, 293-294, 386- 388, 462	229-230, 254, 412-416, 419- 421, 445-452, 483-484, 486- 492	229-231, 307- 308, 343-346, 348-351	109-110, 119- 121, 135-141, 144-147, 164- 165, 167-172	20-24, 240-242, 252, 261, 341- 344, 374-378, 388-392, 457- 459, 481-484, 687-690	109-110
"They think something magic happens"	256		215, 253-255, 257, 270-273, 275-277, 347- 350, 360-362, 366-367	79, 390-393, 400- 403, 405-406, 443-448, 457-458	157-159, 164- 165, 232-236	117-121, 229- 233, 242-247	
"Tossed out on my own"		173-178, 243- 247, 250, 258- 259, 433-434, 469-470, 621-623	356, 376, 386- 389, 444-445, 449-452	170-171, 281- 283, 311, 387- 390, 470-473		21-22, 390-393,	150-151

"In the deep end"	334, 375-376, 385-386, 421- 423, 306, 308- 315	76, 111-114, 283- 284, 334, 488- 490, 527, 598-601	223-226, 235- 238, 242-247, 281-283, 308- 315, 323-325, 339-342, 366- 369, 432-435, 488-490, 587- 599	319, 352-330, 387-390, 432- 433, 470-473	475-476, 587- 590, 647-648, 670-675, 641- 646, 454	390-393, 557- 562, 586-587, 587-591, 630, 641-648	153-155, 306, 308-315, 334, 375-376, 385- 386, 421-423
"You're supposed to care"	398-399	44-47, 298, 302- 303, 321-329, 351-352, 360- 362, 368-369, 375-376, 524- 525, 526-528	64-68, 136-144, 149-151, 237- 241, 463-466, 485-486		322-323	220-223, 278- 281, 387-389, 400- 422, 427- 434, 450-452, 487-495, 696- 700, 721-725	232-234, 244-249
"I feel like an adult"	92-94, 270-272, 281-282	492-496	557-558	388-389, 479-481	202-204, 239- 240, 250-255, 257-259, 266- 267, 383-388	71-73, 181-182, 621-624	114-115, 168- 169, 172-173, 184-185 221-223, 227, 273-274, 283-284, 356- 357, 386-387
"Having someone there"	369-372, 387- 389, 393-394, 398-399	236-237, 262- 264, 380, 551, 612-613, 617-619	364-367, 547- 548, 612-613, 619-620, 678- 679,	164-165, 375, 504-507, 557-578	332-323, 361- 365, 375-379,	522-524, 560- 561, 562-563, 567, 696- 700, 721-725, 762, 770-772, 821	153-155
"Taking hold of your own care"	48-49, 353-356, 417-418	584-588	642, 636-637	530, 533, 547-549	70	757, 773-774, 798-801, 802- 808, 817-819, 844-846, 850	313-314, 317-321
"All in it together"	402-404, 412- 413	631-632, 634-635		466, 566-567	341-347	711-712,773-774, 777	