Leaving School – Transition Experiences and Routes Taken by Disabled Young People

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Abstract

This thesis examines the transition experiences of 17 families leaving five special schools over a period of two calendar years. It is multi-dimensional, exploring the ideas and perspectives of young people, their parents and relevant professionals. The study re-assesses and explores transition preparations in light of current policies and guidelines of good practice, especially transition planning via The Code of Practice (1994). Within the study, professional processes and procedures preparing young people for the transition from school and progression towards 'adulthood' are explored, alongside family experiences of these preparations and future 'adult' aspirations.

The study demonstrates that families welcome and look for professional support during school-leaving preparations, especially school support. A number of important areas are explored, for example, information, family participation and inter-agency working. Positive steps have been, and are being made, but the study reveals that these are areas still in need of improvement. Many families would have welcomed more information, and participation is an area requiring on-going consideration.

Past studies have demonstrated that the transition to adulthood for disabled young people is often extended or even postponed. In this study, even though sample members were still engaged within the transition from childhood, two case studies of positive steps towards greater independence help to unravel the complexity of the concept, 'adulthood'. The case studies also highlight the multi-layered, and often gendered, nature of transition. However, for the majority of young people, 'adult' markers remain aspirations yet to be achieved. For some, the traditional institutional status transitions were not yet available and also, frequently deemed 'inappropriate'. A significant number of these families had come to view residential college as an important surrogate mode of transition. This thesis argues that the role of residential college is important and should not be ignored, even though it remains a controversial issue.

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Acknowledgements

Declaration

Some of the material within Chapter Two, particularly the discussion of the literature surrounding disabled young people and transition to adulthood was drawn upon within a joint paper, presented at the Youth 2000 Conference (University of Teesside, Middlesbrough, UK) on 21st July 1995 by Bob Coles. The paper debates the concept of an 'underclass' with reference to three groups of 'vulnerable' youth (young people leaving care, disabled young people and young people involved in crime) :-

> Baldwin, D., B. Coles and W. Gilbert (1995). <u>Three Groupings and a Framework: Youth Transitions, Social Exclusions and Allegations of 'Underclass'</u>, Department of Social Policy, University of York.

This paper has subsequently been refined (to focus upon two groups) and published within a compilation of papers from the Youth 2000 Conference. Within the process of refining, the case studies within Chapter Seven were noted in passing, however, the published chapter does not report or discuss the fieldwork:-

> Baldwin, D., B. Coles and W. Mitchell *[née Gilbert]* (1997). "The formation of an underclass or disparate processes of social exclusion? Evidence from two groupings of 'vulnerable youth' ", in R. McDonald (Ed.) <u>Youth, The 'Underclass' and Social Exclusion</u>, London, Routledge: 83-95.

I declare that this thesis is the product of my own work and that to the best of my knowledge all sources have been acknowledged.

Signed: _____   Date: _____

Wendy Mitchell

Chapter 1 - Thesis Overview

One of the most important changes within the life-course is the movement from 'childhood' to 'adulthood'. This takes place through many different dimensions of experience, for instance: biological, legal, social, cultural, emotional and attitudinal. It is also important to recognise that the concepts, 'childhood' and 'adulthood' are ambiguous and hard to define (Jones and Wallace, 1992; Coles, 1995). This is partly due to the fact that they are not static concepts but are historically and culturally fluid, open to interpretation and change (Ward et al, 1991; France, 1996). Despite this conceptual ambiguity, the transition from 'child' to 'adult' status is viewed as an important achievement within society. However, it is a complex, involved process, which evolves over a period of time. Of course, not all young people undertake the transition in a similar manner or at the same pace. Social ideas and prejudices, whether these are class, gender, race or disability based, can and do effect the transition experiences of different groups of young people. This thesis focuses upon the transition experiences of disabled young people, a group frequently forgotten or hidden within discussions of 'youth'. However, within past studies (Centre for Educational Research and Innovation (CERI), 1985; Clark and Hirst, 1989; Ward et al, 1991; Flynn and Hirst, 1992; Davies and Jenkins, 1993; Thomson and Ward, 1994; Hirst and Baldwin, 1994) one factor has repeated - the transition to 'adulthood' is frequently extended or "prolonged" for disabled young people.

Appreciating both the conceptual ambiguity and the extended nature of the transition to 'adulthood' for disabled young people, this study focuses upon a more discrete, identifiable and significant period within the transition years – leaving school. As institutions, schools are generally imbibed with social status distinctions and power differences, for example, the clear division between teachers (staff) as 'adults' and pupils as 'children'. Hence, leaving school both on a everyday and an academic level is frequently perceived as a time of potential change for young people, socially and/or economically. Leaving school can also be an emotional experience, especially for disabled young people if they have attended a small, special school from a very early age (Barnes, 1991).

Recognising the significance of this important period within the transition to 'adulthood' this thesis explores the experiences of 17 families leaving five special schools over a period of two calendar years. The study is based upon listening to the ideas and experiences of young people talking about transitions. However, one cannot view the young people in isolation. They live with families/carers and attend 'special' institutions, which in turn exist within wider society. Consequently, a multi-dimensional perspective is adopted, exploring the transition from special school from personal and sometimes different perspectives of young people, their parents and relevant professionals. Furthermore, it is important to recognise that although each is a social actor, the different actors interact. Ideas and actions are frequently influenced and guided by the wider social and material context within which we live. Indeed, as disability theorists demonstrate, society is predominately focused upon, and for, the 'able-bodied'. Hence, disabled people regularly experience prejudice, inequality and exclusion within their lives. Society presents and perpetuates images of disabled people as 'dependent' and in need of 'care' whatever their age (Oliver and Barnes, 1993; Oliver, 1996b). Indeed, Barnes has written of their status as "eternal children" (1991, p.61). For disabled young people preparing to leave school and eager to embark upon the transition towards 'adulthood' this prejudice, inequality and exclusion is frequently accentuated and thus experienced even more acutely.

Within this study two important issues and areas are explored: the policy and practice of professionals preparing young people for transition and family experiences and the future aspirations of the young people and their parents. Within the former, the focus is upon the processes and procedures, which seek to prepare young people and their families for the transition from special school and their progression towards a more 'adult' life. For many disabled young people this also coincides with a service transition from school or 'child' based services to 'adult' services. Secondly, the study explores young people and their parents' experiences of school leaving preparations and moving onto their 'next-step'. It also examines their hopes and aspirations, both as they move onto the 'next-step' and also for the 'future'. The study thus seeks to place the ideas and experiences of those involved within and embarking upon the transition from special school in context, more specifically, both the institutional context of special schools and also a wider policy context. The mid 1990's is an opportune moment to stand back and re-assess the transition experiences of disabled young people, especially their school leaving experiences. This is due to the legislative and policy context, which has developed during the mid 1980's to early 1990's within which familiar but very important themes, such as, early transition planning, inter-agency working and participation have been re-emphasised and reinforced. This study provides an opportunity to re-assess and explore preparations in light of current policies and

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guidelines of good practice. In particular, it examines 'transition planning' within the *Code of Practice on the Identification and Assessment of Special Educational Needs* (DFE, 1994). Furthermore, due to the study's longitudinal element, the thesis explores the young people's initial and ongoing transition towards 'adulthood' within two spheres. Firstly, it begins to unpack or explore the complex concept of 'adulthood' from the perspective of the young people and their parents and secondly, it considers the issue of 'progress'. Have the young people taken steps towards a more 'adult', independent life? – and if so, in 'what' areas and 'how'?

Thesis Outline

The next chapter places the thesis within the context of past research and highlights its contribution to the study of transition for disabled young people within the policy context of the mid 1990's. Before examining the position of disabled young people within previous transition studies, chapter two discusses important areas of debate. The chapter concludes with a consideration of the current policy context, which young people and their parents face when leaving school.

Chapter Three documents the study's research design and methodology. Since research within the sphere of 'disability' is an extremely controversial issue, this chapter initially establishes the study's research aims and defines its parameters. Consideration is also given to the choice of research methods, especially in light of its focus upon the ideas of young people with learning disabilities. The chapter concludes with an assessment of the study's fieldwork, insights and knowledge gleaned and problems encountered.

Chapter Four is the first of four chapters presenting the results of the fieldwork carried out from 1995 to 1997 and provides a professional overview and assessment of the transition from special schools. Chapter four introduces the five focus schools and considers a range of transition issues. In particular, it explores programmes and polices which seek to prepare young people for the 'next-step' and 'adulthood' and also for the movement from school or 'child' based services to 'adult' services. The chapter compares policies and programmes, explores areas of good practice, and highlights areas of concern.

Chapter Five continues to assess school-leaving preparations from a professional perspective within institutional contexts, primarily special schools. In contrast to the general overview in chapter four, this chapter focuses upon the policy of early, inter-agency transition planning. In particular, it examines the Code of Practice's (1994) guidelines for the writing of transition plans for all statemented young people from 14 years. Chapter five examines the focus schools' implementation of transition plans and

professional evaluations. It thus seeks to assess and discuss both progress made and highlight emerging areas of concern.

Chapter Six concentrates upon both educational and welfare transitions. However, in contrast to chapters four and five, the focus is on the personal experiences and evaluations of young people and their parents. The chapter explores their feelings towards, and assessment of, preparations from both a pre- and post-school perspective. In particular, it examines planning, support and information available and the question of participation for young people and their parents. Once again, the chapter highlights areas of good practice and areas of concern.

Chapter Seven moves beyond school leaving preparations to explore the idea of a changing social status interwoven within perceptions of the transition from 'child' to 'adult'. The chapter explores perceptions of 'adulthood' with the aid of two case studies of young people who have begun to take significant steps towards a more independent life. The case studies provide an opportunity to begin unpacking and exploring the concept of 'adult' status. They are also used as a touchstone from which to compare and contrast the position and progress of other young people within the wider sample.

Chapter Eight provides an overview of five themes, which have been continually discussed and highlighted within chapters four to seven. With the aid of these themes the chapter compares the many different perspectives and criteria of assessment that have emerged within the study. Drawing these together, chapter eight summarizes and discusses areas of good practice and areas of shared concern. The chapter concludes by exploring some specific policy developments and then considers, how a number of government policy proposals in the future, could impact upon the transition to 'adulthood' for disabled young people.

Chapter 2 – Literature Review

Introduction

The literature reviewed within this chapter will focus upon young people preparing to leave special schools and the move towards adulthood. This encompasses many different and complex ideas, concepts and policy directives. Hence, this review will provide a brief synopsis of some of the issues, which the literature over the past 20 years has addressed. It will draw together key themes and highlight the many problems and challenges that young people have faced as they prepare to leave special education and seek 'adult' independence. Furthermore, the review will also highlight many of the unanswered questions and issues that have arisen as the policy context has changed during the past decade. The aim is thus to explore important areas, which in the mid to late 1990's require investigation and further consideration.

The review will be divided into three sections. The first will introduce and explore the ambiguity and debate that surrounds three key concepts: 'disability'; 'special educational needs' (SEN); and transition to 'adulthood'. The second section will examine what is currently known about the transition to 'adulthood' for disabled young people. And the third section will consider the changing policy context, its potential for young people as they leave special education, and issues requiring further investigation.

2.1 Concepts, Conceptual Ambiguity and Debate

Considerable ambiguity surrounds conceptualising the terms 'disability', 'SEN' and transition to 'adulthood'. This can be demonstrated most clearly by the fact that different definitions are frequently applied by different acts of parliament to the same young person. For example, a young person can be a pupil with 'SEN' within education legislation (e.g. Education Act, DFE, 1993); a 'disabled' person within disability legislation (e.g. Disabled Persons Act, DHSS, 1986); or a 'child in need' within the Children Act (DoH, 1989). However, these labels are not always synonymous with one another or consistently applied and they are frequently open to interpretation (Middleton, 1992, p.71). There is also some confusion over service inconsistencies (Middleton, 1992; Griffiths, 1994; Fish and Evans, 1995; Cooper, 1996). This is

especially pertinent during the transition years when young people prepare to leave school and move from child to adult services.

2.1.1 The Concept of 'Disability'

'Disabled people' is a frequently used term by the media and within academic writing. However, it is important to recognise that the 'disabled' are in many ways an extremely heterogeneous group. Within the diverse literature surrounding 'disability' there are many different discourses and theoretical perspectives. Fulcher (1989, p.26) has highlighted four: medical, lay, charity and rights discourses. Within these it is important to distinguish between 'impairment' and 'disability' as they are conceptually distinct and have been theorised in different ways. The following synopsis will focus upon the most prominent discourses (medical and rights). In fact, Fulcher argues that the medical discourse has influenced both lay and charity discourses.

2.1.1.1 Medical Discourse/Model

Within medical discourses Fulcher (1989, p.27) argues that 'impairment' is equated to 'loss', hence, the focus upon individual deficiencies. Summarising them, she highlights three key ideas: 'individualisation'; 'professionalisation'; and 'depoliticisation' (see also Barnes, 1991; Dalley, 1991; Barton, 1993; Oliver and Barnes, 1993; Mason and Rieser, 1994; Oliver, 1996b). Medical discourses are felt to individualise disability by emphasising that the individual has the disease or 'problem'. Oliver (1996b, p.32) too has noted the importance of what he terms a negative "personal tragedy theory of disability". This refers to individual tragedy with the onus upon the individual's 'problems' of impairment. This discourse also incorporates a general belief in the importance of professionals, especially the medical profession, their 'expertise' and intervention. It assumes that the disabled person requires medical expertise and input, and that professionals can help to alleviate disabled peoples' problems through 'separate', 'special' services. In this way Oliver (1996b, p. 37) argues that "the ideology of normality rules", professionals seeking to help disabled people towards society's idea of 'normality' and thus acceptability. Ultimately, Fulcher argues that the onus upon scientific status and ideas of 'neutrality' serves to depoliticise disability.

2.1.1.2 Social Model (Rights Discourse)

In contrast, rights based discourses perceive 'disability' as a social phenomena. However, there are many different social model theorists and thus theories. This synopsis will, focus upon some of the key principles underpinning this perspective (see also Barnes, 1991; Abberley, 1987; Swain et al, 1993; Mason and Rieser, 1994; Barnes

and Mercer, 1996). At the heart of this model lies the idea that the 'problem' of disability is a social construction; it is a social problem rather than an individual one. Society creates barriers, which exclude people with impairments from participating fully within society; it 'disables':

> "It [social model] does not deny the problem of disability but locates it squarely within society. It is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide adequate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation." (Oliver, 1996b, p.32)

Social model theorists have understandably rejected the International Classification of Diseases as narrow and medicalised. Furthermore, many also reject the World Health Organisation's (WHO, 1988), International Classification of Impairment, Disability and Handicap (developed from the work of Wood, 1980 – see Baldwin and Carlisle, 1994, p.12). This classification may be broader, introducing a social element and conceptually more sophisticated. However, theorists such as Oliver (1983, 1996b) feel that it still does not address adequately social causes (French, 1994b, p.14). In preference, Oliver highlights The Union of the Physically Impaired Against Segregation's (UPIAS) twofold classification of 'impairment' and 'disability'. Impairment is presented in physiological terms, whereas disability is viewed as a social problem, distinct from impairment:

> "Disability is something imposed on top of our impairments..." (Oliver, 1996b, p.33 from UPIAS, 1976, p.14)

The WHO schema is viewed as seeking "normal social roles" (Oliver, 1996a, p.43) whereas, the social model is felt to move beyond this to celebrate 'difference'. At the heart of this lies the politicisation of disability and questions of equality, hence, the importance of 'citizenship' and 'rights' for disabled people. Furthermore, many social model theorists perceive the legal definition of 'disabled' (e.g. National Assistance Act, 1948 or the Chronically Sick and Disabled Persons Act, 1970) as narrow and medicalised, arguing that it often equates 'illness' and 'disease' with 'impairment' and 'disability' (French, 1994b, p.14).

Many social theorists have focused upon the exclusion of physically disabled people. Walmsley (1994) seeks to redress this by demonstrating the importance and potential of a social model perspective for people with learning disabilities, with the written word as an important dimension through which social exclusion takes place. In addition, Walmsley has also questioned 'normalisation' principles, which underpin many policy directives and service provisions. On one hand, it is important to recognise Wolfensberger's aims to break down the idea of 'difference', and nurture a valued

rather than devalued position in society for people with learning disabilities (see O'Brien, 1981). However, Walmsley (p.150) highlights how the onus is still upon individuals with learning disabilities adapting and conforming, rather than society changing (see also Brown and Smith, 1989; Corbett and Barton, 1992). Furthermore, as the social model has developed, so have internal debates. Indeed, a number of controversial areas have arisen and are debated, a factor Oliver (1996a, 1996b) himself acknowledges. For example, French (1993) has noted that not all impairments can be 'resolved' through social changes, and Crow (1992) has argued that the social model frequently denies the importance and experience of 'pain' within disabled people's lives. Furthermore, some theorists argue that the social model ignores other forms of oppression which disabled people experience, such as gender (Morris, 1991), race (Stuart, 1993) and homophobia (Hearn, 1991). These theorists do not deny the importance of the social model but rather stress the diversity of social reality and, hence, the complexity of disabled peoples' experiences.

2.1.2 The Concept of 'SEN'

The concept of 'SEN' was introduced by the Warnock Report (DES, 1978) and legally enacted through the 1981 Education Act (DES). It replaced the use of eleven different "categories of handicap" (Adams, 1990, p.7) stipulated within the 1944 Education Act. The term 'SEN' has been retained within education legislation and is defined as:

> "For the purposes of the Education Acts, a child has 'special educational needs' if he has a learning difficulty which calls for special educational provision to be made for him." (Education Act, 1993, Section 156:1)

In many ways the term 'SEN' can be perceived as a positive development, homogenising many different impairments into one all embracing concept (Dee, 1993) based on "a broad continuum" of needs (Riddell and Brown, 1994a, p.7). On one hand, social model theorists, such as Barnes, acknowledge this distancing from the 1944 Act's prior medicalisation, but, feels that the concept still focuses upon the "inadequacy of the individual" (1991, p.33). Other social model theorists have reiterated this feeling:

> "The disabling culture transforms ordinary human needs into special needs and corrupts the identity of disabled children into special needs children." (Finkelstein and Stuart, 1996, p.180)

2.1.2.1 Statementing Pupils

Amongst pupils viewed as having 'SEN' it is important to recognise that not all pupils have a statement of 'SEN' and that statementing is used selectively. Warnock (DES) estimated that approximately one in five children could have special educational needs

at some point in their education, but only around 2% would be likely to need a statement. Currently it is estimated that approximately 3% of pupils have a statement. This is a figure the present Government wants to reduce, moving closer to Warnock's 2% (DfEE, 1997, p.9).

Statementing was introduced by the Education Act (1981). However, as a policy it has been beset by problems and inconsistencies (Russell, 1994; Coles, 1995; Dyer, 1995; Fish and Evans, 1995). This was confirmed by the Audit Commission Report (1992, p.1) *Getting in on the Act*, which highlighted three key problems: firstly, the lack of 'clarity' surrounding the concept 'SEN'; secondly, the lack of 'accountability' of schools and local education authorities (LEAs); and finally, inadequate 'incentives' for LEAs to implement the Act (see also Audit Commission, 1994). Indeed, Fish and Evans have highlighted the potential for ambiguity and inconsistencies because the concept of 'SEN' is "... a relative one based on the performance of a child's contemporaries" (1995, p.43). Hence, both schools and LEAs have to make relative decisions deciding if a pupil's learning difficulties are 'significant'. The problem of regional variation has also been frequently noted. Coles (1995, p.156) has argued that financial considerations, in particular, authorities willingness to make resources available, can and does impinge upon statementing procedures. Furthermore, Barnes (1991) has drawn attention to the problem of time delays and a lack of information for parents throughout the process.

The Government has sought, in part, to address these inconsistencies through the Education Act (DES, 1993) with the introduction of the Code of Practice on the Identification and Assessment of Special Educational Needs (DFE, 1994). The Code established what was hoped to be a more comprehensive set of guidelines and procedures for schools and professionals to follow. Five assessment stages were highlighted, the first three were to be school based but the latter two were statutory stages. Thus, it is only within stages four and five that the LEA becomes involved, with stage five culminating in the issuing of a statement. The Code also sought to address the problem of delay, developing targets for the issuing of statements (26 weeks from a request being made to the issuing, p.46). However, inconsistencies still remain. For example, the recent Green Paper – *Excellence for all children: Meeting Special Educational Needs* (DfEE, 1997) has re-emphasised regional variations and lengthy procedures. Within the latter, Audit Commission figures revealed that only 40% of draft statements were produced within statutory time limits (p.41). Furthermore, questions have been raised concerning not only the clarity of the Code's guidelines, in terms of addressing the issue of national criteria, but also how needs will be met once identified (Fish and Evans, 1995, p.30 and 23).

2.1.2.2 Integration or Inclusion?

Integration as a policy has been continually highlighted within education legislation (1981 Education Act; 1993 Education Act). However, in practice developments have been slow and inconsistent. Coles (1995, p.155) has argued that a potential legal loophole has created "conditional escape clauses", which some LEAs have used to bypass moving towards greater integration. Currently, there are approximately 98,000 pupils educated in special schools (DfEE, 1997, p.45). However, integration remains a contentious area. Parents have been repeatedly concerned about the support and education provided within mainstream schools (DfEE, 1997; Barton, 1995), whereas social model theorists have stressed the dangers of social exclusion through special educational provision (Brisenden, 1987; Barnes, 1991; Mason and Rieser, 1994).

Within these debates there is an important conceptual difference between 'integration' and 'inclusion' (see Sebba, J with Sachdev, D., 1997 for a more in-depth discussion). Social model theorists, especially Oliver (1996b, chapter six) stress that 'inclusion' is a political issue, fundamental to disabled people's rights. It is a process that demands moving beyond traditional ideas of simply 'adding on' disabled pupils, to a more 'inclusive' ethos, which celebrates and welcomes 'difference'. On one hand, the growth of disabled people's pressure groups and discourses surrounding disabled people's rights can be seen in the changing use of terminology within official policy documents. For example, the DfEE's recent Green Paper (1997) talks of 'inclusion' rather than 'integration', highlighting this as a key policy objective. Within the Green Paper greater co-operation and collaboration between mainstream and special schools is proposed. Some special schools are to remain, however their role will be redefined and more flexible:

> "We aim to increase the level and quality of inclusion within mainstream schools, while protecting and enhancing specialist provision for those who need it." (DfEE, 1997, p.43)

How far this will be achieved remains to be seen. However, questions still remain concerning the potential for inclusion within a context where "the marketisation of education" (Riddell and Brown, 1994a, p.17) has been important within recent years. Policies of 'competition', 'targets' and 'outcome related funding' can create an environment which does not encourage the inclusion of the most vulnerable SEN pupils (Davie, 1993; Riddell and Brown, 1994a,b; Fish and Evans, 1995).

2.1.3 Transition To 'Adulthood'

"Adult status is easy to recognise but difficult to define ..." (Griffiths, 1994, p.1)

This phrase encapsulates the ambiguity and lack of legal consensus (see also Baldwin and Carlisle, 1994) that surrounds social perceptions of being an 'adult'. Furthermore, within concepts of 'childhood' and 'adulthood' there are frequently taken for granted ideas of 'dependence' and 'independence' but it is unclear when 'childhood' ends and 'adulthood' begins (Jones and Wallace, 1992, Coles, 1995). Thus, the concept of 'youth', as Coles (1995, p.7) suggests, is often viewed as an ambiguous phase within the life-course, a period of both dependence and independence.

2.1.3.1 Youth Transitions

Past literature has focused upon different models of, and approaches to, conceptualising the transition to 'adulthood'. For example, models premised upon phases (child to adult) and models focused upon institutional status transitions. Coles (1995, p.8), drawing . upon past analyses (see Wallace, 1988; Jones and Wallace, 1992; Jones, 1995) highlights three transitions: school to work; housing (movement out of the family home); and domestic (movement from "family of origin" to "family of destination"). The importance of exploring both public and private institutions has been documented (Jones and Wallace, 1992, p.141). However, the transition to adulthood is frequently perceived as more than institutional status transitions. Jones and Wallace (1992) introduce and discuss the importance of 'citizenship', (see Marshall, 1963 for a discussion of the concept) in particular, young people becoming full and active 'citizens'. Furthermore, they recognise inequity. Citizenship rights are not equally bestowed upon all young people or at the same time (1992, p.18). Hence, it is important to explore both the 'processes' that young people can pass through and wider social and structural inequalities, which can influence these processes (1992, pp.141-142).

Within their analysis, Jones and Wallace do not specifically discuss 'disability' as a form of inequality. However, this is obviously extremely important in considering disabled young people's experiences and position within a society, which is frequently disabling and imposes able-bodied norms and perceptions of 'independent' adulthood upon them. From a social model perspective independence is a complex phenomena, much more than the usual taken for granted images of active and physically independent individuals. In contrast, independence involves the individual feeling in control of their own life rather than being controlled by others (see Vasey, 1996 for a personal account). Hence, it is important to recognise that social relationships, attitudes, and the physical environment that disabled young people can and do face in their everyday lives guides their personal experiences of dependence/independence. In light of this, it is important

to recognise that past 'youth' transition models may not always be the most appropriate means to explore disabled young people's transitions to adulthood because the traditional presentation of transition is a very precise and linear one. The transition to adulthood for young people in general and disabled young people in particular is a much more complex and complicated process than the traditional institutional status transitions suggest. Jones (1995) recently highlighted this with regard to able-bodied young people's housing transitions. Furthermore, transition is clearly a process over time, as such, transition preparations within the school years are important to recognise and explore. However, traditional school to work models frequently ignore the important role that pre-school leaving transition preparations can and do play within the transition years.

2.1.3.2 Disabled Young People's Transitions

In contrast, when unpacking the idea of 'transition', Fish (1986, p.9) acknowledges the importance of school preparations. He divides the concept into three key stages: preparations at school; the transition phase, encompassing further education and vocational preparations; and finally, the early years of adult independence. Furthermore, he suggests that 'transition' must be perceived as both a "phase" - service focused and a "process" - of social and psychological development (1986, p.15, see also CERI, 1983; McGinty and Fish, 1992). Within the literature it is clear that past studies exploring disabled young people have prioritised and debated a range of indicators surrounding 'adulthood' and 'adult' status. However, many of these 'indicators' have mirrored the perceived outcomes within the three institutional transitions outlined by Wallace (1988), Jones and Wallace (1992) and Coles (1995).

One of the earliest analyses was Fish's 1986 (p.7) categorisation of four areas. These encompassed: "employment, useful work and valued activity"; "personal autonomy, independent living"; "social interaction, community participation"; and finally, "adult roles within the family". In contrast, Ward et al (1991, p.130) initially focused upon three slightly different areas: "legal aspects"; "the role of employment"; and "living independently". This is, as Tisdall (1994, 1996/97) has noted a more direct and less abstract list than Fish's. However, in a more recent assessment of the surrounding literature Thomson and Ward (1994, p.17) have extended their analysis to a fivefold classification, re-emphasising both direct and abstract themes, whilst also introducing the concept of "post-secondary education" as a significant indicator of 'success'.

An alternative interpretation and approach to the search for 'successful' transition goals has been advocated by Tisdall (1994, 1996/97). Whilst acknowledging Fish's 'psycho-social' approach, Tisdall is also critical of this, and other models which present young

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people as 'adolescents'. This is a concept, which she feels is problematic for three reasons. Firstly, 'adolescence' is frequently presented as a time of 'crisis'. Secondly, it focuses upon the individual and tends to ignore social factors. And finally, 'adolescence' is perceived as a "negative status", one which commands "little respect" within society (1994, p.9). Moving away from 'adolescence', Tisdall follows Jones and Wallace (1992) drawing upon the concept of 'citizenship'. However, for Tisdall, 'citizenship' is perceived as a means "to redefine the 'transition' problem" and challenges "society's failure to recognize young disabled people as full citizens" (1994, p.16). Ideally, disabled young people would be perceived as active and participating citizens, working towards identifying and defining "their own goals" (p.15). Hence, Tisdall has sought to move the transition debate beyond a search for the 'correct' 'adult' goals to a model premised upon respecting and listening to disabled young people.

Within the literature it is clear that the term 'transition to adulthood' remains the focus of conceptual ambiguity and debate. However, it raises many questions surrounding social expectations and presumptions, especially for disabled young people within a disabling society. Recognising this complexity, the thesis seeks to highlight and explore the multi-dimensional nature of transition for disabled young people. In doing so, it will draw upon not only objective and socially valued markers of 'adulthood', but also subjective evaluations and perceptions of 'adulthood' as experienced or aspired to by disabled young people.

2.2 Past Transition Studies and Issues of Concern

Section two explores a wide range of literature, however, it will focus predominately upon UK research as this provides a key point of reference for the ensuing study. Some European and USA literature will be referred to in order to draw comparisons and contrasts. Indeed, the important contribution of the work of Centre for Educational Research and Innovation (1983, 1985, 1986) must be recognised as it was one of the first to explore and compare the transition to adulthood for disabled young people within a European context. Literature from the UK will be divided into two broad sections: earlier studies (conducted during the 1970s and early 1980s) and more recent studies (from the mid 1980s to early 1990s). Within the latter, four key studies emerge. Firstly, Ward et al (1991 – 1995) conducted a series of studies in Scotland which focus upon young people with records of needs (England and Wales, statements of SEN). Secondly, Hirst and Baldwin (1994) carried out a national study of disabled young people (using OPCS criteria) of which Flynn and Hirst's (1992) report into the lives of young people with learning disabilities formed a part. Thirdly, Davies and Jenkins (1993, forthcoming) conducted a localised study of Welsh young people with learning disabilities; and, finally, Tisdall (1996, 1996/97) carried out an in-depth comparison of

Scottish and Canadian transition planning meetings. This research is varied, both in terms of the young people studied, the labels attached to them, and the research methods adopted (e.g. sample scope and data collection methods). However, despite these studies it is still important to recognise that the lives of disabled young people and young people with statements of SEN remain a relatively under-researched area, as the Government's recent Green Paper noted; there is:

> "A lack of reliable information on the routes pupils with SEN take when they leave school..." (DfEE, 1997, p.75)

2.2.1 Preparations For School Leaving

Within the literature the importance of early and planned transition preparations at school is continually stressed. Ideally, the aim is to promote professionals working both collaboratively together and with young people and their families to provide broad and balanced leavers programmes (CERI, 1983; Fish, 1986; McGinty and Fish, 1992). McGinty and Fish emphasise the importance of a varied curriculum for disabled young people, including vocational opportunities (especially real work opportunities); independent living skills and social participation within the local community (viewed as particularly important for special schools) (1992, pp.42-43). Many of these themes are reiterated within past literature from the USA (see Blalock and Patton, 1996, p.14) and the policy of individual transition plans. Writing at the beginning of the 1990s, McGinty and Fish have similarly noted the importance of individual transition plans as a preparational tool, welcoming a more coherent development of them within the UK. The Code of Practice (DFE, 1994 – England and Wales) has recently introduced policy guidelines advocating the writing of an individual transition plan, with inter-agency collaboration for all statemented young people from 14 years (a further discussion of this policy initiative is in section three of this chapter).

Research carried out before the mid 1980's presented a rather dispiriting picture. Both Anderson and Clarke (1982) and Hirst (1985) found that many physically disabled school leavers experienced inadequate leaving programmes and were frequently unprepared for leaving. In particular, Hirst (1985, p.46), although aware of resource constraints and a dearth of skilled professionals, highlighted three areas of concern: the variability surrounding leavers' programmes; poor school links to college and employment services; and a lack of information and guidance for young people.

More recent research reports some positive developments, such as an increasing number of schools extending their links to colleges and, more specifically, providing college link courses to prepare pupils for the transition (Stowell, 1987). However, progress is

not always univocal. For example, Armstrong and Davies' (1995, p.74) study of young people with SEN preparing to leave school found that careers advice and support was generally good whilst at school. However, it was when the young people left school that problems emerged. In particular, they noted an absence of a co-ordinated, post-school support infrastructure for some young people. This raises the important question of post-school support and service coherence for young people with SEN, an issue which will be considered further in section three of this chapter.

Furthermore, inter-agency transition planning in Scotland, as it has taken place, especially through the development of Future Needs Assessment (FNA) meetings has been studied by Tisdall (1996, 1996/97) and Thomson et al (1995). FNAs were introduced by the 1981 Education (Scotland) Act. Within England and Wales the 1981 Education Act advocated a re-assessment at 13½ years for statemented pupils, but this remained relatively undefined and undeveloped (Adams, 1990, pp.21-22). In Scotland, however, the theoretical potential of FNAs to improve pre-school leaving assessments of young people's needs (recorded) within a multi-disciplinary context has been widely recognised (Ward et al, 1991; Banks, 1993; Thomson et al, 1995b). But in practice problems have been noted (Thomson et al, 1995b; Tisdall, 1996, 1996/7). Tisdall found that FNA meetings were frequently narrowly focused and professionally managed. In particular, they were often short, uninformative for both young people and their parents, and conducted within a context which provided few opportunities for young people and parents actively to participate. Tisdall has questioned the role of professional, multi-disciplinary FNA meetings within the process of transition planning. In particular, professional perspectives surrounding "a discourse of 'management' " (1996/97, pp.10-11) which throws into question the ability of FNAs to be an "empowering" experience for young people (1996, p.30). These are important issues and raise doubts about the process and procedures of inter-agency transition planning meetings within England and Wales.

Alternative forms of support and guidance have been explored in Europe, for example, the 'kurator' system within Denmark. Here, a 'kurator' is often a specialist careers teacher with non-teaching hours specifically allocated for liaison with young people after they have left school and associated professionals (McGinty and Fish, 1992, p.82). The idea of a 'kurator' has been widely discussed within the literature and often presented as a potentially continuous point of contact and guidance for young people and their families, both pre and post-school leaving (Fish, 1986; Lovell-Badge, 1992; McGinty and Fish, 1992; Hirst and Baldwin, 1994; Tisdall, 1996). The literature has indicated that transition planning and preparations for disabled young people prior to school leaving are recognised as an important issue. Some developments have been

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made but important areas of concern remain - re-emphasised within literature from the USA by Gallivan-Fenlon (1994). Problems were still encountered within the timing of transition preparations; the level of support and information provided and the degree of participation and involvement both young people and their parents experienced.

2.2.2 The Transition To Adulthood – School to Work

The idea of a direct school to work transition is frequently acknowledged as a rather outmoded model. The transition from school to work has been prolonged for many young people through policies which have expanded further education (FE) provision and programmes of youth training as unemployment has grown. Very few young people move straight from school into work (Jones and Wallace, 1992; Coles, 1995). In addition, it is also important to recognise that when a young person does move into work, employment is by no means continuous; periods of unemployment can be experienced. Similarly, employment is no longer static, workers are expected to be flexible, re-skilling as and when necessary. Thus, the traditional idea of a 'job for life' is somewhat idealistic within the late twentieth century and this must be reflected in transition models and their perception of employment: a more flexible and broader approach is required.

The expansion of FE has also had an important impact upon the transition experiences of disabled young people. Increasing numbers of disabled young people are moving from school into FE and training, in particular and more recently, the former. For example, in 1996, Meager et al estimated that approximately 131,000 students with learning disabilities were attending college, roughly 5% of the total student population (FEFC, Tomlinson Report, 1996, p.6). Post-school education has thus become a significant part of many disabled young people's experiences. Ward et al (1991, p.26) found that for 21% of their sample, this was the first post-school destination. Consequently, it is important to explore the FE sector before one considers the question of the transition to work for disabled young people.

2.2.2.1 The FE Sector

The importance of expanding and developing FE provision for young people with SEN was noted by the Warnock Report (DES, 1978). Recent legislation has subsequently acknowledged this need in particular, the Education Reform Act (DFE, 1988) and the Further and Higher Education Act (DFE, 1992). Within the 1992 Act it is now Further Education Funding Councils (FEFCs), which have a legal duty to ensure that there is adequate FE provision for young people with learning disabilities under 19 years of age.

LEAs have moved to a more residual role, as colleges of FE became independent institutions (DES, 1991, p.14)

In practical terms there has been an expansion in both the number and variety of courses on offer to young people with SEN (Stowell, 1987; Fish and Evans, 1995). However, it is also clear that expansion has been relatively slow and provision erratic (Stowell, 1987; Bradley et al, 1994). Within past literature three concerns have been raised. Firstly, regional variations are evident and expansion has been patchy. Consequently, FE opportunities can depend upon where a student lives (Stowell, 1987, p.viii). Secondly, the persistence of 'special', separate courses has been viewed as a cause for concern (see the HMI Report, 1990 'Standards in Education, 1988-1989'). Barnes (1991) and Corbett and Barton (1992) have raised the danger of FE for students with SEN becoming a separate, segregated sector as in pre-16 education. The third and final concern focuses upon the problem of different levels of provision. Stowell (1987, pp.83-84) demonstrated that not all students were equally provided for within the FE sector, with inequities amongst students with different impairments.

The post-16 sector has faced many changes within recent years. Indeed, Fish and Evans (1995, p.73) suggest that "a post-16 market" has been created. One area of concern is the general move to accreditation and outcome related funding. This has raised many fears surrounding the direction and potential of FE provision for young people with SEN (Fish and Evans, 1995; Tomlinson and Colquhoun, 1995). Specific concerns have been raised following the 1992 Act and the distinction between 'schedule-2' courses and 'non-schedule-2' courses. The former are viewed as 'vocationally' based with an element of 'progress' and are funded by the FEFC. The latter are viewed as predominately leisure based courses, i.e. non-vocational, and hence are not usually funded by the FEFC (see Fish and Evans, 1995, pp.74 and 76). Within the literature there are fears that this could accentuate the exclusion of some young people with SEN, especially those with pronounced learning disabilities if they are unable to meet 'schedule-2' course criteria. Within a national study (National Institute of Adult Continuing Education, 1996), college curricula focused upon 'schedule-2' courses rather than non-vocational and continuing education courses. It was concluded that there was a real danger of "people with severe or profound/complex learning difficulties" facing increasing exclusion.

The Tomlinson Committee Report has recently acknowledged that this is an area of concern and has recommended that schedule-2 course criteria should be amended:

> "... to include specified courses which meet agreed quality criteria and which provide suitable progression opportunities for students with profound and multiple learning difficulties" (1996, pp.20-21)

Furthermore, concern has also been expressed about 'accreditation' and its implications for young people with SEN in relation to employment. Tomlinson and Colquhoun argue that the current trend focuses upon, urging all young people:

> "... that the way to find employment is by constant investment in the self via the acquisition of skills and competences." (Tomlinson and Colquhoun, 1995, p.191)

For Tomlinson and Colquhoun this is potentially dangerous as young people with SEN are likely to find it harder to gain "meaningful skills and competences" (p.199). In addition, questions have also been raised with regard to the course content of 'special' FE particularly, employment preparation courses. Corbett and Barton (1992, pp.40-42) argue that these are often based upon individual flexibility and personal attributes, emphasising that the way to get a job is through individual skill acquisition. Hence, Corbett and Barton (1992, pp.41-42) and Tomlinson and Colquhoun (1995, pp.199-200) argue, that if a young person cannot get a job then the suggestion is that it is the individual who is lacking. This, they suggest, creates a situation imbibed with many negative implications for disabled young people's self-esteem. A de-politicised and simplistic interpretation is thus presented, premised upon personal inadequacy rather than exploring wider structural problems and exclusionary employment policies. Assessing this work, Baldwin et al argue that there is a danger:

> "... that this becomes both another version of a 'self-fulfilling prophecy' and a means of providing an individualising solution to a structural and economic problem." (1997, p.88)

Ultimately, Tomlinson and Colquhoun fear that young people with SEN will be left as a:

> "... special (un)employable underclass, defined largely as 'deficient' or 'less-competent'..." (p.200)

However, this use of the term 'underclass' is highly contentious and, as Craine and Coles (1995) and Baldwin et al (1997) have argued, extremely dangerous and misleading.

It is clear that the FE sector, its direction and content is an important area to consider within the transition to adulthood. Indeed, the role of post-school education as a potential indicator of 'adult' status has already been noted. Griffiths has emphasised FE as an opportunity for disabled young people to move:

> "... from the dependent role in the school based world of childhood to an autonomous and independent role in the adult world." (1994, p.27)

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However, other writers have been rather more sceptical. As far back as 1985, CERI began to question the role of 'training' and its impact upon transition:

"... how far it is realistic to pin faith indefinitely on further education. Perhaps it has to be accepted that a ceiling can be reached, beyond which renewed attempts simply postpone descriptions about the future, and become dispiriting rather than hopeful." (1985, p.10)

Concerns about the value of 'work training' have also been re-emphasised by Ward et al (1991, p.135). They highlight the dangers of a " 'lego-brick' approach", providing more of the same but without any real direction or planned progression. Consequently, one is not surprised that some elements of FE have been perceived as "... a temporary substitute for the day centre" (Swain and Thirlaway, 1994, p.166, see also Todd et al, 1991, p.12) rather than a positive and progressive move towards employment.

2.2.2.2 Employment

Paid employment has been emphasised as an important, if not key indicator of 'adult' status (CERI, 1983, 1985). However, research over the past two decades has indicated that disabled young people are more likely to be unemployed that their non-disabled peers (Walker, 1982; Freshwater and Leyden, 1989; Ward et al, 1991; Hirst and Baldwin, 1994; Thomson and Ward, 1994). For example, Hirst and Baldwin's (1994, p.23) national sample found that after leaving full-time education only 35% of disabled young people, compared to 67% of their peers had entered employment. Similarly, only 18% of Thomson and Ward's (1994, p.31) sample of young people in Scotland were either in open or sheltered employment. In sharp contrast, the majority, just over two thirds, remained in "some form of supervised placement or at home." (p.44). Furthermore, this trend is not confined to the UK. Literature from the USA has highlighted poor employment outcomes for disabled young people (Chadsey-Rusch et al, 1991; Gallivan-Fenlon, 1994)

Within these figures it is important to recognise that young people with different impairments can, and do, experience very different post-school routes and transition outcomes. One of the first to discuss this was Hirst (1983, 1987b). He demonstrated that young people with learning/multiple disabilities and physically disabled young people frequently undertook different transition routes. The studies in Scotland have similarly confirmed this, highlighting a distinction between three sub-groups: 'physical/sensory' impaired; those with 'mild/moderate' learning difficulties; and those with 'severe' learning difficulties (Thomson and Ward, 1994, p.37). In terms of potential pathways and outcomes, employment is suggested for the former two groups, whereas, supervised settings (day centres or residential) are seen as the most likely destination for those with

'severe' learning difficulties. However, it must be remembered that these pathways are generalised. The transition to employment is frequently prolonged for many disabled young people with 'physical/sensory' impairments and 'mild/moderate' learning difficulties (see also May and Hughes' (1985) idea of a "handicap trap" for young people with 'moderate' learning difficulties).

Ultimately, the authors of the studies in Scotland suggest that a "paradox" surrounds employment (Ward et al, 1991; Thomson and Ward, 1994; Ward et al, 1994)

> "On one hand, commentators, professional and lay alike, advocate the necessity for paid work to facilitate independent living and enhance self-esteem. On the other hand, the reality appears to be that such a goal is difficult, if not impossible to attain for the vast majority." (Ward et al, 1991, p.132)

However, they take young people's aspirations seriously and thus advocate both the importance of preparing young people for employment and also tackling wider structural problems (see Riddell et al, 1993). Indeed, the importance of creating employment opportunities has been continually highlighted within the literature, especially in terms of 'open' rather than sheltered employment. One method frequently presented as having potential is supported employment schemes on the open labour market (Ward et al, 1991; McGinty and Fish, 1992; Thomson and Ward, 1994). Within the UK, the growth of such schemes has been much slower than in the USA. However, Beyer and Kilsby (1996, p.7) note that the number of UK schemes has grown in the last decade from five to 20. From the small number of studies evaluating supported employment schemes (Bass and Drewett, 1996; Beyer and Kilsby, 1996, 1997) many positive outcomes have been highlighted for disabled workers, especially in terms of social interaction and satisfaction with work activity. However, some financial inconsistencies with the benefit system have also been noted.

On the other hand, recognition that many disabled young people will not find employment highlights the importance of looking beyond the traditional model of school to work transitions. Considerations of non-work options are important. Within their study, Thomson and Ward (1994, pp.88-89) talk of "productive daytime activity" rather than the narrow concept, 'employment'. Furthermore, Ward et al have emphasised the importance of:

> "... resources to enable and empower such individuals, with specific sometimes complex needs, to live fulfilling lives." (1994, p.140)

One in turn could thus begin to question the focus and adequacy of past transition models – do we need to consider alternatives? This is an issue, which will be explored and discussed further within the current study.

2.2.3 Transition Outcomes and Experiences

The school to work transition, although important, is only a part of the transition process. Past studies have explored and assessed many other indicators. Reviewing the literature, three broad areas will be explored: personal independence; community participation and social relationships; and the movement from 'child' to 'adult' services.

2.2.3.1 Personal Independence

The concept "personal independence" is extremely broad and complex (Thomson and Ward, 1994, pp.17-18). This review will focus upon two areas: economic independence and independent living. Social security benefits frequently form an important part of disabled people's income. However, they can and do play a contradictory role. On one hand, they bestow personal entitlements (from 16 years) and thus some recognition of adult independence. On the other hand, they nurture potential dependence on the state and poverty (Hirst et al, 1991; Barnes, 1991). Furthermore, Hirst has also demonstrated that recognition of individual entitlement at 16 years does not automatically mean that disabled young people gain any more control over the management of their benefits. In practice, Hirst and Baldwin (1994, pp.49-50) found that parents frequently continued to manage them. In terms of more general financial control, the importance of parents 'managing' young people's money has also been emphasised by both Flynn and Hirst (1992) and Davies and Jenkins (1993, forthcoming).

Leaving the parental home is a very visible sign of a move towards greater personal independence. Within past studies the vast majority of disabled young people were living in the parental home. This was partly a consequence of their age as many were still in their teens. However, Hirst and Baldwin's national study concluded:

> "... that young people in the general population set up households of their own at an earlier age than those with disabilities." (1994, p.20)

A prolonged transition to independent living has also been noted within literature from the USA (Chadsey-Rusch, 1991) Furthermore, Hirst and Baldwin found that disabled young people were generally less prepared for independent living than their non-disabled peers. They appeared to have fewer opportunities to taste independence as their parents were inclined to keep a "watchful eye' over them (1994, p.17). Flynn and Hirst (1992) and Davies and Jenkins (1993, forthcoming) have also noted limited personal autonomy and high rates of supervision. Indeed, Davies and Jenkins (1993, forthcoming, pp.11-12) suggest that this element of constant supervision ensures a "uniformity in the lives" of young people with learning disabilities.

Disabled young people's aspirations to live independently of their parents have been frequently noted (Flynn and Hirst, 1992; Hirst and Baldwin, 1994; Thomson and Ward, 1994). However, within this, Hirst and Baldwin found that some disabled young people (12%) were more likely to be unsure 'when' they saw themselves leaving home compared to non-disabled peers (4%, 1994, p.21). Leaving home can also be a very emotive issue. Davies and Jenkins (forthcoming, p.40) found that for some young people it was a very distressing thought to consider, and for others (19 out of 37) it was clear they did not want to leave. Home was a very important part of their lives. However, disabled young people's aspirations must also be viewed within a wider context and practical problems can, and frequently do, hamper a move into their own home. Past literature has highlighted both an inadequate supply of practical aids/adaptations and more generally a dearth of suitable housing (Hirst et al, 1991; Morris, 1993b; Thomson and Ward, 1994). Furthermore, Thomson and Ward (1994, p.68) have suggested that inadequate resourcing raises the wider issue of a "forced dependency" for some young people well into adulthood, in terms of chronological age.

2.2.3.2 Community Participation and Social Relationships

Past studies have frequently presented disabled young people's lives as socially more limited and more oriented towards the home and their families, compared to their peers (Anderson and Clarke, 1982; Conliffe, 1989; McConkey, 1989; Flynn and Hirst, 1992; Hirst and Baldwin, 1994; Davies and Jenkins, 1993, forthcoming):

> "... the social lives of most were closely bound up with those of their parents ..." (Davies and Jenkins, 1993)

A similar, conclusion has also been drawn by a number of studies from the USA (Brotherson et al, 1988; Chadsey-Rusch, 1991; Richardson et al, 1994). Consequently, questions have frequently been raised concerning the absence for many disabled young people of regular contact with non-disabled peers outside the family unit (Conliffe, 1989; McConkey, 1989; Flynn and Hirst, 1992). Exploring disabled young people's attendance at clubs and organised activities, the continuing importance of 'special' clubs has been noted (Flynn and Hirst, 1992; Hirst and Baldwin, 1994; Davies and Jenkins, 1993, forthcoming). It was also recognised that this is a controversial issue (Hirst and Baldwin, 1994). On one hand, there are questions of segregation and, on the other, the positive role that 'special' clubs can play within the lives of many disabled young people, especially the most severely disabled was acknowledged.

Furthermore, gender can also play an important part within disabled young people's social lives, as Flynn and Hirst demonstrated:

"... young women's lives were more restricted or more likely to be supervised than the young men's." (1992, p.27)

This was also emphasised by Davies and Jenkins' study (forthcoming). They found that young women with learning disabilities were more closely supervised with regard to "sexual and related matters" than their male counterparts (pp.25-27). This raises the important question of 'risk' and parents' perceptions of 'vulnerability'. Davies and Jenkins indicate that parents perceived their daughters as more vulnerable and sexually 'at risk' than their male peers. Hendey and Pascall (1997) have also noted this. In fact, the whole issue of 'sexuality' is frequently presented as emotionally charged for parents (McConkey, 1989; Heyman and Huckle, 1995; Shepperdson, 1995). Within Heyman and Huckle's study of the parents of young people with learning disabilities, the question of an adult sexuality for their son or daughter was often viewed "... as a source of dangers to be avoided." (p.152). Sexuality thus became something to be "managed". Parents' perceptions of 'risk' – risk taking and risk assessment are thus highly significant within the transition to adulthood (see also Schloss et al, 1994; Thomson and Ward, 1994, p.83 for a wider discussion of 'risk'). Furthermore, as Heyman and Huckle and Shepperdson highlight, for parents sexuality can raise the question of "letting go" (Richardson, 1989; Richardson and Ritchie, 1989; Swain and Thirlaway, 1994). Within this literature the importance of moving away from negative professional evaluations of parents as 'overprotective' or 'unrealistic', to a position where parents' life experiences and personal circumstances are recognised and respected, is emphasised.

2.2.3.3 Service Transitions

Moving from 'child' to 'adult' based services is a key area of concern within the literature. Ideally, the goal is a smooth, planned and coherent transition. However, within past studies the general picture has been one of discontinuity, poor service provision and unmet needs, especially in terms of health care (Brimblecombe et al, 1986; Fish, 1986; Bax et al, 1988; Bax, 1990). Reviewing the literature Hirst et al (1991, p.143) have highlighted three problematic areas: post-school therapy discontinuity - especially in speech therapy and physiotherapy; problematic transitions from paediatric services to specific adult services; and finally, a lack of GP involvement when young people leave special school doctors.

Within more recent literature, service provision during the transition period, especially school leaving, has remained an area of concern. However, the degree of concern has varied. The series of studies in Scotland (Thomson and Ward, 1994, p.83) found that

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many parents felt general "support systems" ended "abruptly" on leaving formal education. In particular:

"... there seemed to be no key point of reference when information was needed."
(1994, p.83)

In terms of health services both Hirst and Baldwin (1994, pp.100-103) and Ward et al (1991, p.86) have re-emphasised the problem of therapy discontinuity. Hirst and Baldwin (p.110) have also noted that disabled young people's periodic health re-assessments can become ad-hoc on school leaving. The picture presented by Hirst and Baldwin is however by no means clear-cut disabled young people themselves did not regard health service provision as a problematic area, but they were uncertain "about whether, and how" they could take more responsibility for their own health. Many young people clearly lacked personal autonomy in this sphere.

The literature has demonstrated that disabled young people can and do face a more "prolonged" and problematic transition to adulthood than their non-disabled peers. Furthermore, this transition can sometimes be "postponed indefinitely" (Flynn and Hirst, 1992, p.70) (see also Clarke and Hirst's, 1989, ten year follow up study). However, it is important to recognise that different transition experiences can and do exist. Differentiating factors, such as, impairment, level of severity, age and gender have all been noted. In addition, wider social and environmental factors must also be considered the transition to adulthood does not occur in a vacuum (Hirst and Baldwin, 1994, p.111).

2.3 Policy Initiatives and their Potential

The previous section discussed a range of problems that can hamper disabled young people's preparations for school leaving and can also thwart their progress towards adulthood and 'adult' status. For example, earlier studies in particular emphasised inadequate transition preparations with poor information and/or advice. In addition, a number of studies have highlighted three problems. Firstly, there has been a lack of 'real' opportunities for young people and their parents to participate within transition preparations, Secondly, unco-ordinated service transitions with poor inter-agency working have been noted. And finally, a number of studies have highlighted that disabled young people are frequently less prepared for independence than their peers. However, within the recent past there has been some recognition of both the importance of transition to adulthood and the need to help young people, especially disabled young people, prepare and plan for this transition (see for example, the recent guidelines for service providers concerning the transition years in *Making Connections*, 1997). Within the current legislative framework a number of acts have emphasised policies and

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practices which some feel hold a positive future potential for transition planning. This section will firstly examine the current legislative framework and policy context that professionals, young people and their families face, as they approach the transition years. It then assesses the potential of this in three areas as highlighted by Hirst and Baldwin (1994): inter-agency working and coherent transitions; young people's involvement; and finally, participation for parents.

2.3.1   The Current Legal and Policy Context

The Code of Practice (DFE, 1994), introduced via the Education Act (1993), provides an important example of a recent policy initiative (within England and Wales) which crystallises together a number of key policy themes and practices. The Code addresses 'SEN' in terms of identification, assessment and review. However, most importantly from the point of view of this thesis, the Code (chapter six, paragraphs 42-62) supersedes the previously mentioned re-assessment of need at 13½ years (Education Act, 1981).

Within the Code's guidelines (6:44, p.117) the first annual review after a young person's 14th birthday marks the official catalyst for transition preparations. Here, the onus is very much upon LEAs taking a lead role, initiating and convening this first review. This is in contrast to prior and preceding annual reviews, which are predominately school led. Furthermore, at this first transition review it is the duty of LEAs to invite a range of relevant professionals, not only school staff but also careers advisers, social services and health professionals, in addition to parents. The aim is thus to procure a multi-disciplinary meeting. There is also recognition of a potential opportunity for concurrent professional assessments, for example, under the Disabled Persons Act (1986), the Children Act (1989) or the NHS and Community Care Act (1990). The Code also states that the LEA should prepare a transition plan after this initial transition review. Ideally, transition plans are viewed as a means to:

> "... draw together information from a range of individuals within and beyond the school in order to plan coherently for the young person's transition to adult life." (1994, 6:45, p.117)

Theoretically a young person's transition plan should be updated each year before school leaving and, if the young person moves into FE, passed onto their next educational institution. The Code also addresses the issue of participation for young people, advocating that:

"The views of young people themselves should be sought and recorded wherever possible in any assessment, reassessment or review during the years of transition." (1994, 6:59, p.122)

Within the Code's guidelines for transition preparations a number of themes have been raised. Amongst these, four are crucial to the transition years. Firstly, there is a recognition of the importance of early transition preparations, well before school leaving. Secondly, there is a call for coherent and collaborative inter-agency working. Thirdly, partnership with parents/carers is emphasised and, finally, the importance of listening to and involving young people is stressed. Furthermore, these are themes which lie at the heart of nine evaluatory transition criteria listed by McGinty and Fish (1992, pp.92-99). However, it must be recognised that the Code does not introduce these as new policies. They are general themes, which the Code crystallises together. Indeed, the Disabled Persons Act (1986), Children Act (1989) and NHS and Community Care Act (1990 – from 1993) each advocates some, or all, of these policy themes in relation to the transition years. For example, in terms of early future planning, all three acts recognise this as an important objective, in particular, sections 5 and 6 of the Disabled Persons Act (1986). This advocates that social services should assess statemented young people at the age of 14 and provide the LEA with an 'opinion' as to whether or not each young person is viewed as 'disabled' under section 29 of the 1948 National Assistance Act. For those young people defined as 'disabled', at a later date (usually three months prior to leaving full-time education) social services have a duty to assess each young person's future welfare needs. (For a further discussion of this see Madden, 1993; Middleton, 1992). Within sections 5 and 6 the importance of inter-agency collaborative working is emphasised, especially between schools, LEAs and social services. Inter-agency working is similarly also stressed as a key theme within the Children Act and the NHS and Community Care Act (see Ham, 1991,1992; Bornat et al, 1993; Means and Smith, 1994 for a broader discussion).

The Children Act is also clear about the importance of respecting the wishes of children:

"... a local authority shall so far as is reasonably practicable ascertain the wishes and feelings of the child." (1989, section 22:4a)

It has been argued that this introduces the principle of 'advocacy' for children (Russell, 1991, p.128). In fact, the Children Act is frequently presented as a key piece of legislation for disabled children and young people, especially volume six of the Guidance and Regulations (DoH, 1991). This is due to the fact that it draws disabled children into mainstream child care legislation as "a distinct sub-set of 'children in need' ", for whom services are to be provided (1989, section 17:11). Hence, the onus is upon disabled children as children first and foremost rather than 'disabled' (Baldwin

and Carlisle, 1994, p.62). For a wider discussion of the Children Act see the University of Leicester (1990), the Department of Health (1991), Fox-Harding (1991) and Parton (1991).

Theoretically, these themes and principles highlight a potential opportunity within the current legislative and policy context to develop a more coherent and collaborative framework. Ideally, this is one that is able to begin to plan and prepare disabled young people for school leaving and address the transition from 'child' to 'adult' services. Within the literature Hirst and Baldwin (1994, pp.112-117) and Flynn and Hirst (1992, p.71) have also noted the potential of the Acts. However, they are also aware of a number of problems and issues that need to be considered. It is to these that we will now turn.

2.3.2 Inter-agency Collaboration and Resource Issues

Inter-agency working and collaboration appears a very rational policy objective. However, as past assessments illustrate, putting this into practice has been, and continues to be, problematic. For example, the Social Services Inspectorate (SSI) Report (1994) recognised that the Education Act (1981) advocated multi-disciplinary assessments, yet in practice there has been poor collaboration:

> "... given the underdeveloped nature of SSD assessment procedures and practice, it was hardly surprising that there was little inter-agency collaboration to be found." (1994, SSI Report, quoted in Russell, 1994, p.50)

In a similar manner, Madden (1993) notes the potential for collaboration between LEAs and social services within sections 5 and 6 of the Disabled Persons Act (1986), but acknowledges that, so far, it has faced problems of fragmentation, incoherence and distance. On a more positive note, Russell (1994, p.50) hopes that inter-agency working will prove successful within the Code of Practice, especially given social service departments role within 'children in need' assessments (Children Act, 1989). However, the 1994 Review of the Children Act (DoH, 1995) did not find much evidence of collaborative working progress has been slow.

Within such a context it comes as no surprise that Hirst and Baldwin (1994, p.113) have questioned if a multi-disciplinary approach is practically possible. Reviewing the literature Bradley et al (1994, p.49) have suggested that there are important barriers to inter-agency collaboration. Different departments and agencies can, and do, have very different practices and aims. Johnson et al (1987 in Bradley et al, 1994, p.49) have highlighted four areas of potential divergence: inconsistent national policies; conflicting

policy goals; different eligibility criteria; and finally, different patterns of funding across agencies (see also Fish and Evans, 1995; Hudson, 1994).

2.3.2.1 Different Definitions and Eligibility Criteria

Departments using different definitions and eligibility criteria has been raised by Hirst and Baldwin (1994, p.113) in relation to the question of who or "which service will take overall responsibility" for disabled young people when they leave school. For Hirst and Baldwin, service incoherence remains a real concern. Furthermore, within the broader sphere of SEN, the use of different definitions has been frequently discussed in relation to school leavers and continued service support. As noted above, social services have a duty under sections 5 and 6 of the Disabled Persons Act (1986) to assess young people with statements of SEN and give an 'opinion' whether they are viewed as 'disabled' or not. Section one highlighted that the two concepts, 'SEN' and 'Disabled', are legally very different. Some statemented young people will, therefore be defined as 'disabled' and others will not. This legal disparity has frequently been an area of concern within the literature (Middleton, 1992; Griffiths, 1994; Fish and Evans, 1995; Cooper, 1996). Indeed, Armstrong and Davies (1995, p.71, 74) have argued that for those young people with SEN who do not meet the criteria of 'disabled' (especially young people with "moderate learning difficulties" or "emotional and behavioural difficulties") there are important implications for future service provisions and continued post-school support. Some young people can, and do, become "lost to the system" (Thomson and Ward, 1994, pp.89-90). Exploring the situation of 29 school leavers with "moderate learning difficulties" and/or "emotional and behavioural difficulties" Armstrong and Davies concluded:

> "It was evident from the research interview that there was no lack of professional will, but it also seemed clear that a support infrastructure within which different professionals working in partnership could co-ordinate their support, was missing." (1995, p.74)

Definitions and the labels society attaches to young people are, however, extremely complex. On one hand, labels such as 'disabled' can and do provide a passport to services (Middleton, 1992; Cooper, 1996). On the other hand, labels can stigmatise and for disabled young people, impact upon their sense of 'self' (CERI, 1988) and society's perception of them (Todd, 1995).

2.3.2.2 Funding and Resource Issues

The question of funding priorities has been much debated, especially within the context of a market economy of welfare. Woodroffe and Kurz (1989) have noted that increased competition may lead to departments becoming more insular and protective rather than

collaborative. Furthermore, there are very real concerns that hierarchies of prioritisation can and do emerge which may disadvantage disabled young people during the transition years. For example, it has been noted (Hirst et al, 1991; DoH, 1993, 1995; Baldwin and Carlisle, 1994; Hirst and Baldwin, 1994) that the Children Act may recognise disabled children as 'children in need' but within this, social services frequently prioritise those in need of protection. Questions have thus been raised concerning 'needs' assessments, especially the future 'needs' of disabled children as they move towards 'adult' services.

This introduces the wider issue of 'care management' (NHS and Community Care Act, 1990) and the relationship between 'individual needs assessment' and "what is available and affordable" (DoH and DSS, 1989, p.20). This highlights the potential danger of 'need' identification becoming a flexible issue, dependent upon resources and their availability. Thus, if resources are not available then 'needs' can be ignored. This has been critiqued on a number of grounds. For example, Doyal and Gough (1991, p.54) have suggested that individuals have a 'right' to basic human 'need' satisfaction within society, especially shared human needs, such as, health needs and individual autonomy. This begins to question the idea that 'needs' can be defined in association with resources. One can argue that 'needs' can be identified irrespective of the resources through which they can be fulfilled. However, Doyal and Gough's suggestion of universality have been debated, some arguing the importance of recognising that different impairments lead to different needs (see Fish, 1986; Coles, 1995). On the other hand, social model theorists such as Oliver and Barnes (1993), Oliver (1996b) challenge Doyal and Gough's idea that individual needs assessments are the best way to meet disabled people's needs:

> "I am critical of the notion that collective welfare provision can be provided on the basis of assessments of individual need..." (Oliver, 1996b, p.67)

Oliver and Barnes (1993, pp.268-9) suggest the way forward is to move away from debates about individual need within a "needs-based" language, to the question of disabled people's rights. This of course would demand a very different agenda and is thus a contentious issue.

2.3.3   Listening To and Involving Young People

Policies advocating listening to young people and involving them within transition preparations have gained a common currency and legitimacy. However, if one begins to unpack the concept of 'participation' a more complicated situation and set of issues emerges. 'Participation' is not always easy to achieve. Tisdall's (1996, 1996/97) study of FNA meetings in Scotland has highlighted this.

2.3.3.1 Children's Rights

The Children Act (1989) is frequently viewed as an important legal landmark, placing listening to, and respecting children's wishes, firmly on the agenda. Lansdown (1995, pp.9-10) acknowledged that the act raised some "key" issues but also recognised that its scope was limited and narrow, especially in relation to children's rights (see also Lyon and Parton, 1995 for a further discussion of the Children Act and children's rights).

A key landmark within the development of children's rights is the United Nations Convention on the Rights of the Child (1989). This contained 54 articles divided into three broad areas: provision, protection and participation. The UK Government ratified the convention in 1991 (Franklin, 1995, p.16). Article 12 addresses the issue of listening to children and young people:

> "States parties shall assure to the child who is capable of forming his or her own views the right to express these views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child." (UN, 1989)

Lansdown (1995) emphasises that Article 12 goes well beyond the Children Act. However, both Lansdown (p.37) and Beresford (1996, p.7) acknowledge that, in the UK, progress towards actually achieving this has been slow, as a UN report (1995) demonstrated. This report concluded that the "measures" so far taken by the UK Government have been "insufficient" and thus recommended that "… greater priority be given to Article 12…" (Lansdown, 1995, p.37).

Furthermore, young people's participation in decision making is a debated area. Franklin (1995, p.9) suggests that this is a "liberty right" based upon "rights to participate", i.e. an ability to make choices. Within debates surrounding children's "liberty rights" lies the idea of "competence" (see also Morrow and Richards, 1996). Franklin explains that, for those who argue against children's "liberty rights", there is a perception:

> "… that children are not rational or capable of making reasoned and informed decisions." (1995, p.10)

Children are viewed as lacking the "wisdom" that comes from experience. There is a presumption, as Dix and Gilbert (1995, p.104) note, that 'adulthood' is based upon "competence". In contrast, those who advocate children's "liberty rights" suggest that:

> "… children do reveal a competence for rational thought and do make informed choices." (Franklin, 1995, p.11)

Some argue that they lack experience and, hence, are prone to make mistakes. Yet Franklin (p.11) wonders how children will ever begin to make choices if they are "not allowed" to do so.

Perceptions of 'competence' are especially debated in relation to people with learning disabilities. Dix and Gilbert (1995, p.104) suggest that the rights of people with learning disabilities is particularly contentious because of professionals' evaluations of "competence" (see also Hudson, 1988). Here, there is an ever-present danger of "paternalism". Concepts within Article 12, such as 'capable' and 'maturity' can raise questions about a young person's capability and their maturity, especially in relation to chronological peers, and who and through what means these are assessed.

2.3.3.2 *Choice Making and the Importance of Support*

Exploring debates surrounding children and young people's ability to make informed choices, a number of further questions and issues emerge. Flynn and Ward (1991, pp.133-134) and McKenna (1986) have stressed that one cannot expect people (whatever their age), who have previously not made service choices and are perhaps unused to the concept of 'choice', to suddenly be able to make choices concerning their own service requirements. Consequently, they emphasise the importance of providing support and guidance to people with learning disabilities. Furthermore, for young people with learning disabilities facing the transition years (and more specifically, a Code of Practice transition review at 14 years) this is an extremely significant issue because as Tisdall has argued:

> "... young disabled people are trained into passivity, and practice little independent choice." (1994, p.14)

This raises the importance of preparing young people for choice making and participation well before transition (Tisdall, 1994, 1996; Russell, 1996). In terms of policy developments Lansdown (1995, p.15) has mixed emotions. She acknowledges that the Code of Practice recognises the importance of participation and that it does not just occur. However, Lansdown also has reservations about its potential, and, more generally, of society's ability to listen because in the UK she argues that:

> "We do not have a culture of listening to children." (1995, p.38)

Viewed in this manner, there is a constant need to work towards involving young people, especially young people with learning disabilities. Davie and Galloway (1996, p.12) also fear that participation could potentially be a negative experience for young people with SEN if professionals within assessments perceive them as 'deficient'. Participation thus raises questions about professional practices and presumptions.

Within the literature questions of support and advocacy are frequently discussed and debated. One of the most commonly noted forms of support and advocacy for young people with SEN and their parents is the idea of a 'named person'. Both the Code of Practice (1994) and the Government's recent Green Paper (1997) re-emphasise this idea (the Warnock Report highlighted this idea back in 1978). However, translating this into practice is a difficult task. In fact, Russell (1995, p.2) foresees further problems, particularly in terms of defining the role of a 'named person', issues of financial responsibility and accountability, especially given the fact that we live in an increasingly litigious society.

The use of citizen advocates has also been noted, this refers to 'independent' advocates who speak out for, and on behalf of, young people's interests (Flynn and Ward, 1991; Flynn and Hirst, 1992; Young, 1993; Hirst and Baldwin, 1994). Hirst and Baldwin, (1994, p.117) suggest that citizen advocacy also has a potential to encourage and develop self-advocacy skills. This has been described as "... sticking up for yourself." (Simons, 1993, p.7). Self-advocacy can be both positive and progressive for people with learning disabilities, ideally promoting 'empowerment'. This is a term which is frequently used but infrequently defined. For Gilbert (1995, p. 115,120), 'empowerment' as opposed to 'powerlessness' is multi-dimensional and dynamic and has wide social and political ramifications. Clearly, it is important to appreciate the complexity of empowering individuals and the crucial role that disabled people themselves play within this process. This is also emphasised by Oliver's (1991, p.161) assertion that it is disabled people, and only disabled people who can empower themselves. It is a right and not a gift.

It is also important to consider dangers within organised self-advocacy groups, such as professional domination and management something frequently noted within the literature (Flynn and Ward, 1991; Simons, 1993; Young, 1993; Aspis, 1997). At face value, policies involving disabled young people and listening to their wishes appear positive, progressive and relatively straight forward, but, as we have seen it is also a much debated issue.

2.3.4 Parents and Participation

Since the Warnock Report (1978) the idea of 'parents as partners' has been advocated within many educational policies. In practice, the success of schools in promoting and progressing towards this has, as Beveridge (1995, p.15) notes, been erratic and uneven. Once again, ideas of 'partnership' and 'participation' are frequently used but less frequently clearly defined. An exception is Orlowska's (1995) comprehensive review of

literature surrounding the "participation of parents of people with learning disabilities" (p.437). She highlights a number of complex issues and presumptions. These are grouped around: availability and levels of information, service philosophy attitudes, parent and professional responsibilities, and parents' expectations concerning a son or daughter's future (p.438).

2.3.4.1 Responsibilities

Within many policies advocating the participation of parents there is frequently a taken-for-granted presumption that parents will want to participate. Reviewing the literature, Orlowska (pp.439-440) highlights the importance of recognising that parents differ in terms of their attitudes to participation and the level of responsibility they want to adopt. Some parents welcome participation, whereas others do not. Orlowska comments:

> "The emphasis on the desirability of parental participation should not cloud thinking about those who do not get involved." (1995, p.450)

Riddell and Brown (1994a, p.18) emphasise the inequity of what they term "parent power". "Parent power" may work well for some, in particular, parents who are well informed, articulate and have resources to draw upon. However, there is a real danger that these parents may gain at the expense of those who are less informed or well resourced. Riddell and Brown also comment that those who shout the loudest, gain or receive the most (see also Orlowska, p.450). On the other hand, they also appreciate the danger of "trusting in the benign discretion of the professionals" and raise important questions concerning the "balance between collective responsibility and individual rights" (1994, p.18). How to achieve this balance remains a contentious issue.

2.3.4.2 Parents' Expectations

Within Orlowska's review it is clear that parents' and professionals' ideas often diverged. Both parties frequently approached the same issue from different starting points and had different expectations. Furthermore, parents and their son or daughter can, and frequently do, hold different ideas and expectations hence, there is a potential for conflict between them. The transition years frequently involve changing roles and role perceptions for both disabled young people and their parents (Swain and Thirlaway, 1994, p.163 and Orlowska, 1995, p.443). Cattermole et al's study (1988) of young people with learning disabilities moving away from the parental home to a supported hostel highlights this.

Within any examination of the transition years it is important to consider the support that parents require, both practically and emotionally. The transition years can be an extremely stressful time, hence, the focus upon parents "letting go" (see section two of

this chapter). The literature has frequently emphasised the importance of supporting the whole family (Richardson, 1989; Richardson and Ritchie, 1989; Griffiths, 1994; Hirst and Baldwin, 1994; Mittler, 1995).

> "Transitions have meaning for 'the family' not just the individual." (Swain and Thirlaway, 1994, p.163)

Furthermore, Griffiths (1994, pp.60-61) has emphasised the importance of professionals recognising that parents and their son or daughter can frequently require separate forms of support during the transition years:

> "The critical factor in support is the acknowledgement of separate agendas. ... support services must be delivered in ways which acknowledge this difference and legitimise it." (1994, p.60)

Assessing the potential for young people and parental conflict, Hirst and Baldwin (1994, p.115) suggest that the emerging legal framework perhaps accentuates this and thus raises questions of how such conflict should be approached and "resolved".

Chapter Overview and Future Research

This chapter has reviewed literature surrounding the transition towards 'adulthood' and 'adult' status for disabled young people and young people with SEN. It has demonstrated the importance of recognising that this both encompasses diverse populations of young people, and, conceptually, can at times be ambiguous and incongruous. Reviewing past studies of disabled young peoples' and young people with SEN's transition towards 'adulthood' it is clear that many face "prolonged" and more problematic transitions than their peers (Ward et al, 1991, 1994; Flynn and Hirst, 1992; Davies and Jenkins, 1993, forthcoming; Hirst and Baldwin, 1994). However, it is important to recognise that very few young people simply leave school and get a job or suddenly become 'adult' or full citizens overnight. From a theoretical perspective this chapter has demonstrated that what is needed within any analysis of transition, but in particular for disabled young people, is a radical revision of traditional transition models. Transition models must incorporate and appreciate lengthy transition processes, the importance of transition preparations within schools and also the diversity that can and does exist within post-16 transition experiences.

Literature on both sides of the Atlantic has frequently noted the importance of preparing and supporting young people and their families during the transition period, but also demonstrates problems of incoherent and unplanned transitions together with a lack of participation for both young people and their parents. As a result there have numerous calls for policies and practices, which develop more coherent, collaborative and

)articipatory services and help and guide young people and their families during the ransition years (Fish, 1986, 1992; Ward et al, 1991; Hirst and Baldwin, 1994; Tisdall, 1996, 1996/97).

Within the 1980's and early 1990's these policy suggestions have gained an increased impetus, and raised profile, due to an emerging legal and policy framework. Policy developments have been advocated and legislation enacted, which highlight the importance of the transition years, recognises past problems and begin to try and address some of them. This chapter has reviewed four major acts of parliament and/or guidelines of good practice: the Disabled Persons Act (1986); Children Act (1989); NHS and Community Care Act (1990); and the Code of Practice (1994). Together these acts and guidelines have potential for a more planned, coherent and participatory transition for young people and their families. On the other hand, the literature has also demonstrated that the transition to adulthood involves complex "processes" and "phases" for many young people and their families (Fish, 1986, 1992). Implementing the policies; practices and objectives advocated by the acts 'and the 1994 Code of Practice is by no means a clear or simple task (see Hirst and Baldwin, 1994). This review has demonstrated that there are many complex issues surrounding inter-agency collaboration and participation.

Ward et al (1991; 1993; 1994) and Tisdall's (1996, 1996/97) research has provided important insights into young people with 'recorded needs' as they leave school and seek 'adult' status in Scotland. However, the legal and policy context within England and Wales can, and does differ, especially with regard to educational provisions. Other studies, such as Flynn and Hirst (1992), Hirst and Baldwin (1994), have explored disabled young people's transitions but within the legislative context of the 1980's. Clearly there is a need to re-examine this in light of the policy developments reviewed in this chapter. Furthermore, Tisdall's evaluation of FNA meetings in Scotland provides an important base from which to draw comparisons/contrasts and assess any potential developments.

This study explores the youth transitions of a diverse population of young people with learning disabilities and their ideas of 'adulthood'. The study examines the young peoples' own perceptions of 'adulthood' and their evaluations of their progress towards it. The methodology of the study is outlined in the next chapter.

Chapter 3 – Methods and Methodology

Designing this research project proved to be both a complicated and personally informative process. It was one where a balance between researcher ideals, ethical considerations and everyday practicalities was continually sought. This chapter will explore this complex developmental process in terms of both the theoretical ideas and the practical research methods within which the study is grounded. Four discrete, yet interwoven areas, will be explored: the study - background information and research aims; methods and methodology; ethics and research practice and finally, the research design and fieldwork undertaken.

3.1 The Study: Background Information and Research Aims

3.1.1 Background Information

The previous chapter highlighted the problematic and often "prolonged" nature of many disabled young people's transitions to 'adulthood'. Issues of service coherence, professional collaboration and participation for young people and their families during the transition years were discussed and debated. Past research demonstrated a need to both update the literature and assess the potential and impact of current legislation and policy initiatives, especially following the introduction of the Code of Practice (1994).

Recognising that 'transition' can be a complex and often-extended process for disabled young people it was decided that one key phase would be studied in-depth - young people approaching school leaving age in the sphere of special education. Within this, special schools were chosen as the study's focus for three reasons: Firstly, they are frequently a rather peripheral and somewhat ignored sphere within the education system, both in terms of interest fostered and research undertaken. Secondly, a key aim of the study was to explore the transition from school for a diverse population of young people, including those with pronounced learning disabilities. Finally, there were practical considerations, of time and manageability. Whilst including mainstream schools would have incorporated a different dimension, it was felt this would lead to a study with too many variables to be explored satisfactorily and analysed within a three

year period. However, links to mainstream educational establishments were made, primarily, in the form of young people attending college-link courses in preparation for the transition from special school.

Chapter two demonstrated that the concepts - 'SEN' and 'disability' are frequently contentious. Within this research, a diverse population of young people from five special schools formed the main sample. All the young people had a statement of SEN and had differing degrees of learning disability. Beyond this, their impairments varied enormously. This study does not seek to categorise or medicalise the young people and their impairments. To avoid this, terms such as, 'disabled young people' and 'young people with learning disabilities' will be used whenever possible. From a social model perspective, categorisation merely serves to further 'disable' people (Finkelstein, 1993). In legal terms, not all of the young people were either labelled or would perhaps have been perceived as 'disabled' by professionals, under the terms of the National Assistance Act (1948). Indeed, they many not be defined as 'disabled' by the Act. Yet in terms of their education they were defined as having learning disabilities which were 'moderate' or 'severe'. The study will consider the use of such official definitions. It will also seek to be both sensitive towards, and questioning of, the use of such labels and their effects upon young people during the transition from school. This is particularly relevant to the services or opportunities that a young person receives or is offered for the future.

3.1.2 Research Aims and Questions

This study has two principle aims:

> (i). To explore the processes and procedures of preparing disabled young people for the transition from special school and progression towards 'adult' life.

> (ii). To explore the experiences and future aspirations of young people and their parents as they approach and move beyond school leaving.

These aims and concerns can be seen as Coles has suggested as "two sides of a 'careers equation' " (Craine and Coles, 1995, pp.6-7, Coles, 1997, p.71). Within this study the equation encompasses both the social and economic "opportunity structure", i.e. the institutional policy context that professionals both work within and help to create, and also the decision making role of disabled young people and their parents, as they approach school leaving and transition towards 'adulthood'. However, as Coles emphasises, the two sides of this equation are closely interrelated. Disabled young people's and their parents' decision making is frequently guided by the specific

"opportunity structure" that they face and perceive. In this study the "opportunity structure" will be explored largely through the general policies, programmes and philosophies of a range of special schools and associated professionals as they help families prepare for school leaving. Three sets of questions and concerns have guided the research:

1. What further education, training or work transitions are available to disabled young people? and following this, What are the first post-16 career destinations and/or planned vocational routes of young people on leaving special school? (chapter four)

2. 'How' and 'when' are disabled young people and their families prepared for the transition from school and where appropriate, from 'child' to 'adult' services? (chapters four and five)

3. Has current legislation and the Code of Practice influenced preparations for transition, and more specifically, policies for, and the provision of, 'support'?

   In what ways and through what processes, do the relevant professionals feel that they are 'supporting' young people and their parents as they approach school leaving? (chapter five)

The study will pay particular attention to assessing the aforementioned policy areas: service co-ordination; professional collaboration; listening to young people; and involving parents. In particular, the study will focus upon the initial introduction and implementation of transition reviews and their associated transition plans within the Code of Practice (1994). The study thus explores and assesses the direction and degree of transition planning within the Code, how successful it is felt to be and for whom.

Within the second side of the equation there are two broad areas of concern surrounding the decision-making role of young people and their parents:

1. What are the responses to, and experiences of, both young people and their parents to preparations for leaving school and progression towards adulthood?

   Do the young people and their parents feel 'prepared for' and 'supported' during the transition? - if so, in what ways and through what processes.

   Do young people and their parents feel 'active' or 'empowered' participants within transition procedures? (chapters six and seven)

2. What are the key issues, concerns and future aspirations of young people and their parents during this period? (chapters six and seven)

This study will thus probe school programmes and the opportunities offered to young people and their parents and will also begin to consider the question of 'adulthood'.

In addition, a longitudinal element will be developed in order to procure a more rounded and in-depth picture of the transition period. Longitudinal insights will be explored in two areas: firstly, the progress or otherwise of 'transition planning' within the focus schools, via The Code of Practice (1994); and secondly, the feelings and experiences of the young people and their parents, pre and post-school leaving. The study aims to explore both policy implementation and personal experiences at two key junctures in time. However, it is recognised that this longitudinal dimension is somewhat truncated. This is due to the practicalities of researching a period, which for some young people can be prolonged and extended over a substantial number of years. Two key junctures does not provide a complete overview of the transition years but it does provide important insights into the lives of disabled young people and their parents during an often complicated and stressful period within the life-course.

3.2 Methods and Methodology

The previous section highlighted the exploratory nature of this study, in particular, exploring professional policies and practices, and young people's and their parents' ideas and experiences of school leaving and transition towards 'adulthood'. It was therefore important to adopt a methodological approach which enabled the researcher to explore participants' meanings. Hence, a qualitative rather than quantitative approach was considered most appropriate. Quantitative methodology is frequently characterised by standardised and structured research methods, pre-defined concepts and the testing of hypotheses. Within this study it was felt inappropriate to impose a structure and pre-defined concepts upon young people's and their parents school leaving experiences. Instead, the idea was to procure "rich" personal data (Parker, 1993, p.131), whilst also recognising and respecting that school leaving is a complex social process for families and can thus be an emotional experience, raising sensitive issues. A qualitative research approach was felt to be more sensitive, flexible and, hence, more informal and personal for participants. In a similar manner to Parker's study of *caring and disability in marriage* (see also Davies and Jenkins, forthcoming, p.4) it was felt that:

> "A quantitative approach would inevitably have constrained the extent to which this complexity and richness could be drawn out and might have imposed on it a structure which did not tally with respondents' own experiences and views." (1993, p.131)

This question of structure has also been discussed by Hirst (1987, p.12) and Flynn and Hirst (1992, p.1). Within both studies it was recognised that the use of structured

research tools can be problematic for young people with learning disabilities. In contrast, a more un-structured qualitative research approach enables both the researcher to explore, and participants to express, how they "...experience, interpret and structure their lives." (Burgess, 1984, p.3) A qualitative approach thus enabled the researcher to explore both sides of "the careers equation" (Coles, 1995, 1997), the "opportunity structure" that families face, and also their interpretations of, and actions during, school leaving.

The importance of a humanistic approach with participants as thinking and feeling actors was central. Within qualitative literature the focus is frequently upon the importance of trying to "get inside" (Walker, 1985, p.12) and appreciate the lives of participants. Within this study there were three sets of participants – young people, their parents and professionals. In order to try and appreciate the diverse social realities that each faced, the study drew upon the idea of 'methodological triangulation' as discussed by Hammersley and Atkinson (1995, pp.230-231) (see also Burgess, 1984 and Bryman, 1988). Two types of 'triangulation' were adopted: "respondent validation" and "technique triangulation". Within "respondent validation" (p.230) interpretations of the school leaving process were gleaned from young people, their parents and professionals. This enabled the researcher to explore the complexity of social reality, in particular, how different meanings and interpretations of the same process can and do emerge between different participants. "Technique triangulation" (p.231) was also adopted. Three different data collection methods were used – individual interviews, observation and participation, and destination statistics. Drawing upon and comparing data from different methods enabled the researcher to broaden the study's scope. Interwoven within this triangulation it is important to recognise the significant role that researcher "reflexivity" played. Hammersley and Atkinson stress that "social researchers are part of the social world they study" (1995, p.16). Thus, within any research it is as they suggest important for the researcher to recognise and reflect upon their own role and its effects upon the research process. This is especially important for research such as this, exploring potentially sensitive issues and life-course events. Hence, the question of research ethics was often highlighted. Furthermore, researcher "reflexivity" was also applied as Hammersley and Atkinson (1995, pp.18-19) suggest to the study's methods. During fieldwork the researcher continually assessed the methods used, considered problems that had, or may occur, and potential improvements that could be made. Once again, the importance of researcher flexibility was paramount. Within this chapter these practical and philosophical issues will be explored and discussed in greater depth.

3.2.1 Disability Research - Issues and Debate

Within the sphere of disability research, methods and methodology have become a much-debated area. Radical social model theorists, in particular Oliver (1992, pp.106-107), have criticised the general methodological approach adopted within past research, both positivistic and interpretivist (see also French, 1994a). Oliver argues that although they may employ very different approaches, ultimately they both present the researcher as an all-powerful 'expert', and employ methods which alienate disabled participants from the research process and the researcher. Oliver advocates a radical alteration to "the social relations of research production" and proposes a more "emancipatory research paradigm" (p.107) which "facilitates" disabled people deciding to "empower themselves" (pp.110-112).

Morris has similarly emphasised the potential nature of research but from a feminist perspective:

> "The disability movement needs to take on the feminist principle of the personal is political, and in giving voice to such subjective experiences, assert the value of our lives." (1992, p.164)

For Morris it is important to recognise and enable disabled people to express their personal experiences of disability, whether these are positive or negative.

However, moving from rhetoric to practical implementation, especially in terms of "emancipatory" research is by no means an easy task. The very concept of "emancipatory" research is an elusive term with political connotations. Indeed, Shakespeare (1996, p.118) acknowledges that the aims of "emancipatory" research are rather "grandiose". Furthermore, Zarb (1992, p.125) although himself ultimately aspiring to emancipatory research methods acknowledges practical constraints upon researchers, especially from funding bodies. In his later work Oliver (1993, p.66) has also acknowledged material and institutional problems. Zarb makes a distinction between "participatory" and "emancipatory" research with "participatory" being a 'prerequisite' to emancipatory research (p.134). Here, the onus is upon disabled people actively taking part in the research and its design. This suggests a radical shift in power for disabled people both in terms of their role within research and how society perceives them, i.e. as active commissioners and designers rather than passive respondents. Others have questioned radical social theorists' ideas. For example, Bury (1996, p.35) fears the politicisation of research and thus its "independence". However, the idea of "independent research" has been widely debated (Barnes, 1996a).

Practically, steps have been made towards more participatory research by some researchers, such as Booth and Booth (1994). In addition, the Joseph Rowntree Foundation (Ward, 1997) has recently developed guidelines of good practice for researchers in terms of involving disabled children and young people within research projects. However, as Beresford (1996, p.41) has noted, the focus in the past has been upon involving adults rather than children and consideration of children's involvement has only begun to emerge. In a similar manner dissemination of results to participants with learning disabilities is now being considered. Here, the work of Townsley and Gyde (1997) and the development of "plain facts" research summaries are central. Consideration of participation and dissemination within this study will be further discussed, later in the chapter.

3.2.2 The Study's Methods

As noted above, the study used three methods of data collection: semi-structured interviews, primarily with individuals or couples; observations and participation; and finally, career destinations.

3.2.2.1 Interviews

The most important research method was the use of flexible, semi-structured interviews. Semi-structured interviews were chosen and drawn upon for their potential, as Quinn Patton (1980, p.205) highlights, to enable participants to present their ideas in a manner which is meaningful to them. Due to the multi-dimensional nature of the research (professionals, young people and parents), slightly different interview formats were adopted. Thus, the interviews, whilst being semi-structured, were responsive to each party's differing needs and different interview contexts. For example, there was the relative formality of a head teacher's office compared to the informal setting of a young person's living room. In general, the format for both professionals and parents was a "basic checklist" of areas and issues that the researcher wished to address. Such a topic guide was, as Quinn Patton suggests, only a guide (1980, p.198). Hence, the sequence and timing of issues and areas was flexible, explored as and when they arose or introduced at what were perceived to be the most appropriate moments. Topic guides were used rather than a completely open and unstructured approach in order to enable a degree of comparability between interviews. Furthermore, it was accepted, as Jones (1985a, p.47) suggests, that "... there is no such thing as presuppositionless research".

The literature surrounding interviewing people with learning disabilities (a small body but within recent years it has begun to grow) has raised a number of suggestions, issues and concerns, which are primarily questions of structure and approach. These issues and debates are important to consider because they have informed the researcher's own methodological understanding and research decisions; most notably, the decision to aim, as far as realistically possible, for predominately open-ended questions. Before reviewing the literature it is important to note, as Booth (1996) and Booth and Booth (1996) have highlighted, the general exclusion of people with learning disabilities from past research and the exclusionary nature of traditional research methods. Furthermore, this neglect, until relatively recently, has been particularly marked for children and young people with learning disabilities. Wyngaarden in 1981 (p.107) stressed the importance of gaining the ideas and experiences of people with learning disabilities, recognising that they alone can tell us about their personal feelings. More recently, Beresford's (1996, p.6) review of the literature surrounding research with disabled children has stressed that adults, more specifically parents, "cannot be proxies" for their children. The same, of course, must be stressed for young people with learning disabilities. The ensuing review explores a range of literature surrounding interviewing people with learning disabilities, predominately adults. However, general principles of good practice are, in many ways, applicable for both adults and children.

Interviewing people with learning disabilities has raised a number of issues, debates and challenging areas within past literature. Atkinson (1988, pp.79-80) has summarised three general issues from her own personal experiences: firstly, the potential communication difficulties that people with learning disabilities can face; secondly, the danger of participants trying to please the researcher; and thirdly, comprehension – potential problems can arise in understanding between the researcher and participants. (see also Biklen and Moseley, 1988, pp.157-159). Bearing these in mind, one may ask what is the most advantageous approach? Within the literature a number of researchers suggest that it is a less structured approach, one that allows the person with learning disabilities to develop their own ideas and answers (Malin, 1980 in Flynn, 1986; Atkinson, 1988; Biklen and Moseley, 1988; Cattermole et al, 1988; Prosser, 1989). However, other researchers such as Sigelman et al have largely focused upon the "technical difficulties" (Simons et al, 1989, p.12) of interviewing people with learning disabilities. More specifically, Sigelman et al (1981b, pp.120-121, p.126; 1978, 1981a,c, 1982 referred to by Roberts et al, 1988, pp.7-9) have compared and assessed different question formats (yes/no, either/or, multiple choice and open-ended) in relation to measures of responsiveness, reliability and validity. Problems such as "acquiescence"

and "recency" (i.e. choosing the last option) have been noted, especially for those with pronounced learning disabilities. Roberts et al's (1988, p.9) and Prosser's (1989, p.9) reviews of the literature highlight that for Sigelman et al this whole sphere of question format, validity and responsiveness when interviewing people with learning disabilities is complex and often beset with problems.

In contrast, Simons et al (1989) question Sigelman et al's approach to, and testing for, "acquiescence" as a problematic issue. They suggest that "acquiescence" in itself may be an interesting phenomenon to study because it perhaps reflects people with learning disabilities personal experiences of the world, thereby introducing wider social and environmental considerations.

> "Thus acquiescence is part of the way people relate to their environment and is therefore of interest." (1989, p.13)

Furthermore, some literature raises the issue of checking for consistent responses from participants. Wyngaarden (1981, p.109) advocates asking the same question in different ways and thus comparing responses. Other researchers have drawn upon significant others to confirm responses (Biklen and Moseley, 1988 and Flynn, 1986). This may be useful for verification of objective facts or answers. However, on a more subjective and emotional level, one can argue that this may be confusing as some answers are personal responses (Simons et al, 1989, p.13) and as Biklen and Moseley (1988, p.159) note, 'significant others' can act "... not just as a translator, but as a filter as well". Thus, on one level, a participant may present seemingly mixed or confused feelings but this may be perhaps how the individual feels. As Simons et al suggest "... it need not simply be interpreted as a technical problem." (1989, p.13)

Interviewing is usually perceived as a verbal activity. Thus, past studies have tended to focus upon the 'most able' or 'verbal' people with learning disabilities (Simons et al, 1989, p.14). However, for those with communication difficulties, the use of non-verbal methods is an extremely important area to consider. Sigelman and Budd (1986, p.179) have found that the use of visual stimuli (multiple choice or either/or questions using pictures and photographs) stimulated interest and ideas amongst participants, especially those with communication difficulties. Prosser (1989, p.19) has also noted the benefits of 'visual stimuli' and 'pointing' if verbal open-ended questions are problematic. Furthermore, Simons et al (1989, p.14) and Minkes et al (1994, p.56) suggest that visual stimuli can help researchers to understand participants. One method, which has been debated within the literature, is the use of 'faces' and differing expressions, usually ranging from happy to sad. Simons et al (1989) and Roberts et al (1988) have all used faces as an aid whilst interviewing. However, the literature presents a rather mixed and ambiguous assessment of their usefulness. Simons et al (1989, p.15) suggest that the use

of 'faces' aided participants' understanding and encouraged responsiveness. However, Roberts et al, whilst using 'faces' were rather more unsure of their benefits and voiced a number of reservations concerning the dangers of bias and of being patronising. Within the former they noted how one participant chose the 'happy face' because she liked "happy faces" rather than it surrounding an answer to the question being asked (1988, p.20). Secondly, there is also a danger of appearing patronising to some participants in a group with different degrees of learning disability. Whilst piloting, Roberts et al (p.18) found that the use of faces could be "insulting" to some of the young people who were able to articulate their own ideas. This will be further discussed, later in this section.

Ultimately, within this somewhat complex and often confusing array of ideas and approaches, there appear to be three general but important areas to consider, although many of these are applicable to any 'good' interviewing guidelines. Firstly, it is important to create a non-threatening atmosphere, one within which the participant feels relaxed and at ease. Interwoven within this is the importance of the interviewer building a rapport with participants before an interview (Wyngaarden, 1981;Atkinson, 1988; Biklen and Moseley, 1988; Cattermole et al, 1988; Hirst et al, 1990; Beresford, 1996; Marchant and Page, 1997; Ward, 1997; Prosser, 1989). Secondly, it is vitally important to be "patient" and to ensure that participants have the time and space to answer questions (Wyngaarden, 1981, p.111). Finally, there are issues around question format. Here, Hirst et al (1990, p.80) and Wyngaarden (1981, pp.109-110) advocate the use of "simply phrased ... questions", which avoid the use of abstract ideas or concepts. They suggest that researchers begin with the easiest questions, enabling participants to gain confidence and thus feel more relaxed. Furthermore, advice is given to avoid time related questions whenever possible – the present is perceived as more meaningful, a factor which is true of any interview (see also Malin, 1980 in Flynn, 1986; Simons et al, 1989; Beresford, 1996; Prosser, 1989).

Developing Topic Guides

In addition to the above three principles, 'participation' was also prioritised within this study. An element of participation was initially addressed by consulting and visiting the self advocacy group 'People First' and a local resource centre. Here, talking and listening to the ideas and experiences of some young people who had attended special schools, at an early stage, provided important information and comments, suggestions and areas of concern for the proposed research. Time was also spent getting to know the young people within the focus schools, especially those with the most pronounced learning disabilities. In particular, the researcher attended college link courses within three of the five focus schools. This provided an informal context within which to get to know the young people, the young people to get to know the researcher and to break

down some of the social and communication barriers that were initially apparent. However, rapport was also aided by a general knowledge of non-verbal communication techniques gained whilst working as a classroom assistant within a residential Scope school. In addition, an element of reciprocity was sought within the interviews, as Walmsley (1993) has suggested. Consequently, the young people were encouraged to ask the researcher questions, especially at the end of the interview. However, questions were answered, as far as possible, at whatever point they arose, thus moving away from the idea of the researcher as a detached non-participant. 'Participation' was thus considered and sought. However, it is recognised that this does not by any means meet Oliver's (1992) criteria of 'emancipatory research' or, perhaps, even more radical participatory ideas of 'accountability' (Zarb, 1992). However, practical steps were taken towards involving disabled young people within the development of relevant research areas and the presentation of their own ideas.

Within the young people's interview guides the general aim was to develop simply phrased questions, located predominately in the present tense and, as far as was realistically feasible, an open-ended format. However, it was recognised that achieving a balanced approach was not an easy task, as Biklen and Moseley, drawing upon Spradley (1979) have indicated:

> "Interviewers feel challenged to provide enough structure so that the subjects know what is being asked of them, yet not so much that subjects' answers are proscribed." (1988, p.157)

Thus, the young people's topic guides were more direct than those of parents and professionals. The focus was primarily upon concrete issues within the young people's lives such as college link courses, annual reviews, familiar personnel and work experience rather than abstract ideas.

When formulating the young people's topic guides insights and ideas from the meeting with 'People First' and a local resource centre plus college link observations were used to develop a range of themes, issues and ideas, which were considered important to discuss: for example, leaving school preparations; feelings towards leaving school and moving onto the next step; personal aspirations; becoming an 'adult'; and issues surrounding leisure and personal independence. Furthermore, when considering the concept of 'adulthood' insights from past transition studies and their topic guides were drawn upon, in particular Roberts et al (1988, Appendix 1, pp.1-38) and more generally Ward et al (1991, Appendix 2, pp.155-159) and Thomson and Ward (1994, Appendix 2). For example, within the young people's topic guides when exploring 'leisure and personal independence', areas such as leisure pursuits, friends and shopping were explored areas which Flynn and Hirst (1992) similarly prioritised using Roberts et al's

(1988) interview schedule. This enabled the research to draw upon past knowledge and explore a wide range of issues relating to the transition period, (surrounding leaving school and moving to 'adulthood'). Furthermore, it also provided a point of comparison to previous studies, such as Flynn and Hirst (1992) and the series of studies carried out in Scotland (Ward et al, 1991; Thomson and Ward, 1994).

Eventually, two similar but different topic guides were developed (see Appendix 2). Both explored the same themes and issues but differed in the phrasing of questions and the incorporation of visual stimuli. One topic guide thus contained relatively more open-ended questions and the other more direct questions and opportunities for the use of visual aids. When considering the use of language, basic rules of simplicity and directness were followed as far as possible. More specifically, as Walmsley's (1993, pp.40-41) past experiences suggested, using language which was meaningful to the young people was imperative. This required standing back from professional terminology, which is so often taken for granted, and trying to explain concepts such as, careers lessons or annual review meetings as clearly as possible to the young people. Three specific visual aids were drawn upon to aid communication: faces; photographs; and rebus symbols. Roberts et al's (1988, Post-Appendix 2) five faces were initially drawn upon. However, it was then decided to limit the faces to three key expressions (happy, OK and sad) in order to avoid the complication and confusion that five faces can procure, as Simons et al (1989, pp.14-15) have suggested. Overall, three of Roberts et al's (1988) five faces (depicting 'happy','OK', 'sad') and two rebus symbol faces ('happy', 'sad') drawn from Meldreth Manor School's *Signs and Symbols Handbook* (1989/90, p.18 and 19) were used (these symbols often accompany Makaton sign language) (see Appendix 6). Furthermore, Simons et al (1989); Minkes et al (1994) and Beresford's (1996) suggestion of using photographs was followed. In order to aid participation and personal recognition, photographs of three focus schools (Oaksmere, The Laurels and Cedar Drive), young people and staff members were taken. Finally, rebus symbols (primarily drawn from the Meldreth Manor Handbook, 1989/90) were drawn upon flashcards. This provided a visual depiction of key words and ideas, which were to be explored. The use of visual stimuli can be a controversial issue. There is a danger of appearing patronising as Roberts et al (1988, p.18) have highlighted. In general, interviewers are encouraged to be responsive to participants' non-verbal cues (Flynn, 1986; Atkinson, 1988; Hirst et al, 1990; Beresford, 1996; Ward, 1997). Consequently, when drawing upon visual stimuli the researcher was receptive to the young people's non-verbal cues. Furthermore, this was also prioritised within the selective use of an ice breaking picture game suggested by 'People First'. Pictures were chosen which did not perpetuate or stereotype people with learning disabilities as 'eternal children'. Ultimately, there is a very fine line for the researcher to negotiate

between being responsive to the wishes and needs of young people and avoiding being patronising.

3.2.2.2 Observations and Participation

The second method of data collection was the use of observation and some limited participation. Within a school context active participant observation is often extremely difficult to negotiate. Consequently, active researcher participation was undertaken on college link courses. The researcher accompanied young people from three schools (Cedar Drive, Oaksmere and The Laurels) to their respective local colleges and participated within all activities and events. In addition, a small number (five) of review meetings, following the Code of Practice's guidelines (1994) and with the consent of young people and their parents, were observed at Oaksmere and Cedar Drive. Obviously, as Beresford (1996, p.30) has noted, one could argue that any observations can be considered obtrusive and inhibiting for participants, especially in a formal school setting. However, situations were purposively chosen within which the researcher's presence would be least obtrusive. Within college links courses, the young people are frequently in a new environment with different members of staff. Adaptation and change are thus important aims for the young people. Furthermore, transition reviews are already an unusual situation for many of the young people with different and perhaps unknown professionals in attendance. Ultimately, these periods of observation and participation enriched the research in three ways: they aided understanding; increased rapport; and helped to develop ideas gleaned from the interviews.

3.2.2.3 Career Destination Statistics

The third and final method drew upon past and present career destination statistics of the focus schools. Theoretically, one could use general destination statistics published by the Careers Service. However, this was found to be problematic as special school and mainstream school figures were compiled together. Consequently, one could not decipher the career destinations of those young people who have attended special schools from the general statistics. Ethically, this is correct because it does not differentiate those who have and those who do not have a formal statement of 'SEN'. However, for the purposes of this study, where the onus was upon special education, the research drew upon the focus schools' own records or those of their careers adviser. Comparing the career destinations of students past and present provided a broader picture within which to place the specific ideas and experiences of the sample young people. In addition, the statistics provided a comparative element between past and present career destinations. The career destination figures inevitably focused upon a relatively small number of young people, due to the smaller size of special schools.

Furthermore, it must be recognised that this study explored a small percentage of the population, i.e., those who attended special schools. Within this, it must also remembered that the focus schools were located within a limited geographical area and were a purposively selected sample of special schools. Consequently, one cannot make generalisations regarding all special schools or even all special schools in the two authorities. However, bearing these considerations in mind the figures helped to produce a more informed and rounded analysis one, which set the case studies within a wider and more structured context.

3.3 Ethics and Research Practice

3.3.1 Understanding Disability

Embarking upon a research project such as this, one issue, which a non-disabled researcher ought to consider is the debate concerning whether able-bodied researchers can or should research disabled people's lives. For example, Moore somewhat emphatically suggests, when reviewing Hirst and Baldwin's book - *Unequal Opportunities* (1994) that:

> "... as disabled writers point out, the very idea that 'experts' divorced from the direct experience of disability can set an agenda for disability research is anathema." (1995, p.301)

In one sense this cannot be denied. Able-bodied researchers are, as Moore highlights, "divorced from the direct experience of disability". However, one can argue that a similar lack of "direct experience" besets most researchers in terms of race, gender or age. There are frequently social or cultural differences beyond disability, as Barnes has noted:

> "Having an impairment does not automatically give someone an affinity with disabled people, nor an inclination to do disability research. The cultural gulf between researchers and researched has as much to do with social indicators like class, education, employment and general life experiences as with impairments." (1992, pp.121-122)

For Barnes, research is a learning process for everyone. He argues that one of the most important factors is:

> "... for researchers, with or without impairments, to gain a comprehensive understanding of the meaning of disability it is essential that they [researchers] interact with disabled people on a regular basis" (1992, p.122).

Furthermore, this idea of different life experiences and the development of diverse self-identities amongst disabled people was noted within chapter two, in relation to internal

social model debates. Theorists such as Stuart (1992, 1993) and Morris (1992, 1993a) have argued that disabled people's identities are complex and multi-dimensional. They cannot simply be viewed, as Stuart notes, as a "double oppression" of being disabled and black or Morris, as a "double disadvantage" of disability and gender. Therefore, although a non-disabled researcher may not share "the direct experience of disability" (Moore), there are many other areas where life experiences can be shared.

In addition, one can argue that research aims to inform, to raise issues and also raise public awareness. If research undertaken by non-disabled researchers helps to do this then this should be welcomed. Indeed, the aim of this research is to inform future social policies and highlight the ideas and experiences of young people leaving special schools and the transition towards 'adulthood'.

3.3.2   Ethical Considerations

In all research, ethical considerations are important. Within a study, where a key aim is to listen to the ideas and experiences of a diverse population of young people with learning disabilities, they are paramount. In particular, disabled young people can be potentially vulnerable and as such may feel powerless and unable to say 'no' to what may seem to be the 'all powerful' presence of a researcher. Hence, it comes as no surprise that past researchers such as, Wyngaarden (1981), Flynn (1986) and Walmsley (1993) have highlighted the importance of ethical issues for people with learning disabilities, particularly, informed consent; ensuring confidentiality; and considering participant's perceptions of the researcher. Furthermore, in line with Article 12 of the United Nations (1989) Convention on the Rights of the Child (see chapter two), the importance of listening to young people has raised ethical questions and issues for research involving disabled children (Alderson, 1995, Alderson and Goodey, 1996; Beresford, 1996; Ward, 1997).

3.3.2.1   Informed Consent and Confidentiality

Informed consent is a complex but ethically important issue to consider. This study faced the challenge of ensuring that the diverse sample of young people were, to the best of the researcher's ability, well informed. Beresford (1996, p.21) reviewing the literature highlights the importance of two considerations: "the issue of understanding and competence to give consent ...". More specifically, she suggests that 'informed consent' can be explored with the aid of three characteristics: firstly, knowledge, gained via appropriately presented information; secondly, the voluntary nature of research; and finally, the ability or 'competence' of each person to provide consent (p.22) (Dix and Gilbert, 1995, p.104 and Ward, 1997, p.20 also discuss this). Beresford suggests that

these characteristics raise two potential issues for researchers to consider when working with disabled children: firstly, the difficulties that disabled children may face in actually understanding what it means to take part in research and secondly, that children are frequently socialised into doing what adults tell them to do. Responding to these considerations Beresford (p.22) emphasises the importance of presenting information in an accessible manner and ensuring the voluntary, confidential and flexible nature of research (see also Ward, 1997, pp.19-22).

In this study when considering the issue of 'informed consent' the sample of young people were informed both verbally and in writing of the research and what was involved. Each focus school was visited and an informal collective meeting with all potential leavers was held in which the researcher explained the proposed research and requested permission to send a letter to the young people. A letter was chosen as the method to gain consent from the young people and their parents (separate letters were sent to the young people and their parents). It was felt to be perhaps easier to say 'no' to a letter, as opposed to a face to face or verbal encounter. However, it introduced the challenge of how to develop a letter, which was both accessible and informative for the young people. A progressive learning curve for the researcher was discernible between the writing of initial letters sent to young people, with regard to accompanying college link courses, and those later sent requesting an interview. The idea of a symbol letter was considered but rejected as potentially patronising. On the other hand, Margaret Flynn's advice to use a photograph of myself when writing to the young people proved to be invaluable. This created a more informal and personal approach and was a great success with the young people. Ultimately, how far an informed understanding was actually achieved is, of course, open to debate and difficult to quantify. However, when a positive written reply was received from a young person and their parents, each young person was, as far as possible, asked verbally for their consent during a telephone conversation. This was felt to be particularly important for those young people who had to rely upon parents to complete their letters of consent.

In addition, participants were encouraged to choose a name that they wished to be called within the study. This 'made-up' name helped the researcher to explain and demonstrate to the young people that their own name would not be used within the report and thus they would remain anonymous. Furthermore, the voluntary nature of interviews was emphasised before each young person's interview. Drawing upon Lowe et al's (1987, p.75) suggestions, the researcher explained to the young people that they could stop the interview whenever they wanted, or decline to answer any questions (see also Ward's 1997 recent guidelines).

3.3.2.2 Researcher Effect and Participants Perceptions

Within this study it was also important to consider the potentially emotive nature of the research area - a period of transition and change within participants personal lives. This makes sensitivity and respect for participants even more important. In particular, the researcher must try to be aware of the danger of asking questions or raising issues concerning potentially stressful or unrealistic options, which could cause distress or dissatisfaction now or in the future. Researchers may frequently be aware of these dangers but just how far they manage to control them is often unknown. However, within this study, one positive indicator to note was the largely enthusiastic response from the sample of young people and their parents when a second interview was requested.

Furthermore, one must also consider, as Walmsley (1993) suggests, how participants interpret and make sense of the researcher and their role, because:

> "... the perceptions people have of you, the researcher all feed into the data and alter it." (1993, p.44)

Furthermore, Wyngaarden (1981, pp.111-12) highlights the danger of some participants having a misplaced view of the researcher as someone who has the power or ability to alter conditions or events within their lives. This issue and its potential dangers was exemplified during a visit to one of the focus schools (Ash-hill). During an informal chat, prior to sending out letters of consent, one young person asked about options and jobs if she could not gain a college place. She appeared to presume, even though the researcher's position as a student had been explained, that the researcher could either organise a place for her at college or a job. This situation highlighted the need for extreme clarity; hence, Lowe et al's (1987, p.75) advice that the researcher should explain their position very clearly at the beginning of each interview was followed (see also Ward, 1997). Once again, whether this was clear to the young people remains as Walmsley suggests:

> "The sad thing is, you may never know how people explained you to themselves, yet that might be crucially important." (1993, p.42)

However, the researcher was able to gain a more insightful perspective within second interviews as the young people and their parents appeared to be more relaxed and at ease with the interview situation. Overall, it is important to recognise that at the beginning of any research project the researcher cannot foresee or pre-empt all ethical issues that may evolve. Hence, designing this research and undertaking its fieldwork was an important 'reflexive' learning experience, one where ethical issues and considerations were continually arising and being explored.

3.4 Research Design and Fieldwork Undertaken

3.4.1 Research Design

This study was designed to explore a small but varied sample of special schools with a range of provisions and policies within differing authorities. Diversity was thus a key element within the choice of focus schools. Within each focus school, a small but relevant sample of young people and their parents were interviewed. Furthermore, relevant professionals such as head teachers, class teachers and where appropriate school health professionals (physiotherapists, nurses) were also interviewed (see Table 2). Within each authority a range of 'other' professionals such as, social services, careers advisers and education officials were also consulted (see Table 3).

3.4.1.1 Authorities and Focus Schools

During the winter of 1994 two contrasting local authorities were approached as potential study areas. These were a large metropolitan authority (Authority 1) and a large county council, covering both a rural and urban population (Authority 2). Within Authority 2, one specific city was chosen as a focal point. Authorities 1 and 2 were chosen for both their geographic and socio-economic contrasts and provided an opportunity for the research to explore regional and authority differences. They also provided a contrast of policies, practices and philosophies.

After selection and during the research period local government changes occurred (April 1996) as a result of this the city chosen within Authority 2 became a unitary authority (henceforth known as Authority 3), but one school studied remained in Authority 2. The research design thus grew from two into three authorities. However, this development was not as central to the study as one might initially imagine because the vast majority of fieldwork had been conducted by the end of July 1996. After July 1996 the separation and development of individual policies by the unitary city (Authority 3) were still being developed and had not really been fully implemented. Within the study, Authorities 2 and 3 are therefore recognised as separate entities but are often considered together.

Five special schools were selected from the above authorities as the study's focus, four-day schools and one residential (Monday to Friday). The schools[2]: Cedar Drive, The Laurels, Beechview, Oaksmere and Ash-hill were chosen for their diversity and because

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[2] Names have been changed to ensure anonymity

they provided education to a broad and varied population of young people (see Table 1). All five chosen schools served young people with learning disabilities, officially the schools were educationally labelled for young people with either 'moderate' or 'severe' learning disabilities. However, as noted above, the use of such official definitions will, as far as possible, be avoided. In addition, Cedar Drive and Beechview were chosen for rather more specific reasons. Cedar Drive has an extremely diverse population of young people, some with complex medical conditions. This provided an opportunity to broaden the study and explore the interface between physical/medical disabilities and learning disabilities during the transition from special school. Furthermore, the Head appeared to be an advocate of new ideas and policies. For example, Cedar Drive had been one of the first to pilot Individual Action Plans in special schools within Authority 3. Beechview was chosen for its residential status as this provided an opportunity for the study to explore preparations for, and the process of transition within, a residential as opposed to a day school context. Beechview was also selected for its diversity, not only in terms of the students it served, but also because it provided a post-16 independence course. (A more detailed portfolio of each school is provided within chapter four.) This choice of five focus schools thus provided a comprehensive sample of young people and different, contrasting authorities.

Day Schools				Residential School
Authority 1 (Metropolitan)		Authority 3 (Unitary – April'96 detached from Authority 2)		Authority 2
Oaksmere	Ash-hill	The Laurels	Cedar Drive	Beechview
Usual school leaving age(s)				
19	*16 to 19*	*19*	*16*	*16 to 19*
Key points to interview				
18/19	*15/16 and 18/19*	*18/19*	*15/16*	*15/16 and 18/19*

Table 1: The Authorities and Focus Schools

	Schools				
	Oaksmere	Ash-hill	The Laurels	Cedar Drive	Beechview
Head Teacher	1	1	1	1	1
Deputy	1	1	1	0	1
Leavers Tutor	1	1	1	1	1
SENCO	0	1	0	0	0
School Nurse	1	0	1	1	1
School Physiotherapist	1	0	1	1	0
Total	5	4	5	4	4	22

<div align="center">Table 2: Interviews with Professional Staff in the Schools</div>

	Professionals				
	Social Services	Health	Education	Careers Service	
Authority 1	4	2	2	1	
Authorities 2 & 3	4	1	4	1	
Total	8	3	6	2	19

<div align="center">Table 3: Additional Professionals Interviewed</div>

3.4.1.2   Gaining a Sample of Young People and their Parents

Whilst one focus was upon institutions, the second focus was upon young people and their parents. Within any qualitative study an important objective is to glean a small but relevant and not a-typical sample, from which a range of issues can be explored in-depth. Practically, such a sample does not seek to claim to be random nor to make statistical generalisations. These were not key aims within the study. The aim was to procure rich qualitative data.

The target group for the sample of young people and their parents was 1996 school leavers. The actual number of young people leaving anyone of the focus schools was small, ranging from five to 20. All potential leavers and their parents were sent a letter which explained the research and requested an interview. At Beechview the procedure was slightly different as the head preferred to write personally to each family. The names of 11 positively responding families (from a total of 20) were then passed onto the researcher and letters subsequently sent. 37 young people and their parents were contacted. The aim was to gain a sample of between 15 to 20 young people and their parents, ideally, three or four young people from each school. 30 families responded, 20 positively and 10 negatively (see Table 4). Two reminder letters were sent out during this period, although eventually seven families did not respond. Teachers at two of the

focus schools (The Laurels and Oaksmere) suggested that this may have been due to the stressful nature of school leaving. In addition, the initial sample proved to be somewhat volatile and by the time interviews were conducted three families had decided to withdraw: two as a result of family problems and one moved out of the area (see Table 5). Ultimately, 15 young people and 17 sets of parents were interviewed (see Table 6). This was complicated by one family (from Oaksmere School) not consenting to their daughter being interviewed and one young person (from Ash-hill School) deciding that he did not wish to participate when the researcher arrived at his house. Paradoxically, this latter example can be interpreted in a positive light as it demonstrated that the young person obviously did feel he could say 'no'. However, this led to a slightly lower response rate at Ash-hill than was initially hoped for. Acknowledging the sample's refusal/non-response rate it is important to recognise the potential for bias within this sample. For example, the sample could have been biased in terms of personal experience, with those who felt that they had points to raise more willing to participate. Class could also have been a factor, with middle class families perhaps feeling more at ease with involvement. However, it is also important to stress that the sample fulfilled the key criteria that were sought - young people from all the authorities and focus schools; male and female representation; an age mix; and young people with different impairments. Furthermore, within the 37 potential leavers there were two ethnic minority families, one of these families formed part of the sample. (A more detailed portfolio of each family is also provided within Appendix 1).

School	Status of Replies				
	Replies Received	Positive	Negative	No Response	Number of Leavers ('96)
Oaksmere	3	3	0	2	5
Ash-hill	7	3	4	0	7
The Laurels	4	4	0	2	6
Cedar Drive	5	3	2	3	8
Beechview*	11	7	4	0	11
Total	30	20	10	7	37

* Head wrote to all leavers: the 11 young people are those families who responded positively to the Head's letter and were followed up.

Table 4: Family Response Rate

	Number of Positive Replies		Number "dropping-out"	
School	Young People	Parents	Young People	Parents
Oaksmere	2	3	0	0
Ash-hill	3	3	2	1
The Laurels	4	4	1	1
Cedar Drive	3	3	0	0
Beechview	7	7	1	1
Total	19	20	4	3

Table 5: Young People's and Parents' Response Rates

School	Young People	Parents
Oaksmere	2	3
Ash-hill	1	2
The Laurels	3	3
Cedar Drive	3	3
Beechview	6	6
Total	15	17

Table 6: Sample of Young People and Parents Interviewed Spring/Summer 1996

3.4.2 Fieldwork Undertaken

The fieldwork conducted fell into three broad phases:

First Phase – Getting to know the field

(Spring 1995 – Spring 1996)

- Getting to know the schools and staff.

- Observation/participation of college links.

- Semi-structured exploratory interviews with external professionals and school staff.

- Developing topic guides for the young people and their parents.

Second Phase – Interviewing

(Spring 1996 – Summer 1996)

- Pilot interviews.

- Interviews with the sample of young people and their parents.

Third Phase - Selective	- Reinterviewing of focus school staff, the person
Reinterviewing	responsible for implementing Code of Practice
	'transition' reviews.
(Winter/Spring 1997)	
	- Reinterviewing young people and their parents, via
	depth or telephone interviews.

The first phase of fieldwork was 'getting to know the field', discussed in section two. This section will focus upon phases two and three, the main collection and analysis of data.

3.4.2.1 Second Fieldwork Phase

Within the second fieldwork phase pilot interviews were conducted in spring 1996. Eight young people and seven sets of their parents were drawn from three of the focus schools (Cedar Drive, The Laurels and Oaksmere). Focus schools were purposively selected; the aim was to enhance the relevance of topic guides. The young people interviewed were due to leave school, either in 1997 or had left school and moved to college in the previous year or two. A diverse sample of young people were interviewed with different forms of communication in order to explore the appropriateness of the visual aids. All the interviews were held in the family home and the young people were, as far as possible, interviewed separately from their parents (see also Hirst et al, 1990, p.80). Interviewing the young people and their parents separately was an important aim within the study. However, this was something which frequently had to be negotiated. This was found to be extremely difficult at first as the situation required both persuasiveness and firmness on the part of the researcher. However, during piloting it was found that clarifying each meeting as two separate interviews, when initially arranging an interview date and time, could be beneficial and eased the situation. On the other hand, the researcher also recognised the importance of being flexible, sensitive and responsive to each family and the interviewing context. All the interviews were tape-recorded. This made the interview less obtrusive and intimidating for the young people compared to note taking, especially as some of the young people could not read or write (see Atkinson, 1988; Flynn, 1986; Hirst et al, 1990 and Prosser, 1989). In addition, the researcher found, as Biklen and Moseley have suggested, that:

> "Taping interviews ... may help researchers to better understand the informants pronunciation." (1988, p.158)

Interviewing young people who have yet to leave or alternatively have left school could perhaps be criticised as producing prospective and retrospective data. Furthermore, it has been noted that people with learning disabilities can have difficulties with the

concept of time. However, the pilot interviews were by no means merely focused upon time related issues. Their purpose was much broader. Three key aims were paramount. Firstly, they were used as a means to explore how best to approach specific topic areas and ask questions in a clear manner. Secondly, they enabled the researcher to practise using visual aids and stimuli, where appropriate. Finally, they provided an opportunity for the researcher to 'sensitise' herself to, and learn from, the young people and their parents. They were thus an important learning experience. Furthermore, from insights gained and suggestions of past literature a checklist of good interviewing ideas and practices was collated together for the personal use of the researcher (see Appendix 5).

The main data collection phase involved interviews with the sample of young people and their parents; these were conducted during the summer of 1996, in the months prior to school leaving. Once again, they were held within the young people's homes and the young people were, as far as possible, interviewed separately from their parents. The interviews were all tape-recorded and lasted between half an hour to an hour for the young people, and one to two and a half hours for parents. Booth and Booth (1996, p.61) have emphasised the importance of continuous researcher "sensitisation" and learning, drawing upon Tremblay's concept of "self-developing" (1957). This idea of researcher "sensitisation" and "self-developing" was paramount throughout each interview. This was especially true for those young people who communicated with the aid of symbols. Furthermore, it was frequently found to be advantageous to interview parents before the young person. This gave the researcher an insight into the young people's lives, important events and people involved. One could argue that this raised the danger of the interviewer entering with pre-defined ideas and a parental perspective (see Atkinson, 1988, p.88 for a similar argument re interviewing social workers first). However, these concerns were offset by the advantage of gaining background knowledge, which enabled the researcher to talk in more concrete terms to each young person and be more responsive to their answers.

Section two of this chapter noted that the use of visual aids and stimuli, especially 'faces', is a contentious issue. Within this study, amongst those who drew upon 'faces', the majority frequently chose the 'happy face'. However, 'OK' or 'sad' faces were not completely ignored. Furthermore, questions were repeated at different points during each interview and non-verbal cues, such as facial expressions and mood were drawn upon. Beresford (1996, p.38) has highlighted the advantages for a researcher of making sure that participants have symbols pertinent to the research. Within this study, drawing pertinent rebus symbols onto flash cards worked extremely well. They gave young people both a visual depiction of the subject being discussed and something to point to. However, it is recognised that participants were limited to the symbols that the

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researcher had previously considered. The use of photographs, especially those taken at Oaksmere, The Laurels and Cedar Drive of staff, classmates and college link courses proved to be extremely successful as they both aided the young people's understanding of the interview subject and encouraged responsiveness. The use of visual stimuli did therefore, help to retain and aid some participants' interest and concentration. This was particularly important as some of the young people had a very short concentration span.

3.4.2.2 Third Fieldwork Phase

Within the third fieldwork phase, selective reinterviewing of young people and their parents was undertaken during the winter/spring of 1997, after they had spent at least one term at their next educational establishment or training programme. Ideally, it would have been advantageous to reinterview the young people later within the year but this was not possible due to time constraints. Bearing these in mind it was decided that approximately half the sample of young people and their parents would be reinterviewed, via a second face to face 'depth' interview and the other half, via a telephone interview (see Table 7). The sub-sample of families to be reinterviewed in-depth were purposively selected to encompass the previously highlighted criteria (young people and parents from differing authorities and schools, a gender and age mix and a mix of different impairments). This sub-sample also contained a range of post-school options. Only one family (from Beechview) declined the offer of a second depth reinterview. However, from a brief conversation with the young person some post-school information was gleaned.

Telephone reinterviews provided an efficient means to collect general post-school leaving information and ideas. However, these focused upon those young people who communicated verbally, in one form or another. The importance of time constraints upon the choice of method for the second interviews highlights some of the practical problems that a researcher can face. This re-emphasises Zarb's (1992, p.127) acknowledgement of the "material relations of research production" and their ability to impinge upon a researcher's participatory ideas. Eventually, from the initial sample of 15 young people, three were not directly reinterviewed and one parent (from Ash-hill school) withdrew due to family illness. Overall, 11 young people (one was spoken to very briefly) and 16 sets of parents were reinterviewed. Thus, the actual rate of non-response or withdrawal was very low. Indeed, the vast majority of young people and their parents were pleased and eager to be reinterviewed.

School	YP: Depth reinterviews	Parents: Depth reinterviews	YP: Telephone reinterviews	Parents: Telephone reinterviews
Oaksmere	1	1	0	2*
Ash-hill	1	0	0	1
The Laurels	2	2	0	1
Cedar Drive	1	1	2	2
Beechview	3	3	1	2
Total	8	7	3	8

* One response was via a short written questionnaire, as the family did not have a telephone.

Table 7: Second Interviews – Face to Face or by Telephone

3.4.2.3 Data Analysis and Dissemination

Each depth interview with the young people and their parents was transcribed in full. Analysing the data, the approach taken was largely premised upon Strauss and Corbin's (1994, p.274) ideas. They argue that research theory should be grounded in the ideas and perspectives of participants and that theory should evolve from data collected. In practice, this was done after the collection of data rather than simultaneously as an ongoing process with data collection as Glaser and Strauss advocate (Bryman, 1988, p.84). Within the literature, Glaser and Strauss (1967) have been criticised for suggesting that concepts 'emerge' from data collected. Jones argues that this is a rather elusive idea because "... there is no such thing as presuppositionless research"(1985a, p.47). What one researcher might see within the data, another may not (see also Jones, 1985b and Bryman, 1988). Consequently, within this study a pragmatic approach was taken, similar to steps suggested by Hammersley and Atkinson (1995, pp.210-213). Transcripts were read, re-read and important concepts or themes for participants identified and refined. Sometimes, as Quinn Patton (1980, p.306) has suggested, participants could and did introduce ideas or themes for which they did not attach labels or terms. In cases such as this, the researcher introduced a label or term. During this process transcripts were continually read and re-read in order to compare and contrast participants' ideas in light of the highlighted concepts or themes. However, analysing the data was far from straightforward due to the fact that the young people's interviews were frequently pitched at different levels. Consequently, some of the transcripts were in-depth and others (predominately five) focused upon symbols and the choosing of different faces. The five transcripts, which focused upon symbols and 'faces', were initially analysed together. Their ideas and feelings were then compared and contrasted to the wider sample of young people, in order to provide a more rounded picture and overall assessment. Underpinning this analysis was a process of constant interplay

between the transcripts and the analysis or as Hammersley and Atkinson suggest "systematic sifting and comparison ..." (1995, p.213).

Disseminating the study's results is recognised as an extremely important part of the research process. In order to make the research as accessible and as relevant as possible, especially to families, their experiences and concerns, a short résumé based upon Townsley and Gyde's (1997) "Plain Facts" guidelines will be developed and sent out to participants.

Conclusion

This chapter has explored an extremely important area. Until relatively recently, interviewing people with learning disabilities, especially young people with communication difficulties, has been largely ignored. This study has sought to contribute to and help develop this small but growing body of methodological knowledge, experience and insights. It has explored and discussed four discrete aspects of the study's methodology. In terms of aims and objectives, this multi-dimensional study seeks to explore and assess both professional policies and procedures, and young people and their parents' personal experiences of leaving special schools. It also seeks to assess progression towards 'adulthood' for the sample of young people and their families. The analysis was placed within the current legislative and policy context, especially the Code of Practice (1994), in order to explore and assess developments. Due to the exploratory nature and philosophical stance of the study a qualitative approach was chosen. Methodologically, the study draws mainly upon semi-structured, individual interviews.

When considering the research design, a range of issues surrounding both the concept of disability research and, more specifically, interviewing people with learning disabilities has been discussed. Here, the concept of 'participation', especially for young people with learning disabilities was an important consideration within the study's research. With the aid of past researcher's knowledge and suggestions, especially from Roberts et al, 1988, Simons et al, 1989 and Minkes et al, 1994, three visual stimuli were used and developed: faces; photographs; and symbols drawn upon flashcards. Ethical issues were also of considerable importance, particularly issues of: informed consent; confidentiality; researcher effect; and participants' perceptions. The chapter has also described the main phases of data collection and outlined the principles behind the analysis of the study's data. This analysis is now reported in the next four chapters.

Chapter 4 – School and Professional Preparations

Introduction

Within this chapter, a general professional overview and assessment of the transition from school and the movement from 'child' or school based services will be explored. The discussion will be wide-ranging examining school and professional policies, philosophies and provisions. In order to provide an insight into the multi-dimensional nature of transition preparations, a range of professional experiences both within and beyond the focus schools will be drawn upon, largely from interviews conducted in 1995. When these professional interviews were undertaken the 1996 local authority re-organisation had not taken place. After local authority re-organisation (April 1996), fieldwork was undertaken within a changing context as the city within Authority 2 became a unitary authority (Authority 3) with its own services. However, in order to aid clarity and continuity between chapters (particularly, chapters six and seven when families were interviewed during the re-organisation process), Authorities 2 and 3 will be linked together as one (Authorities 2/3) unless there are important differences between them.

Structurally, chapter four will be divided into four sections. The first section will provide brief pen portraits of the focus schools, highlighting key background information and school aims or philosophies. Sections two, three and four explore professional assessments of transition preparations. Areas of good practice, areas of concern and any comparisons that emerge between authorities will be explored. More specifically, section two will examine school leaving preparations, section three, post-school provisions and destinations; and section four, service provisions, especially, the movement from 'child' to 'adult' services. In order to aid assessment, chapters four to seven draw upon some of McGinty and Fish's (1992, pp. 92-99) suggested evaluatory transition criteria. These criteria encompass important factors, such as school preparations, young people's participation, family involvement and inter-agency working; criteria highlighted and discussed in chapter two. On one hand, these provide

an analytical structure from which the researcher can begin to unpack and assess transition preparations as experienced by young people and their parents. However, it is also important to recognise that they are only a starting point. Within the following chapters the ideas and experiences of all participants (professionals, young people and parents) will be explored. Consequently, additional factors and issues which go beyond McGinty and Fish's criteria will be discussed as and when they arise. However, within this chapter the following criteria will be considered: balance within transition programmes; service priorities; coherence; and inter-agency co-operation and joint working.

4.1 Pen Portraits Of The Focus Schools

4.1.1 Oaksmere

Oaksmere, a local authority school within Authority 1, accommodates approximately 70 children and young people with pronounced learning disabilities between the ages of two to 19 years. Geographically, the school covers a wide catchment area within the city. However, the Head indicated that the school's population had many less affluent families with a significant number dependent upon state benefits. Oaksmere has ten full-time teachers plus the head. In addition, each class has the support of a nursery assistant or a non-teaching assistant. In terms of health provision the school has on-site nursing and physiotherapy.

Within Oaksmere there is an emphasis upon a policy of integration, as the school prospectus clearly illustrates:

> "Our philosophy is to integrate our pupils regardless of their special needs, within the school, and within the local community, wherever it is possible and appropriate." (p.9)

Practically, the Head suggested that the school tries to develop links with both mainstream primary and secondary schools. However, this is usually only for a small number of 'appropriate' pupils. Structurally, the school is divided into three departments: primary; secondary; and tertiary. Within the tertiary department, i.e. post-16 years, there are two mixed aged pastoral groups (16 - 19 years). The vast majority of young people leave at 19; indeed, it is very unusual for anyone to leave at 16 years. One, if not the, key aim of the post-16 course is working towards independence, whether socially, educationally or personally. The Head explained:

"Yes, well the curriculum first of all is very much a life and social skills, self-help, independence curriculum, er interlaced with the national curriculum in terms of core subjects... generally speaking what we're aiming at is independence ..." (September'95)

4.1.2 Ash-hill

Ash-hill is also a local authority school within Authority 1. The school is relatively new because in 1991, due to local authority special educational re-organisation, two schools were amalgamated to form Ash-hill. Within the last five years, Ash-hill has also faced internal upheaval as the Head left and the post remained vacant for a long period. At the time of fieldwork a new head had just arrived. This was clearly welcomed by the staff and was hoped would signal a period of stability for the school.

Ash-hill is a secondary school with a growing post-16 department. It serves approximately 115 young people with learning disabilities (less pronounced than at Oaksmere) from 11 to 19 years. At Ash-hill there are 16 teachers plus the head. Geographically, the school is located on the edge of the city at the top of a steep hill making it rather inaccessible. The catchment area is similarly large and once again encompasses many less affluent families, as the post-16 tutor indicated:

" ... if you sort of looked at the kids in school, it's er, there's a very heavy concentration of very poor families, um there's a range but it's skewed distribution." (March'95)

Structurally, the school is divided into the main school and the post-16 department, once again a key aim of the post-16 course is to help students become more independent:

" ... to help the students develop their full potential and hopefully develop their independence to an extent where they are doing better than they were." (Post-16 tutor, March'95)

Academically, GCSEs are not usually taken by students, but in the post-16 department an externally moderated, pre-vocational foundation course is followed. Opportunities for students to link in with mainstream schools are valued and within Ash-hill there is an established link with a local comprehensive. This enables some of the young people to experience lessons within a mainstream setting.

4.1.3 The Laurels

Located within the newly formed unitary city (Authority 3), The Laurels is an authority run, secondary school for young people with pronounced learning disabilities. The school caters for up to 65 pupils ranging in age from 11 to 19 years. In a similar vein to

Oaksmere School, it is very unusual for anyone to leave before 19. However, The Laurels' catchment area is broader than Oaksmere's, stretching across and beyond the city. Hence, its socio-economic composition is more diverse, both urban and rural. Within the school there are ten teachers, eleven classroom assistants and the head. Medically, The Laurels has on-site nursing and physiotherapy provision. Structurally, the school is divided into two large departments: secondary and post-16. Here, the young people are grouped chronologically. However, within the secondary department there are two distinct classes where young people are grouped by 'severity'.

A whole school ethos of 'empowering' young people and working towards their independence is emphasised, especially, in the post-16 department:

> "... the ethos again is expressed through the curriculum about empowering students to be as independent as possible, that is, it is linked into the curriculum as much as there's an emphasis upon social independence..." (Head, July'95)

Next door to The Laurels there is a large comprehensive school. The Head stressed that the comprehensive is generally very willing to foster links and opportunities for his pupils to join mainstream lessons or activities. However, it is once again 'where appropriate'.

4.1.4   Cedar Drive

Cedar Drive, located within the unitary city (Authority 3) is similarly a local authority school. It serves approximately 80 odd pupils, children and young people with physical impairments, on-going medical needs and learning disabilities (the latter less pronounced than at The Laurels). The school caters for children aged from three years to young people of 16. They are drawn from a wide urban and rural catchment area, once again socio-economically diverse. Structurally, the school is divided into three distinct departments: a part-time nursery; a primary; and a secondary department. In terms of staff there are 11 teachers and the Head, plus a mixture of 12 full and part-time non-teaching assistants or nursery nurses. The school has a comprehensive on-site medical staff providing nursing, physiotherapy and speech and language therapy. Opportunities for some young people to link into mainstream schools at both a primary and secondary level were highlighted. Within the latter, this could take the form of attending subject classes at a local comprehensive. Furthermore, some students have an opportunity to take selected GCSEs.

At Cedar Drive the importance of independence is once again emphasised. In addition, developing a sense of self-esteem and self-confidence amongst the young people is also prioritised:

"We always encourage the students to talk for themselves, however they do it ... but that's part of self-esteem, that's part of recognising that you have a right to an opinion and it should be valued." (Head, March'95)

4.1.5 Beechview

Beechview is predominately a weekly residential school for young people with a range of impairments both physical and learning. The school is based within an Elizabethan manor house, aesthetically a beautiful setting but, practically, one not without its problems. The local authority maintains Beechview but in the recent past it sought grant maintained status after receiving a positive parental ballot. Their application was however turned down. Furthermore, at the time of writing the very future of the school was being discussed.

The residential nature and geographical location of Beechview within Authority 2 (two miles from a small market town) fosters a wide and diverse catchment area. Young people are drawn in from the whole of Authority 2 and some neighbouring counties. The school is geographically rather isolated. However, the Head stressed that the young people have plenty of social opportunities within the community, such as attending a local youth group. The school itself caters for up to 60 pupils ranging in age from eight to 18 years and is separated into the main school and a post-16 independence unit. Academically, there are opportunities for some young people to take core subject GCSEs. The majority of students leave at 16 years, but do not move into the independence unit. Students within the independence unit are usually drawn from other schools, such as Cedar Drive. Within the post-16 unit the aim is to promote personal and social independence:

> "Students are helped to acquire knowledge, skills, and self-esteem to reduce their dependence on other's assistance and direction, so that they may live as full and rewarding a life as possible..." (Handbook, p.3)

Within Beechview there are ten teachers, six non-teaching assistants, thirteen residential care staff and the head. The school, like Cedar Drive, has comprehensive medical provision with on-site nursing, physiotherapy, speech therapy and occupational therapy.

4.2 School Leaving Preparations

In this section three programmes within the schools' leaving preparations will be explored: college links; work experience; and careers advice. Of course, there are many more aspects interwoven within school leaving preparations; however these were the most clearly and consistently discussed by professionals. In recognition of the many

additional elements, a brief discussion of overall programme balance, as raised by McGinty and Fish (1992, pp.94-95), will initially be considered.

4.2.1 General Balance of Leaving Preparations

Chapter two demonstrated that although indicators of 'adulthood' and 'adult' status are much debated four key areas emerge: living independently and/or personal autonomy; employment and/or economic independence; social participation and/or adult role taking; and, finally, post-secondary education (Fish, 1986, p.7; Thomson and Ward, 1994, p.17). These four areas will be used to explore the degree to which there is a balanced leaver's programme.

Generally, there did seem to be an element of balance within the focus schools' leaving preparations. Indeed, the schools frequently talked of their preparations as a 'leavers programme'. Viewed as a whole, the focus schools at one point or another demonstrated preparations which sought to nurture Fish, and Thomson and Ward's indicators of adulthood. In comparison to earlier studies of school leaving preparations, such as Anderson and Clarke's (1982) study of physically disabled young people, particularly in special schools, the focus schools here provided a more comprehensive programme. For example, they all explored the world of work via, either work experience, work visits, company links or talking about work and employment within the curriculum. Life-skills lessons presented in a variety of guises such as, personal and social education courses or activities for daily living sought to encourage students to develop independence skills and greater personal autonomy. Finally, social interaction and further education was addressed, to varying degrees, within college link programmes. The actual form, and degree within which these elements were addressed and presented to the students, will, however, be explored more fully and critically in the ensuing sections.

Fish and Evans (1995) suggest that staying on at school post-16 can have both positive and negative effects. On one hand, a young person's statement continues; however, there is the danger that they may not be taught within "an environment that encourages increased maturity and a more detailed approach to learning." (p.80). Hence, it is important to consider the idea of an 'adult' environment. School tutors frequently stressed that they tried to make their students feel more 'adult' within the school and thus distinct from younger pupils. This was demonstrated through the idea of 'difference'. Providing privileges, such as not having to go out at lunchtime but rather being able to choose, or having separate and distinct social areas, was felt to bestow a more 'adult' social status upon forthcoming leavers. Furthermore, in post-16 departments, especially those within schools with much younger pupils (see Barnes,

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1991), it is important to consider the physical space allocated to forthcoming leavers. A physical distance from the main school can help to reinforce a status differential and thus promote a feeling of 'adulthood'. Within the four focus schools providing post-16 education, three (The Laurels, Ash-hill and Oaksmere) had their 16-plus departments located within the main body of the school. Two of the tutors (Ash-hill and Oaksmere) stressed they were not comfortable with this but felt currently unable to alter it due to physical practicalities. For example, the tutor at Oaksmere saw it as a basic "entitlement" for his students:

> "I feel my ideal would be to have us in another building outside of this school, out there somewhere ... it's a very simple entitlement, it's what, um, you know, if you go into the sixth form would expect." (October'95)

Beechview's independence course had the clearest physical distinction as the second years lived in a separate bungalow from the main school. This enabled students to develop and practise their independent living skills. However, this distinction became less clear during school hours when lessons were often shared with main school, year 11 pupils. An 'adult' environment was thus valued within the focus schools. However, there were practical barriers towards creating such an environment in some of them.

4.2.2 College Links and Work Experience

4.2.2.1 College Link Programmes

All the focus schools organised college link courses in one form or another. The Laurels and Oaksmere provided a weekly day release course for students within their post-16 departments and, at Cedar Drive and Ash-hill, there was a weekly half-day release course for students (Cedar Drive, years 10 and 11; Ash-hill, years 11 to 14). In contrast, although Beechview provided a weekly half-day release course for students within the independence unit it did not provide a college link for main school students. Thus, a student could leave Beechview at 16 years without experiencing any of the benefits of a college link course. Factors of cost and travelling distance were blamed by the careers teacher at Beechview. Ultimately, provision thus varied both in terms of 'when' students embarked upon college links and their 'length'. Practical factors inevitably play a significant role; however, school priorities were also important.

In general, college links were viewed as an important opportunity for the young people. In fact, there was a distinct philosophy amongst the schools that college education was a 'right' for their students, just as it was for any other young person. The post-16 tutor at Oaksmere suggested he felt it was:

"... almost an inalienable right for a 16 year old youngster to have access to a college course." (October'95)

Post-school education has been presented as one potential indicator of 'adult' status (Thomson and Ward, 1994, p.17). Consequently, college link courses can be a very important part of not only school leaving preparations but also moving towards adulthood. In fact, McGinty and Fish (1992) present college link courses as a valuable opportunity to bridge the gap between school and college, thus aiding a smooth transition and reinforcing the very idea of progression. This was felt to be especially important at Oaksmere School. Here the post-16 tutor recognised, as Barnes (1991) and Brotherson et al (1988) have highlighted, that students leaving special schools may not have previously made an educational transition, perhaps having spent their whole educational careers in a single school. Hence, the notion of 'transition' and progression can be both difficult and rather frightening concepts to comprehend:

"... many of our youngsters if they haven't been in this school from the age of three, four, five, they've been in one kind of special school or special school setting since that age and there's no obvious cut off point. There is not a junior school and then a senior school, so the sense of transition is quite a difficult one for many..." (Oaksmere post-16 tutor, October'95)

The organisation of college links differed between authorities. In Authority 1, college link courses were organised by a steering group consisting of special school and college representatives, whereas in Authorities 2/3 such a group was not mentioned. The steering group was valued by both schools' post-16 tutors (Oaksmere and Ash-hill) as an opportunity for joint planning and co-operation amongst the city's special schools. Financial considerations were also raised as an area of concern by both Authority 1 school tutors. There was felt to be a continuous need to justify the financial backing of college link courses from an ever-dwindling school budget.

One consequence of this joint planning within Authority 1 was that special schools joined together to share college courses, whereas in Authority 3, special schools attended separately, remaining within their own school group. In fact, the learning support manager within the unitary city's college noted that Authority 3 special schools had chosen this option. From a personal perspective she could see the benefit of students sharing courses. However, the decision to attend separately may be practically based, as there are a smaller number of special schools within the unitary city, compared to Authority 1. The benefit of sharing courses was stressed by both Authority 1 schools'; in particular, the social aspect of students meeting and mixing with new peers. In fact, the tutor at Oaksmere prioritised this as an opportunity for his students to mix with fellow special school peers. This was regarded as a wider social group that would be meeting regularly in the future, whether at college or the day centre. On one hand,

the young people were extending their social network beyond 'their' school. On the other hand, it was still a very segregated and specific population of people with whom the students were socialising. This duality was recognised by the Oaksmere tutor:

"... the first real opportunity for our youngsters at post-16 to be working with and to integrate with what ultimately will be their um a community that they will be attached to for a long time ... to whatever degree we like or don't like it, that's the reality." (October'95)

Amongst the focus schools, mainstream college links were valued as an opportunity for students to develop skills in three broad areas: social; practical independence; and vocational, many of Fish (1986) and Thomson and Ward's (1994) indicators of 'adulthood'. Tutors at three of the focus schools (Oaksmere, The Laurels and Ash-hill) highlighted social skills. College links were presented as an opportunity for students to socialise with fellow peers, observe 'acceptable' social behaviours/norms and learn to cope with new lecturers. Fieldwork observations (with Oaksmere, The Laurels and Cedar Drive) indicated that there was indeed an opportunity for Authority 1 students to meet fresh faces and make new friends from sister special schools. Furthermore, amongst both Authority 3 and Authority 1 students the college canteen was an important social venue and lunchtimes in the canteen were enjoyed. However, one cannot escape the fact that within the observed college links, students had very little interaction with non-disabled peers. When in the canteen, the young people may have been sitting with other students and thus physically integrated but levels of social interaction were low to non-existent. There is thus a subtle difference between 'integration' and 'inclusion' (see Mason and Rieser, 1994; Oliver, 1996b). If, and when young people from the Authority 3 schools (The Laurels and Cedar Drive) did socialise, it was generally with old friends from their own school who had already moved on to college. However, it is also true that the whole canteen was socially made up of course cliques with many layers of social differentiation. 'Integration' as an issue was however raised by two tutors. At Oaksmere the tutor acknowledged that integration was limited. The tutor at Ash-hill went one step further and questioned whether there was enough integration within college links, but practically could see problems in trying to address this:

"See it's almost enough for our students to manage the college environment in a safe, secure sort of group. Er, the problems of sort of integrating our students we haven't really tackled really, it's a step that we ought to tackle more, we ought to do more I'm sure but just maintaining the level of er provision at the moment is quite hard work..." (October'95)

Practical independence skills were another set of factors valued within college link programmes. In particular, the idea of learning to cope within a large, mainstream

'adult' environment and taking on more responsibility for oneself in moving away from the familiarity and sheltered context of special school. In terms of personal autonomy, college link observations (with The Laurels, Oaksmere and Cedar Drive) illustrated that the canteen routine did indeed provide an opportunity for the young people to gain confidence within a more unsupervised and socially mixed situation, compared to their school dining room. The young people also had more opportunities to make decisions about what they ate, and to varying degrees, their own money. Furthermore, some of the students, especially those at Cedar Drive, were given an opportunity during lunch to manage their own time, i.e. they could go to the library or the bookshop if they wanted. However, this tended to depend upon the severity of the young people's learning disabilities. In many cases the young people at The Laurels and Oaksmere remained highly managed and supervised by their tutors, especially those with pronounced learning disabilities. This was felt to be a practical necessity. For example, the Oaksmere tutor stressed the need for a structured and well-organised introduction to college after the protected and safe environment of special school:

> "The link itself is, it's carefully structured if you like, it's almost inevitably a contingent of school staff who accompany these links, we couldn't run it without." (October'95)

Furthermore, college link observations indicated that symbols of belonging to college, such as a student card or a college library card were highly valued by the young people. In effect, they provided social recognition of a 'changed' status for the young people, indicating that they were preparing to move beyond school and thus 'pupil' status. However, the young people, especially those from Oaksmere and The Laurels were still highly visible as 'pupils'. They frequently moved around the college as a distinct group, often with their class teacher. In many ways they were, as Todd's (1995) analysis of a special school's leavers programme has suggested, "the school on tour" (p.15) with the young people as "the tourist" (p.18).

The final group of skills were vocationally based. On one level, tutors (especially Oaksmere, Cedar Drive, The Laurels) recognised college courses as an opportunity for students to experience activities which their school could not provide. On another level, the tutor at Ash-hill stressed wider 'core skill' opportunities such as numeracy, literacy, team work and problem solving.

The common theme throughout these skill groupings and tutor comments was the value placed upon college links as providing 'real' experiences. The Oaksmere tutor stressed that these were invaluable when young people came to make post school decisions. Tutors thus viewed the links as an important and invaluable component of leavers

programmes. However, one must not forget that the links were frequently highly managed and supervised with little opportunity for interaction with non-disabled peers.

4.2.2.2 Work Experience Placements

Within the focus schools, work experience was also regarded as an invaluable experience for the young people. However, not all the schools or all students within a year group had the opportunity to undertake work experience, especially, a work placement outside of school. Three of the focus schools (Cedar Drive, Beechview and Ash-hill) had formal work experience programmes for students. However, it was also apparent that at Cedar Drive and Beechview there were some students either pursuing work experience only within the context of school or not at all. At The Laurels, there was some work experience opportunities for older students within the post-16 department, either within or beyond school. These were provided by a small and select group of employers that The Laurels had built up over the years. Here, work experience was thus limited to a small group of students each year, a factor the Head acknowledged and stressed that he wanted to change. His aim was to extend work experience opportunities to younger members of the post-16 group. In contrast at Oaksmere, although work experience was valued and promoted whenever possible, the post-16 tutor noted, that in recent years none of.his students had actually undertaken work experience outside of school. In fact, the tutor highlighted that it was five to seven years ago that students had regularly undertaken such placements.

These differences between and within schools raise a number of important questions and issues. The first is that of 'appropriateness'. Work experience beyond the school was often viewed as 'inappropriate' for some pupils, especially those with pronounced learning disabilities:

> "And for those who we feel are not suitable to go outside school and do work experience, we occasionally try and find them a work experience scheme in the school..." (The Laurels tutor, December'95)

It is interesting to note that although further education was seen as a 'right' for disabled young people, similar sentiments were not voiced for 'all' young people in terms of work experience. One could argue that this is only being 'realistic'. However, it perpetuates very subtle ideas and social messages concerning the world of work and the exclusion of some people from it. Ideas of 'appropriateness' were also fostered and perpetuated by wider socio-economic factors, often beyond the school's scope. Some tutors lamented these. For example, at The Laurels the number of placements available and the number of employers willing to offer placements to students, especially for those with more pronounced learning disabilities, was recognised as being limited:

"... even though we've got such lovely people who are prepared to offer us places a lot of people aren't, they're not prepared to offer us placements." (The Laurels tutor, December'95)

Furthermore, the tutor at Oaksmere highlighted the issue of support levels. Here, it was felt that the level of support students from Oaksmere would require within an open placement was in fact currently unrealistic to expect:

"... you know, I could apply for a Trident place and I might well get it but if the youngster's actually incapable of er telling the difference between Alpen and er Branflakes when he's stacking the shelves in Morrisons then there's no point in him being there because the amount of support that's going to be required is not efficient and wouldn't be appropriate..." (Oaksmere tutor, October'95)

This comment raises interesting issues surrounding notions of 'efficiency' and 'appropriateness'. Supported employment projects, such as Bass and Drewett's (1996), have illustrated that many severely disabled people can cope within an open working context if properly supported. However, such a scheme does have initial cost implications, both financially and in terms of support provided. These are factors which the tutor at Oaksmere, perhaps realistically, suggests are often unacceptable within our economy.

On a more positive note, work experience within Cedar Drive, Beechview and Ash-hill was clearly seen as part of a wider careers programme. It was highly valued as a positive learning experience for students both socially and in terms of fostering independence skills, especially within post-16 departments. It was much more than preparing for a specific job. However, on a more pessimistic or perhaps realistic note, tutors at The Laurels, Cedar Drive and Ash-hill simultaneously acknowledged that they feared many of their students would not find employment. Work experience would remain just that, an experience.

4.2.3   Careers Programmes and Advice

In terms of careers service provision and advisers input, the focus schools were positive and generally satisfied with the service they received. A similar situation was also reported within Armstrong and Davies' study (1995). In fact, the careers service within Authorities 2/3 was praised enormously. The idea of a 'specialist' with 'special' knowledge and understanding was valued, as illustrated by the Head at The Laurels:

"... the one thing that struck me quite forcefully when I came here from another authority was the quality of the careers service which was offered to the school. I'd previously worked with a generic career officer who because of the nature of that responsibility didn't fully appreciate the needs of the students. There is no shadow of a doubt in my mind that it is much more advantageous to have a specialist careers officer who is very clear about the abilities of the students and also very aware of the provision that's available." (July'95)

However, during the research period, the careers service within Authorities 2/3 stressed that they had moved away from 'specialist' advisers to having a limited number of careers advisers with a special needs case load. However, beneath this organisational shift the idea of 'special' was still apparent. Within Authority 1, officially the onus was upon having 'generic' advisers and a designated person with 'specialist' knowledge for others to draw upon. In practice, the designated person with 'specialist' advice was the career adviser within a number of special schools, including Oaksmere. Furthermore, this 'specialist' knowledge and the idea of 'specialisms' was valued and welcomed by both tutors at Oaksmere and Ash-hill:

"... so yes, they are generic careers officers but some are operating with special expertise and are being kept in that area. I think by choice, they want to do it, which is good for us..." (Ash-hill careers tutor, April'95)

It is clear that the schools valued 'special' and 'expert' careers knowledge. However, the idea of having a 'special' adviser once again illustrates the special versus generic debate. Specialist careers advisers may offer 'specialist' knowledge but they can also reinforce ideas of difference and perpetuate 'segregation'.

Career programmes within the focus schools were frequently presented and interpreted in a broader fashion than mainstream schools:

"Careers guidance isn't careers guidance as it would be in a mainstream school. A lot of the pupils will never have a paid full time job or a part time job for that matter, so careers is very much in the wider sense looking at their future, a meaningful, worthwhile existence..." (Cedar Drive careers tutor, July'95)

Within this analysis, careers provision at Ash-hill, Cedar Drive and Beechview will be discussed before careers provision at Oaksmere and The Laurels. Ash-hill, Cedar Drive and Beechview stressed that they had regular contact with the careers service. In terms of school careers provision there was a structured annual programme beginning in year nine or ten, led by a clearly designated teacher with responsibility for careers. Furthermore, there were organised times when the careers adviser visited the students, times, which corresponded to each school's careers programme. The situation was more complex within Beechview. Here, the local careers adviser regularly visited the school but it is also recognised that there was a need for students to see their own home careers

adviser, in order to gain local information about post-school opportunities. The issue of 'distance' at residential schools thus makes leaving preparations more complicated with additional professionals being drawn in. Furthermore, the careers tutor at Beechview acknowledged that keeping parents informed was difficult. In fact, it was an area she felt could and should be improved. The danger of parental detachment at residential schools was acknowledged:

"If their *[the students']* careers lesson happens to be on the Monday, they've forgotten about it on the Friday. They're not going home and saying, 'look what we did in careers' ... so I think they *[parents]* need involving more and that the next thing." (Beechview careers tutor, January'96)

'Individual Action Planning' was generally valued as an important process for students at these three schools. The most passionate advocates were the Head and the careers tutor at Cedar Drive:

"I think one of the most exciting developments within the school is er an individual action planning programme..." (Head, March'95)

Here, the programme (especially years 10 and 11) was viewed as an important transition planning process for each student. It was a process of self-analysis and choice making with the student being involved as an active and participatory learner. However, the careers tutor was also aware that there were problems attached to Individual Action Planning: namely, school time constraints:

"I think it is useful but to be quite honest it's so difficult to get the time to do it properly..." (Cedar Drive careers tutor, October'95)

Furthermore, the tutor at Ash-hill noted that, although he valued 'Action Planning', his students often found it difficult to apply self-analysis and problem solving skills. The careers adviser at Cedar Drive reiterated this idea. She voiced concerns regarding the actual level of understanding that was achieved within Individual Action Planning amongst Cedar Drive students. At times she feared it was rather superficial; students maybe having the words but not actually understanding the underlying concepts:

"I ... have sort of qualms of conscience about whether they're really going through the process themselves or whether it's being done to them." (Careers Adviser, Authorities 2/3, November'95)

Consequently, pitching individual action planning at the right level is an important consideration but potentially difficult to achieve.

At Oaksmere and The Laurels it was similarly suggested that the careers adviser had an important input and came into the school regularly, either to meet parents, or to see the young people:

> "... the careers service are very, very involved with us. We have our own careers officer who attends all interviews, all reviews and also has a contract to come into the school with a view to doing very limited work." (The Laurels tutor, December'95)

However, there appeared to be less emphasis upon the careers adviser seeing the young people individually. In fact, the careers advisers interviewed, within both authorities, highlighted difficulties when working with students with pronounced learning disabilities. They stressed the importance of involving and working with parents. Severity levels and degrees of parental involvement are thus closely interwoven.

> "... it really is a difficult thing with youngsters with more severe learning difficulties um because the time scale, you know, you're talking about things so far ahead and I do depend so much on parents ..." (Career adviser Authorities 2/3, November'95)

Careers programmes within Oaksmere and The Laurels are focused upon the post-16 years as students leave at 19 rather than 16. Programmes are, once again, planned and structured. However, in comparison to the previous three schools there seemed to be less distinct and separate 'careers' lessons and, rather, a more integrated approach within the general leaving programme. This was demonstrated by the fact that both post-16 tutors had taken responsibility for careers. It is also related to the general programme of education adopted within the two schools.

Careers was clearly valued at both Oaksmere and The Laurels. In fact, The Laurels Head wanted to further develop and formalise careers input within the post-16 programme. He recognised that it could be more integrated within the curriculum:

> "... during the last year we've had a couple of sessions when the careers officer has come in ... it's something we again perceive to be a developmental need for the school, to try and take what we have done so far and make it a bit more structured, really set it down into the curriculum in a more forceful way." (The Laurels Head, July'95)

Furthermore, the careers adviser within Authority 1 noted that careers work within the authority's special schools, especially for students with pronounced learning disabilities was a fairly recent phenomenon:

> "Kids you would class as SLD have not been dealt with too comprehensively by the careers service simply because it is something which has not been wanted by schools or parents." (June'95)

The past problem, he suggested, was that 'careers' was not really viewed as relevant. The idea of 'careers' conjuring up images of only employment and training, which many special schools had seen as irrelevant. Hence, his prioritisation of a gradual introduction.

On a more positive note, careers programmes and the significant input of career advisers within *all* the focus schools must be recognised. This should be welcomed, especially when one considers earlier findings such as Anderson and Clarke's (1982, p.316) conclusion that physically disabled young people at special schools lacked careers advice and Hirst's (1987b, p.70), suggestion that those with learning disabilities were more likely to see a social worker than a career adviser. Here, the focus schools valued the role of careers advisers for *all* students. However, this does not mean that provision was uniform. Indeed, there were subtle differences in programme delivery. Overall, these developments generally reflect both changing professional priorities and changes within further education provision for disabled students. This is an area that we will now address.

4.3 Post-School Provision and Destinations

In this section two broad issues will be explored: firstly, opportunities available to the focus school students and their first post school destinations. Secondly, a range of further education and training issues will be discussed, especially those surrounding the Further and Higher Education Act (1992) and the introduction of the FEFC, and within youth training, the idea of 'appropriateness'.

4.3.1 Opportunities and Routes Taken

Discussions within the focus schools and with career advisers indicated that there were six main options available to students approaching school leaving:

- At 16 staying on or moving to another school, predominately another 'special' school.

- Moving to an FE College, either day or specialist residential. Initially, many students pursued a discrete 'special' course.

- Youth Training - within Authorities 2/3 this was known as NVQ (National Vocational Qualification) options, whereas in Authority 1, it was called 'OPEX' (Opportunities and Experience).

- Employment, either full or part-time.

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- Social Services provision, usually within a day centre.

- Pursuing a combination, usually part time attendance at a local college combined with attending a local day centre.

The following tables provide a more concrete analysis of both the sample of young people and the focus schools post-school routes over a number of years. The information, as one can see, is not always complete. There were some years when information could not be gleaned either from the schools concerned or the careers service. This in itself indicates a lack of comprehensive statistical record keeping and more generally, following-up students post-school careers. This is similar to problems reported by Ward et al (1991) and Thomson and Ward (1994).

Authority	School	Young People	Routes Taken
Authority 1 (metropolitan)	Oaksmere	Susan	Local College
		Jason	Continuing Education Course .
		Fiona	
	Ash-hill	Laura*	Local College
		Steven	Combination of College and Day Centre
Authority 2	Beechview	Ian	Training
		Louise	Local College
		Lisa	
		Ellen	
		Charisa	Specialist Residential College
		Linda	Combination of College and Day Centre
Authority 3 (unitary, detached from Authority 2 in April'96)	The Laurels	Eric	Specialist Residential College
		Julie	
		Janet	
	Cedar Drive	Bob	Residential School (post-16 independence Course)
		Luke	
		Geoffrey	Special School (post-16 unit)

*Left during first two weeks.

Table 8: Destinations of The Sample of Young People

Routes Taken	Year 11	Year 12	Year 13	Year 14
FE College	4	3 (2ft, 1pt)	1	3$
Moving To Another School	1	1	0	0
Youth Training Appointment	1*	0	3**	0
Employment	1	0	0	0
At Home	0	3	0	0
Unknown	3	0	0	0
Total No. of Leavers	10	7	4	3

Year 11* - Did not attend training appointment

Year 13** - 1 attended a training appointment and two did not attend.

Year 14$ - 1 of the young people left college.

Table 9: Ash-hill - 1996 Destinations

Routes Taken	1991	1992	1993*	1994	1995	1996
Specialist College	2	0		1	2**	3
FE College	1	6		2	5	4
School Based Independence Course	2	6		0	0	0
Staying on at School	13	9		0	0	0
Youth Training	5	2		0	0	1
Employment	1	1		0	0	1
Social Services	0	1		1	0	0
Moved Away, Left or Unknown	1	3		2	0	1
Voluntary Work	0	0		0	0	1
Total No. of Leavers	25	28		6	7	11

* Figures not available for 1993

** One of the Specialist College places was in county

Table 10: Beechview Destinations at 16 Years

Routes Taken	1991	1992	1993	1994	1995	1996
Specialist College	2	0	1	2	1	0
FE College	0	2	2	2	4	0
School Based Independence Course	2	3	1	2	2	3
Moving to Another School	2	1	1	2	0	2
Youth Training	3	0	0	0	0	1
Employment	1	1*	0	1	0	0
Social Services	0	0	0	0	1	0
Moved Away, Left or Unknown	0	0	0	0	0	1
Total No. of Leavers	10	7	5	9	8	7

*Part-time employment

Table 11: Cedar Drive Destinations at 16 Years

Routes Taken	1995	1996
FE College	4	3
Continuing Education Unit	0	2
Social Services	0	1
Total No. Of Leavers	4	6

Table 12: Oaksmere Destinations at 19 Years

Routes Taken	1991	1992	1993	1994	1995	1996
FE College	2	1	4	4	5	5
Staying on at School	1	0	0	0	0	0
Youth Training	4	3	1	3	1	3
Employment	0	1	0	1	0	0
Voluntary Work	4	0	0	0	0	0
Social Services	0	1	0	0	0	0
Moved Away, Left	1	1	0	0	0	1
Total No. Of Leavers	12	7	5	8	6	9

Table 13: Beechview Destinations (Independence Unit) at 17/18 Years

Routes Taken	1991	1992	1993	1994	1995	1996
Specialist College	3	2	1	2	1	5
FE College	5	4	1	1	3*	0
Social Services	0	5	4	5	2	1
Moved Away	0	0	0	0	1	1
Total No. Of Leavers	8	11	6	8	7	7

* Two in part-time FE

Table 14: The Laurels Destinations at 19 Years

[Source of information for tables: Oaksmere and Ash-hill – the school; Beechview, The Laurels and Cedar Drive – authority careers adviser]

When making observations or drawing conclusions from these tables it must be remembered that they represent very small numbers of students within each school. However, four broad observations can be drawn from Tables 9-14. Firstly, what is apparent is the obvious importance given to continuing within education post-16, whether at school or at college. Education was the preferred option for 70% of all leavers in 1996. This first destination route mirrors both the expansion of further education for students with learning disabilities and a general social trend for more

young people to remain in education post-16. The second factor of note is based on an authority difference in the take up of specialist residential college places. In schools within Authorities 2/3 there are a small but significant proportion of young people pursuing this option, even after the introduction of the Further and Higher Education Act (1992) and the move to FEFC funding. For example, in 1995, 14% and in 1996, 23% of all leavers from Authorities 2/3 chose a specialist residential college. In contrast, within Authority 1 residential college placements do not appear to be an option. This was reinforced by both careers advisers and summarised from personal experiences as a shire/metropolitan difference by the careers adviser within Authorities 2/3:

> "... it seemed that the shire counties tended to send people to specialist college and the smaller metropolitan areas tended to keep them all within their, but that's just something, er a general feeling that I had ... I just don't know for the country." (November'95)

Employment is the third factor deserving comment. It is clear that movement into employment is consistently low as a post-school destination, whether at 16 or 19 years. The school to work transition is clearly delayed for the majority. On one hand, this mirrors a general social trend. However, it is in later years when many of the young people's non-disabled peers move into employment that differences can and do emerge, as past literature has demonstrated (Hirst and Baldwin, 1994, Thomson and Ward, 1994). Some of the focus schools' tutors reiterated this:

> "No, I think there's a lot of casualties out there ... I think there's a large proportion of students who leave a school like this who only ever go on benefit..." (Ash-hill tutor, October'95)

The fourth and final observation concerns youth training. It was apparent that there is a low take up of training both at 16 and 19 years. However, slightly more pursued training from Beechview after a period of further education, at 18/19 years. It is interesting to note that at Ash-hill in 1996, although a significant number of students initially sought to pursue training, no one ultimately embarked upon it. Questions of suitability or 'appropriateness' thus arise. These will be explored further within the section upon 'training issues'.

4.3.2 Further Education And Training Issues

4.3.2.1 The importance of Further Education

The idea that young people have a 'right' to further education was, once again, raised by many within the focus schools, especially Oaksmere and The Laurels. Hence, the

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relatively recent expansion and development of courses within local colleges was highly valued:

> "... five colleges in Authority 1 have discrete special needs college courses and that's five compared to about two, about four years ago, so that's one sector which has increased." (Careers adviser, Authority 1, June'95)

On one hand, the Cedar Drive Head felt that this expansion was probably interwoven with colleges becoming independent institutions and a market economy. Disabled young people were potential clients. Fish and Evans have highlighted the creation of a "post-16 market" (1995, p.72). However, the Oaksmere Head was more sceptical than the Cedar Drive Head and feared greater selectivity within a market economy and colleges as independent institutions:

> "I believe very firmly in further education for our students with learning difficulties and it's a very, very sad case nowadays that colleges of FE are far less interested in students with severe learning difficulties." (Oaksmere Head, September'95)

The Oaksmere Head feared that only certain types of disabled students may become 'acceptable' and made welcome within local colleges:

> "... provided students fit into the mould that they have, there isn't a problem. Um, it's only if that individual particularly presents behavioural problems will they be rejected." (September'95)

This raises concerns about future trends and the exclusion of some disabled students, especially, if local colleges continue to become more cost conscious and cut levels of support. This fear mirrors Fish and Evans concerns surrounding the new "post-16 market" (1995, p.80).

Problems of physical access were also noted. Both the Head and tutor at Beechview felt that access and meeting students physical needs remained a barrier for some, depending on severity. It was frequently a matter of degrees of access.

> "One or two of the local colleges can cope and provide very good help up to a certain level of disability ... you know, it's um access for the disabled, special support and everything else until you take a specific problem and then it all falls down. Um, access for wheelchairs, fine, they've got lifts, a special mobile platform; a toilet for the disabled but no changing table and no room to put one in." (Beechview tutor, January'96)

Thus, some of the focus schools felt that yes, access had improved for their students but there were still problems attached, whether physical or philosophical in terms of who was 'acceptable'. Financial issues and considerations of provision were an acknowledged reality, a factor which, relates to wider issues within a market economy.

With regard to longer term opportunities, there was a general feeling at both Oaksmere and The Laurels that students should aim to get as much education and for as long as possible, because social services day provision was seen as the ultimate destination:

> "... because if we're realistic about it our students are going to end up in training centres, 95% of them and they're going to end up in training centres at 21, when they've gone through a two year college course." (Oaksmere Head, September'95)

Hence, there was a feeling of trying to put off what was seen as the inevitable. College as a stopgap has also been noted by Todd et al (1991, p.14) and Swain and Thirlaway (1994). In fact, Swain and Thirlaway suggest that further education is often "a temporary substitute for the day centre" (p.166). Taking this a step further, one is reminded of the debate surrounding the issue of prolonging transition, via training and education, as raised by the Centre for Educational Research and Innovation (1985, p.10) and Ward et al (1991, p.128).

Residential college, as indicated within the destination tables, was an important consideration within Authorities 2/3. However, specialist residential college is a controversial issue. In this study residential college was discussed at length by professionals, young people and their parents within Authorities 2/3. For a small but significant number, residential college was valued as playing both an important and positive role within the transition to adulthood. Thus, it is important to explore and understand the ideas of professionals, young people's, parents' and their perceptions of the role that residential college played (see chapter seven for young people and parents ideas). However, in doing so, it is also important to place residential college within a wider theoretical and political social model context. Philosophically and practically residential colleges are still 'specialist' and 'separate'. They continue to provide segregated education in an environment focused upon disability, which is often distant from a young person's local community.

At The Laurels and Cedar Drive, residential college was presented by staff as a positive and progressive option for both students and their families. For example, at The Laurels it was actively promoted via school organised visits to two residential colleges. Amongst the positive comments expressed by the different professionals three key factors were raised. The first was developing independence skills, especially, independent living skills within the context of a 24-hour curriculum. The second highlighted increased social interaction and activities. Residential college was seen to provide opportunities for students to socialise with 'their' peers and pursue a variety of activities. This was emphasised by the Beechview Head. He felt that many disabled young people were often socially isolated and inactive at home. The final factor related

to the future and independence from the parental home. Residential college was seen as a positive means of helping parents to 'let go'. It was viewed as a gradual and 'natural' process, in the same manner as siblings frequently leave home for university or college. For The Laurels post-16 tutor, residential college was much more than an academic education:

> "... our students educational needs probably could be met in most cases at the local FE college but that's not what our students need ... it's life-skills, independence training ... they will get a fully twenty four hour education programme which will enable them to learn, hopefully to become more independent in their future lives." (October'95)

Fish and Evans (1995, p.81) and Anderson and Clarke (1982, p.345 and 347) acknowledge independence benefits but also highlight problems of social isolation and distance from a student's home community, especially on return. This issue of social isolation was similarly a concern for the learning support manager at the unitary city's college. Furthermore, there was also a certain amount of realisation by The Laurels Head and the tutor at Cedar Drive that, on return from residential college, students did not always have an opportunity to continue or develop the independence skills learnt at college. Concern surrounding students' futures, post residential college, has also been explored by Sinson (1995) (see chapter seven for family experiences).

Finally, on a practical level, there is a financial dimension to the residential question. The careers adviser within Authorities 2/3 and the Head at Oaksmere were quick to note that some parents would be reticent to consider their son or daughter moving away from home due to the loss of benefit.

> "So in many cases the income one of our students can bring into the family can double the available er um revenue to a family. So you talk to them about hostels and things like that and they're not going to be all that interested unless life is unbearable." (Oaksmere Head, October'95)

There are many complex issues surrounding young people's benefits. First and foremost they are the young person's but as the Oaksmere Head and past studies (Flynn and Hirst, 1992, p.30; Hirst and Baldwin, 1994, p.39 and 50; Thomson and Ward, 1994, pp.83-84) have indicated, for many families young people's benefits are essential to the household income.

Within this study it is clear that further education as an important policy and 'right' for disabled young people was highly valued. In fact, education was prioritised as a stimulating period within the life-course, especially for students at Oaksmere and The Laurels. This was partly fuelled by a recognition that social services provision was many young people's ultimate destination. Furthermore, there was also a marked

contrast between authorities in terms of the promotion and take-up of residential college places. Many professionals within Authorities 2/3 emphasised the benefits for students. However, it is also important to recognise that in many ways residential college can be a short-term solution to deeper and longer-term issues, such as, social inclusion and independent living away from the parental home.

4.3.2.2 The Further and Higher Education Act (1992)

The Further and Higher Education Act (1992) introduced many changes, including the creation of the FEFC and an important distinction between 'schedule-2' and 'non-schedule-2' courses (see chapter two). The destination tables here indicate that the number of students initially moving to residential college has not, as yet, significantly altered since the introduction of the FEFC. However, many professionals felt that in the future there may be a more marked shift away from funding students residentially to funding students at local colleges. For example, a social services principle officer (1995, pre-local authority changes) within Authorities 2/3 foresaw this shift but also stressed that it took time to build up local resources to meet such a demand. The implication was that local resources needed to be built up. Indeed, the issue of post-16 educational provision for disabled young people within Authority 3 was highlighted by the calling of a 'special educational needs' forum (Spring 1997) as a result of the city becoming a unitary authority.

Since a significant number of students still pursue the residential option within Authorities 2/3, it is important to consider the funding process. Gaining funding from the FEFC was generally viewed as a long and complicated bureaucratic process. Hence, the importance of starting early was stressed by the focus schools (The Laurels, Cedar Drive, Beechview) and careers adviser. However, even with an early start there were still problems; most frequently - uncertainty and anxiety. Families were often informed of funding decisions at a very late stage, sometimes after a young person had left school. This was something a number of the sample parents felt strongly about (see chapter seven). Consequently, the FEFC funding process could introduce families to more stress and anxiety within an already stressful period.

> "I suppose the only effect it's [FEFC] had is one of inducing uncertainty." (The Laurels Head, July'95)

Furthermore, if a student does not hear that they have received funding until a very late stage there is a danger that the college may not have reserved a place for them. Hence, late FEFC funding confirmation can lead to co-ordination problems between the FEFC and residential colleges.

Residential funding can also take a joint form with social services and health contributing if there are felt to be 'significant' care or medical needs. Within Authorities 2/3, at the time of interviewing (1995), it appeared that health had not as yet really become involved within joint funding ventures. However, it was prioritised as a future requirement by social services. At a strategic level, Authority 2 had developed a joint protocol between education, careers and social services with regard to provision for young people over 13 years, thus addressing the process of joint funding, roles and responsibilities. However, at an operational level, clarity with regard to the role of social services was not really apparent to the careers adviser. She was confused about how social services actually came to base their decisions - to joint fund or not. Thus, there was somewhat a lack of clarity, with differences of perception between agencies.

The concept of 'accreditation' was discussed in chapter two. Amongst professionals within this study it produced a mixed reaction. Some viewed it positively; for example, the careers adviser within Authorities 2/3 presented 'accreditation' as having a positive potential. Within her assessment two ideas were important. Firstly, 'accreditation' was viewed as an opportunity for the FEFC to make colleges generally more accountable, in terms of 'what' they are doing and 'why'. Secondly, recording students' achievements was viewed as a morale booster. Consequently, recent developments to create assessment tools to chart the progress of students with pronounced learning disabilities were welcomed:

> "I recognise it's difficult to measure um how much the young person has gained but I don't think that should be any reason for not trying to do so. So, I think accreditation is on the whole, is good and that we should be looking at things nationally that young people can achieve." (Careers Adviser, Authorities 2/3, November'95)

On the other hand, concerns were voiced around the separation of schedule-2 and non-schedule-2 courses. The latter are not funded by the FEFC but are frequently undertaken by those with pronounced learning disabilities. Before examining these concerns it is important to note that within Authority 1 there were a small number of non-schedule-2 courses for young people to take. Within Authority 3, The Laurels post-16 tutor suggested that some students with pronounced learning disabilities went straight onto social services provision. This raises the question as to whether 'all' young people have a right to further education. In practice within both authorities there were concerns that young people with pronounced learning disabilities could be disadvantaged, as there would be fewer courses on offer for them to pursue. In particular, the careers officer within Authority 1 highlighted an underlying feeling that non-schedule-2 courses (i.e. continuing education) were not really 'education' (see also Fish and Evans, 1995,

pp.74-76; The National Institute of Continuing Education, 1996). This, he felt could perhaps lead to a loss of status and recognition for those students:

> "... um the implication is that these kids, I suppose the implication is that this isn't education, which is a bit controversial. I know that some schools are quite annoyed by this, particularly from the point of view of equality of opportunities." (Careers Adviser, Authority 1, June'95)

This question of schedule-2 courses and young people with pronounced learning disabilities has been recognised as an issue within Authority 1 and was being explored by the local council. Furthermore, as chapter two demonstrated, the Tomlinson Committee Report (FEFC, 1996) has recently recognised it as an important national issue and area of concern.

4.3.2.3 Training Opportunities

Within Authority 1, a new training scheme, 'OPEX', was being introduced when interviews were conducted. However, questions were raised by three Authority 1 professionals (Ash-hill tutor, careers adviser, deputy Head seconded to LEA) regarding its 'appropriateness' and ability to actually meet the needs of special school leavers, as indicated by Ash-hill's destination statistics. Concern revolved around two issues. Firstly, there was concern expressed about the move to accreditation and the emphasis upon vocational qualifications. Here, there were fears that some students may well be excluded if they could not meet the criteria within designated vocational qualifications. For example, the tutor at Ash-hill highlighted how his students were initially being assessed as to whether they would be likely to achieve the required vocational qualifications necessary to trigger funding for the training supplier. If it was thought that they would not, then there was a danger that their training programme would end. Hence, the scheme was criticised for operating at too high a level for students leaving special schools, such as Ash-hill. The second concern focused upon the closure of some of the training courses that students from Ash-hill had previously utilised, thus raising fears that a gap in provision would be created:

> "I think that yet again there is always a gap for our students, there is basically always a hole for them to fall into ... by closing these sort of places down it has withdrawn that opportunity from a proportion of our students who would want to go onto youth training rather than onto college." (Ash-hill tutor, April'95)

The tutor at Ash-hill was aware of the wider socio-economic context and suggested that his students were frequently "casualties" of a competitive market economy. He felt it only really valued vocational qualifications:

"... it's not good business to invest in kids who aren't going to achieve any qualifications, I think that's some part of it." (April'95)

On the other hand, there were some positive examples of supported training scheme, in particular, a Barnardos catering scheme which had centres within both authorities. However, as one can imagine, places were limited but extremely sought after. Consequently, it could only serve a relatively small and quite specific group of students. Hence, the feeling that there was a 'gap' remained. This was reiterated by the careers adviser within Authorities 2/3. Her concern focused upon young people who could not manage supported training but were also inappropriately placed within social services provision, thereby falling between two stools. This is reminiscent of Hirst's 1983 conclusions for many physically disabled young people. More opportunities for 'meaningful' daytime activities, such as organised voluntary work, were seen as the way forward by the careers adviser. Parents (see chapter seven) also valued this idea of 'meaningful' daytime activities. Furthermore, it re-emphasises the importance of moving away from narrow interpretations of 'adult' status merely in terms of paid employment (see Thomson and Ward, 1994, p.89 and their suggestion of "productive day time activity"). However, 'valued meaningful activities' suggests flexibility and changing social attitudes. This is quite a tall order within a society where employment is valued as an important indicator of adult status (Anderson and Clarke, 1982; CERI, 1983, 1985). Hence, the suggestion of a "paradox" by Ward et al (1991, p.132; 1994, p.140).

4.4 Service Provision and the movement from Child to Adult Services

This fourth and final section will explore professional assessments (predominately 1995, pre-local authority changes) of the movement from child to adult services. This is an extremely important area for many disabled young people because service transitions frequently coincide with the transition from school and, thus, on-site medical services. The picture presented by past literature in chapter two (Fish, 1986; Bax et al, 1988; Brotherson et al, 1988; Bax, 1990; Hirst et al, 1991; Thomson and Ward, 1994) for disabled young people (with both physical impairments and/or learning disabilities) is a disjointed and uncoordinated period when services can be withdrawn or lost. Hence, the provision of good quality services with well co-ordinated policies during the transition years is a key objective. However, one must also be aware of the danger, as some social model theorists' highlight of medicalising the lives of disabled people (see Barnes and Mercer, 1996 for a wider discussion). Here, four broad areas will be examined: firstly, a general assessment and oversight of transition services, both past and present; secondly, specific service provisions for the transition years; thirdly, areas of concern raised by professionals within the study; and, finally, some professional suggestions.

4.4.1 General Evaluations

Professional evaluations of past provisions identified a range of opinions, both positive and negative. However, those who expressed the strongest opinions generally highlighted a rather ad hoc situation. This was pivoted upon two problem areas: firstly, poor planning and a lack of professional co-operation, leading to 'crisis management' as the norm rather than the exception; and, secondly, unequal and erratic planning where those parents who shouted the loudest, frequently, received the best services. This was summarised by a Deputy Head seconded to Authority 1's LEA:

> "... very dependent on who the parent was in terms of whether they were vocal or not ...last minute, little preparation, very frustrating for schools and for parents..." (July'95)

In terms of present provision, there was a general feeling that services during the hand-over period were slowly improving. More specifically, there was greater continuity and coherence for young people and their families and more collaboration and joint working amongst professionals. Furthermore, within both authorities at a strategic managerial level, social services officers highlighted joint working between themselves, health and education. A collaborative approach was seen as becoming much more of a cultural norm. Similarly, at an operational level, the focus schools highlighted positive joint working amongst on-site and visiting professionals. Sharing information and working together was emphasised. Hence, on-site school medical professionals stressed that it was common practice to pass on information, via written reports, to a student's next service provider, thus aiding service continuity.

In terms of specific transition services, the authorities noted the benefits of developing respite services for young people aged between 18 to 25 years. At the time of interviewing (1995), Authority 1 had an established transition respite hostel and Authority 3, was developing one. Similarly, a significant number of social services professionals viewed the introduction of transition planning within the Code of Practice (1994) as a positive development. Potential opportunities to improve service provisions during the transition period, via, improved multi-disciplinary planning were recognised. However, chapter five will demonstrate that problems can, and do, still remain within the practice of multi-disciplinary transition planning.

4.4.2 Serving the Transition Years?

Within the authorities there are specific transition services for disabled young people, in Authority 1, the Young Adult team and Transition officers within Authorities 2/3. This

sub-section will focus upon the post of 'transition officer' because within its short lifetime, the post has raised a number of interesting issues and debates.

However, it is important to note that in Authority 1, the Young Adult Team is a multi-disciplinary team of six professionals (Doctor, physiotherapist, speech therapist, occupational therapist, social worker and psychologist). The team was established in 1988 to serve young people from 16 to 25 years and is extremely well regarded by many schools. In fact, many professionals frequently lamented the team's specific remit, i.e. young people with physical impairments rather than those with learning disabilities. Young people with learning disabilities fall under the auspices of community learning disability teams (CLDT). Within Authority 1, community learning disability teams follow people through childhood to adulthood; there is not a specific team for the transition years. Within the Young Adult Team (serving the physically disabled), young people setting their own goals and working towards independence was emphasised:

> "I suppose the first thing is the need for the young people to take control ... I think that's the main thing we want to get involved in and to get people to make their own decisions, decide what they want and help them to achieve it." (Team Doctor, November'95)

Ideally, referral occurs when a young person is still at school. However, gaining this information was viewed as a problematic area by the team's social worker. In practice, young people appeared frequently to be picked up post school. Consequently, the team's social worker feared that some young people slipped through the net. Information passing from schools to service providers was an area of some concern for her.

Within Authorities 2/3, community learning disability teams once again serve both children and adults with learning disabilities. In contrast to Authority 1, these teams are predominately health orientated. For young people with predominately physical impairments there is not an equivalent to the Young Adult Team within Authority 1. However, specific transition provision is found in the form of a relatively new social services post - a Transition Officer. This post was established in 1995 and is funded by adult social services. Prior to local authority reorganisation there were four officers within Authorities 2/3. Post reorganisation (1996), Authority 3, as a unitary authority has retained its transition officer.

Professionals from many agencies valued this new post. Social services presented it as a liaison point, a professional with a specialist interest within and knowledge of the transition years:

"... there was a need for some specialist services for this particular age group and some specialist expertise and knowledge ... it's giving the young people and their parents some form of a point of contact..." (Transition officer, Authority 3, September'95)

'Planning' was a key aim of transition officers within Authorities 2/3: 'planning' services for young people, in order to ensure a smooth transition to adult services; and 'planning' for the future, i.e. identifying forthcoming needs and how best to meet them. Hence, the importance of forecasting was emphasised; planning ahead in order to make sure resources were available, as and when they were needed. Interwoven within this aim there was a recognition that in the past, social services' knowledge of leavers with disabilities had been limited:

"... it's building contact with them, with the schools that we know, the local schools, so that we don't miss er people coming out like we have done in the past." (Adult social services manager, Authorities 2/3, July'95)

This suggests that the procedures recommended under the Disabled Persons Act (1986, sections 5 and 6) to ensure that social services were informed of disabled school leavers who may require their services had not been fully utilised. Those felt to be most at risk of slipping through the net were physically disabled young people without statements of SEN, as statements were frequently used as an indicating factor. However, chapter two demonstrated (Middleton, 1992; Fish and Evans, 1995; Cooper, 1996) that a statement of SEN and being defined as 'disabled' are not always synonymous. This suggests that the transition process within social services has in the past been ad hoc, with no one-person actually co-ordinating services.

The 'transition officer' post also raises a number of important issues for the transition years. This arises primarily from the variability in age ranges that the four transition officers within Authorities 2/3 encompass. For example, the transition officer within Authority 3 serves young people 18 to 25 years, whereas, in other districts it can be as young as 14 to 21 years. This variability re-emphasises an underlying ambiguity within the concept of 'transition' and its chronological parameters. Within educational legislation (Education Act, 1993 and its ensuing Code of Practice, 1994) 'transition' is officially considered from 14 years. However, here within social services both 14 and 18 years are seen as starting points.

The transition officer within Authority 3 suggested that 18 to 25 years had been chosen for the unitary city because this was primarily where there was felt to be the most 'need':

> "The other areas felt that the need in their particular divisions were earlier ... and they decided to take them from 14 through to 19, 20's. Er, that to me seemed the wrong age group because they're already catered for by children and families teams at that age..." (September'95)

However, social service colleagues located the choice of transition years within a more financial framework:

> "Originally we were going to do transition on 16 to 18 year olds because we felt that was the critical age but we've had to rethink that because the post holder is funded er, from STG [Special Transitional Grant] money ... which states very clearly that we can only deal with er 18 year olds and up..." (Adult social services manager, Authorities 2/3, July'95)

The post is thus funded by adult services, officially they cover only 18 year olds and upward. Consequently, it seems that financial reasons and budget demarcations between child and adult services are playing a significant role in directing 'need', transition service boundaries and priorities. This calls into question the idea that the post is first and foremost a 'needs' led and responsive service.

The transition officer within Authority 3 noted that he often 'unofficially' started working with young people from 16/17 years. However, the careers adviser within Authorities 2/3 was concerned that there was still a service 'gap' for young people leaving school at 16, such as those from Cedar Drive.

> "I think social services involvement with er younger children, I think there's a big gap there still, with the sort of 14, 15, 16 year olds ... I don't know what the barriers are, why social workers or people are not attending review meetings for that younger group. But if they're leaving school at 16, you know, that really is the key time for them and they need to be aware, otherwise we have crisis management, which is what quite a few of them are getting at the moment." (Careers Adviser, Authorities 2/3, December'95)

Furthermore, the learning support manager at the unitary city's college also expressed concerns about the severity level surrounding 'who' the transition officer would and would not support. This takes us back to the fact that in terms of legislation, concepts such as 'SEN' and 'disabled' are not synonymous and can thus lead to service discontinuity for some young people when they embark upon the transition years.

4.4.3 Areas of Concern within Health

The previous section has indicated that, although specific transition services were welcomed and viewed as a positive development, problems still remained, as in the case of transition officers. Furthermore, beneath general and often rather bland pronouncements of smooth and well co-ordinated services a number of important issues were raised as areas of concern, predominately, by health providers.

4.4.3.1 Leaving the Paediatrician and moving to GPs as a Referral Route

Within past literature (Hirst et al, 1991; British Paediatric Association, 1994; Hirst and Baldwin, 1994) leaving paediatric services, especially, the paediatrician is recognised as a potentially important loss for many disabled young people. The majority of health professionals interviewed expressed similar concerns. In fact, two key areas were raised within both authorities (The Laurels nurse; Authority 1's nursing co-ordinator; and Cedar Drive's physiotherapist). Firstly, the loss of general medical oversight from paediatric services was missed. Only those with a specific 'condition' were usually transferred to an adult specialist. However, in the past within Authority 2, The Laurels nurse suggested that there had been a general medical consultant to pass young people onto, a service she had valued. Fragmentation, when a young person sees a number of specialists, was the second concern. Hence, the perceived danger was of loosing a holistic and coherent approach. These concerns are similar to those raised by Begum and Fletcher, (1995), Hirst et al, (1991), Johns and Fiedler, (1995).

> "What they tend to do, the GPs will pick out individual medical things and refer to gyny or a skin specialist, but there's no-one really who could see the person as a whole." (The Laurels nurse, November'95)

On leaving paediatric services many young people move back to their GPs for general medical supervision and as a source of referral to other services (see Hirst and Baldwin, 1994, p.92). Here, a significant number of health professionals within both authorities viewed GPs, especially fund holding GPs, as an important but potentially problematic source of referral. There was a general feeling that GPs were not always an adequate referral route for disabled young people. This arose from two concerns. Firstly, there was a lack of knowledge amongst GPs, both in terms of experience of disabled young people and of services available. This leads to issues surrounding attitude and approach. GPs, it was felt, could frequently hold different attitudes, i.e. some were more "tuned into" disabled young people's needs than others (see also Begum and Fletcher, 1995, pp.14-15). The question of GPs' 'knowledge' has also recently been raised by Fiedler and Johns (1997, p.45). The second issue was of time – GPs' lack of time. These

concerns were succinctly summarised by an Authority 1, special school nursing co-ordinator:

> "... I think in the past that GPs knew very little about disability and they find it quite hard to communicate with them [disabled patients] ... or just not being able to spend the time that they need." (December'95)

This raises important questions regarding future, post-school accessing of services for disabled young people, and, more generally, for all disabled people who rely upon GPs as a referral route. However, all professionals did not voice this assessment. In fact, a CLDT nurse within Authority 3 saw GPs as an adequate referral route.

4.4.3.2 Post-School Therapy Provision

The provision of therapy (especially physiotherapy or speech) post school has continually been an area of concern (Bax et al, 1988; Bax, 1990; Hirst et al, 1991; Hirst and Baldwin, 1994). The general feeling amongst health professionals here was that there might be an adult physiotherapy service to be accessed but compared to that provided at school it was a reduced service.

More specifically, of the three physiotherapists interviewed, two viewed post school physiotherapy as an area with provision problems. In terms of 'who' provided post school physiotherapy there were differences. Different service teams depending upon a young person's impairment provided physiotherapy. For example, in both authorities community learning disability teams provided physiotherapy for young people with learning disabilities. In contrast, for those young people with predominately physical impairments, the Young Adult Team within Authority 1 and in Authority 3, a team of generic adult physiotherapists, provided a service.

Moreover, the physiotherapist at Oaksmere suggested that this differential provision was not equitable, especially for young people with learning disabilities. Provision for these young people depended upon their post school choices. More specifically, for those attending local colleges she feared that there was not always physiotherapy provision, whereas, if a young person with learning disabilities chose a day centre then physiotherapy was usually provided:

> "If they go to a training centre they are seen, if they have a physical disability but no medical handicap then they can be seen under the Young Adult Team but if they fall between the divide then they've got big problems." (Oaksmere physiotherapist, July'95)

This inequity was viewed as an important issue, due to the general policy at Oaksmere that young people transfer to local colleges on leaving school.

Within Authority 3, the Cedar Drive physiotherapist generally viewed day placements as more problematic than residential college placements, where physiotherapy was still on-site. However, a key area of concern was post residential college, when physically disabled students returned home. Here, it was felt that service contact may have been lost. This helps to emphasise the importance of retaining home links.

4.4.3.3   An Absence of Formal Follow-Up

On one hand, an absence of formal post school follow-up was recognised by school nurses and physiotherapists within both authorities. However, The Laurels nurse only raised it as an area of concern:

> "... really as far as my manager's concerned, once they've left school, that's it, you know, there's no real provision in my role to follow-up and make sure they're getting the service they need or that they're getting the access to the medical service that they need. It's a very cut off, sort of cut off point in that sense." (November'95)

On a practical level, health professionals' interviews indicated that some provided follow-up on an informal level, but there was no actual formal procedure or requirement to do so. In fact, boundary divisions were very sharp. Once a young person leaves school, they move beyond the school's formal scope and responsibility.

4.4.3.4   Nursing Provision within Day Colleges

Amongst the health professionals interviewed, general knowledge of nursing provision at local colleges was vague. However, one nurse, once again from The Laurels, raised this as an area of considerable importance. Her concern focused upon a perceived lack of nursing provision that she felt existed within her local college. Her interpretation of the situation was that a nurse was employed but s/he focused upon providing nursing support for residential rather than day students. For day students, support was in the form of educational care officers who provided 'care' rather than nursing support. Consequently, The Laurels' nurse had concerns for students with complex and ongoing medical requirements, fearing that the local college would not be able to meet their everyday nursing needs:

> "I think really if the special needs course is going to continue in somewhere like the [unitary] college of Further Education then I think these issues will need to be explored because of the increase of youngsters with profound and multiple disabilities..." (November'95)

If not addressed she anticipated a situation which could lead to the exclusion of some students. A danger of exclusion was also feared in relation to day centre provision for young people with complex medical needs. Looking to the future, The Laurels' nurse

foresaw a population of future leavers where on-going medical support was increasingly important. Hence, she stressed the need for early planning and forecasting.

4.4.3.5 Barriers to Professional Collaboration and Joint Working

Past literature has highlighted this as a problematic issue (Bradley et al, 1994; Means and Smith, 1994; Fish and Evans, 1995). Here, health and social services professionals shared three areas of concern. Firstly, there was a perceived dearth of guidance and guidelines during the transition period. For the physiotherapist at Cedar Drive and The Laurels nurse this was felt to lead to ambiguity concerning 'who' should be doing what and 'when'. Secondly, 'professionalism' as a barrier was raised. Within the authorities social services managers indicated that elements of professionalism and power bases still remained an important phenomena which could hamper joint working. For example, a social services manager within Authorities 2/3 suggested that although the NHS and Community Care Act (1990) may have made social services the lead body, other professionals sometimes resented this:

> "I think sometimes people forget that the role of care managers is really pulling information together before you even make a plan, trawling information and asking people, sometimes that's a very difficult task because other agencies don't like being told what to do..." (July'95)

Consequently, issues surrounding power and autonomy remained important. The third and most commonly expressed problem was financial, with the question - who is going to pay?

> "I wouldn't want to be too cynical and pessimistic but the whole wrangle over money does increasingly determine all of these processes. I mean everyone's trying to control their budgets." (Social services principle officer, Authority 1, October'95)

This can frequently hamper professionals working and thinking together. More specifically, some professionals felt that they were hindered by limited resources, a need to protect budgets and establish clear professional roles, especially financial demarcations between health and social services. Taking this a step further it is also important to recognise that such a separation of medical and social tasks/responsibilities can further segregate and artificially compartmentalise disabled people's lives as Macfarlane (1996, pp.6-7) has highlighted.

4.4.4 Suggestions Made

In response to these concerns three general but practical suggestions were made. The first was a call by three professionals (crossing the authorities) for more resources and manpower within adult services, especially physiotherapy:

> "... it's more resources and more staff to cover the children as they move on into young adult life when they leave school." (Oaksmere physiotherapist, July'95)

However, intermingled within this the nurse at Beechview simultaneously acknowledged that resources were finite and health provision demands, potentially were a bottomless pit. The second suggestion focused upon a call for more routine, formal following up of young people post-school. Here, health providers at The Laurels indicated that they would welcome an opportunity either, personally to follow-up leavers, or liaise more closely with post-school service providers. Furthermore, clearer, written transition guidelines and improved role clarity as a means to aid joint working and thinking was raised by The Laurels' nurse and the physiotherapist at Cedar Drive:

> "... I think people are now realising that if we had guidelines then that would be much better and if we all knew the kind of things that we had to work towards or who to inform ... then, in fact, we might be able to get a much better system worked out, so people wouldn't fall through the net, which is what's happening in some cases." (Cedar Drive physiotherapist, November'95)

The third, and final suggestion was a call from health providers at The Laurels for more future planning and forecasting of forthcoming leavers requirements by service providers, especially social services. However, social services were keen to stress that they recognised this and were already working towards it: for example, within Authorities 2/3 via transition officers and more generally, transition planning within the Code of Practice (1994). How this will actually work remains to be seen.

In addition, the nursing co-ordinator within Authority 1 suggested that she would like to see a specialist consultant for disabled adults, a person who would provide a more holistic and less fragmented specialist service:

> "... it would be nice if ... there was a consultant who particularly dealt with adult people who had disabilities and they didn't have to go to all these people." (December'95)

This suggestion raises a wider issue, namely, the question of special, separate services for disabled people. Within the NHS and Community Care Act (1990), one of its stated aims is to promote a 'normal life', thus advocating normalisation principles and the accessing of generic community services. The idea of a specialist consultant for disabled adults clearly challenges this. In a similar vein, the idea of 'normalisation' and

the practice of accessing generic services was questioned by The Laurels' nurse, especially for young people with multiple disabilities:

"... you know, this thing of normalisation really is, is, in a way handicaps some of these youngsters because people think when they're adults and they leave school, well that's it and they should just fall in with everyone else. You know, the general population does when they leave school and you know, their medical needs will be picked up in the ordinary way, but I mean they're not necessarily forced to be picked up." (November'95)

In this way, separate, specialised services rather than generic services were seen as the most responsive mode of provision.

Normalisation, as a theory and a practice is frequently advocated as the way ahead. However, one must not forget that it has also been critiqued by some social model theorists as oppressive to disabled people (Walmsley, 1994, pp.149-150; Corbett and Barton, 1992, p.28). In contrast, rather than a move towards perpetuating separation, working to improve generic services could foster more responsive provision. For example, three professionals in response to GPs lack of general knowledge and understanding, highlighted the importance of education and information:

"So I think it's an education, you know, we've got to teach the GPs about these young people they're going to have within their practice..." (Cedar Drive physiotherapist, November'95)

Johns and Fiedler (1995, p.42) voiced similar sentiments when they evaluated transition services for disabled young people. One could take this a step further and view the idea of more education for some GPs as an opportunity to challenge social attitudes and barriers. This perspective introduces sentiments more in line with a social model of disability, one which seeks to challenge social barriers and prejudices rather than reproducing difference and continuing segregation.

Following on from this wider perspective, it is also important to recognise that beneath these professional concerns there was a general acknowledgement of the fear many families felt at the prospect of leaving familiar 'on-site' school services when they left school (see also Swain and Thirlaway, 1994, pp.170-171). The majority of professionals interviewed recognised that school was a key resource for parents. Much more than merely an educational institution, it was frequently a microcosm of service provision:

"... because it's viewed not just as school but social services, health, everything, it's been the focal agency..." (Seconded Deputy, Authority 1, July'95)

Taking this a step further, when leaving school (usually schools access and organise services for families) many families have to move to a more independent position,

accessing services themselves. This move from dependency was noted by the learning support manager at the unitary city college:

> "So, I'm trying to tell them what we can do ... but also help them to make that transition from a situation where they've been very dependent on an education system that has done it all, made the decisions, to one where they may have some say in decisions." (November'95)

The idea of special schools inculcating dependency rather than independence has been highlighted by a number of social model theorists (see Barnes, 1991, chapter 3; Mason and Rieser, 1994, p.17; Brisenden, 1989, p.218). In response to this recognition of the need to be more independent within adult services, and the difficulties that this can cause, five professionals stressed the importance of preparing families for this transition to a more independent status, whilst still at school. This was clearly demonstrated at Cedar Drive. Here, the physiotherapist and school nurse noted that they had developed programmes to help families' bridge this transition. Amongst students this involved, whenever possible, promoting personal health awareness and self-medication; and for parents, using summer holidays as a time to practise accessing services independently of school:

> "At the moment I'm the point of contact and I access the services for them. What I want to get them into the idea of doing is, accessing each of the services, so when they get to a point where they're saying goodbye to everything here at school they know that they can do it if you like, you know, they've accessed it." (Cedar Drive physiotherapist, November'95)

On one level, it seems somewhat paradoxical and perhaps rather confusing for families that the very institution which fosters dependence then turns round and seeks to counter this in the period prior to school leaving. On another level, the idea of parents, especially of young people with multiple disabilities, taking more responsibility post-school, was viewed by The Laurels' nurse as placing, at a time of great stress, a further burden upon families. The Laurels' nurse clearly takes a much more protective and paternalistic approach to the provision of post-school services for these families. However, the danger within such a perspective, as social model theorists highlight, is that it perpetuates and feeds a "disabling culture" (Finkelstein and Stuart, 1996, pp.175-181).

Viewing the transition from child to adult services, it is clear that amongst some professionals there is a feeling that improvements have been made. On the other hand, it is also very apparent that there are *still* a number of specific areas which are of great concern, especially within Cedar Drive, The Laurels and Oaksmere, schools with 'on-site' health provision and students severely disabled. Within the five issues of concern discussed, four have clearly been highlighted within past studies. This study has

demonstrated that they are *still* felt to be areas, which need to be addressed. However, the issue of nursing provision within local colleges seems to be a relatively more recent area of concern, and one, interwoven with the expansion of FE for disabled students, especially severely disabled students. Furthermore, it is an important area to consider in the future, due to changing special school populations and policies, advocating local rather than specialist residential colleges. Health professionals need to address important issues surrounding service provisions within local colleges. Having said this, one does not want to fall into the trap of reproducing a model of special school service provision within local colleges, with its inherent dangers of medicalisation and dependency (see Barnes, 1991 for a discussion in special schools). There is thus a fine line between a danger of exclusion, due to an inability to meet needs, and medicalisation and a continuation of special school dependency.

Conclusion

This chapter has introduced the focus schools upon which the research is grounded and provided a synopsis of essential, background information. Building upon this information, sections two, three and four explored a range of transition issues and professional assessments of these issues within three important areas: school leaving preparations; post-school provision and destinations; and the movement from child to adult services. The overall picture presented is one in which all the professionals involved seemed to be clearly aware of the importance of the transition period, in particular, the need for transition preparations, early planning and professional collaboration. However, areas of concern *still* remain, areas, some of which the professionals themselves highlighted. These issues and concerns can be summarised as follows:

1. College link programmes were highly valued by school professionals. In fact, some tutors raised the idea of further education as a *right* for disabled young people. However, within these programmes there were still important issues surrounding social interaction and inclusion (see also Todd, 1995). Yes, the young people were moving into a more 'adult', mainstream environment with their peers but this was still discretely organised with the disabled young people being a 'special' group, separately provided for and separately managed.

2. Work experience programmes were similarly valued and presented by school professionals as an important learning experience for many students. However, there was a significant element of selectivity interwoven within these programmes. The world of work was not available to all students. Inherent within this there were attitudinal factors, professional assessments of *appropriateness*. However, it was also

clear that the focus schools and the programmes that they could offer were influenced by wider socio-economic factors such as placements and support.

3. On a positive note, careers programmes and advice was valued within the focus schools for 'all' young people. However, there was recognition by some school professionals that this was still a developing area, especially for those with pronounced learning disabilities and, thus, continually open to improvements.

4. School and careers professionals warmly welcomed the relatively recent expansion of college courses and provisions for disabled students, especially those with learning disabilities. However, these were areas of concern and it was felt inequity remained. Concerns were expressed, both in terms of who were deemed 'acceptable' students, and within local colleges, questions of access were raised.

5. The introduction of the Further and Higher Education Act (1992) and the FEFC was viewed as an important development. They were seen as having had, or potentially to have, significant ramifications, both positive and negative in areas such as funding and the move towards accreditation. Within the latter, the separation of schedule-2 and non-schedule-2 courses raised concerns for a small number of professionals surrounding potential disadvantages for those with pronounced learning disabilities (see also Tomlinson Committee, 1996). Furthermore, this general move to 'accreditation' also raised concerns with regard to the *appropriateness* and availability of training schemes for young people leaving Ash-hill. These are issues which are interwoven within the wider debate surrounding vocational qualifications (see Tomlinson and Colquhoun, 1995).

6. Transition service provisions seeking to ease the movement between child and adult services, such as the Young Adult Team and Transition Officers, were welcomed as a positive development. However, the post of 'transition officer' raised two controversial issues: transition age ranges; and the role that financial and service boundaries can play in helping to direct service provision and ideas of 'need'.

7. Evaluating the transition from child to adult services it was apparent that positive developments and progress have and are continually being made. However, there are *still* a number of specific areas of concern, especially amongst school health providers. Areas where problems of inadequate provisions, inconsistencies and barriers towards collaboration were felt to persist. Significantly and rather depressingly, a number of these health problems have been highlighted within past studies: most notably, leaving paediatrics; post school therapy; and multi-disciplinary

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working (Bax et al, 1988; Bax, 1990; Hirst et al, 1991; Bradley et al, 1994; Fish and Evans, 1995).

Chapter 5 - Transition Plans: Initial Implementation

Introduction

The previous chapter provided a general assessment of how the focus schools approached preparing students and their families for the transition from school and movement from child to adult services. The importance of professionals being aware of and helping families plan for this transition was highlighted. This chapter will continue to explore transition planning within an institutional context and from a professional perspective. However, it will focus more specifically upon exploring the policy of early, inter-agency transition planning via the Code of Practice (1994). In particular, chapter five will examine the Code's guidelines advocating writing transition plans at the first annual review following a statemented young person's 14th birthday. It will explore the focus schools initial implementation and interpretation of developing transition plans, assess progress made and discuss a number of emerging issues. Chapter two highlighted Tisdall's (1996, 1996/97) study of multi-disciplinary Future Needs Assessments (FNAs) within Scotland for young people with records of SEN (statements in England and Wales). Within this chapter a number of Tisdall's criticisms and concerns surrounding FNA meetings are also relevant to the implementation of the Code of Practice's 14-plus transition review.

Ideas presented are drawn from professional interviews, primarily those with school heads, deputies and annual review co-ordinators during the two winters of 1995/1996 and 1996/1997. Each school designated a spokesperson, either the Head or review co-ordinator. This spokesperson was interviewed twice and it is their ideas that form the basis of the chapter (see Appendix 4 for topic guides). Comparisons over time have been made in order to examine where opinions either remained consistent or altered. However, in the main responses did not change over time. In addition, a small number (five) of review meetings were observed at two schools, Cedar Drive and Oaksmere. The four observed at Cedar Drive were review meetings where transition plans were initially discussed. Comparisons between authorities are at times rather difficult to make

as different authorities introduced the 14-plus review and transition plans at different times. For example, when Authority 1 schools were interviewed, during the winter of 1995, they had not undertaken any transition plans, whereas, schools within Authorities 2/3 had. Consequently, when reinterviewing, (during the winter of 1996/97) schools within Authorities 2/3 were speaking from the experiences of two rounds of transition planning, whereas Authority 1 schools had only one year's experiences to draw upon. Irrespective of this difference, invaluable insights were gleaned surrounding implementation which in turn raised some very important questions concerning 'how' and 'who' writes transition plans.

These ideas and insights will be divided into four sections. The first section will examine the focus schools' attitudes towards the Code's policy on transition plans and some general organisational issues. The second section will explore the development and writing of transition plans. Two important policy themes - 'involvement' and 'support' will be assessed within the third section. The final section will explore how inter-agency working has been approached and developed. The chapters scope is wide ranging. Consequently, many of McGinty and Fish's (1992, pp.92-99) evaluatory transition criteria (assessment; information availability; participation; coherence; and inter-agency working) are addressed and discussed.

5.1 Organising Initial Transition Reviews

The Code of Practice (1994) moves away from a reassessment at 13½ years (The Education Act, 1981) to focus upon the first annual review after a young person's 14th birthday and the introduction of transition plans. This invariably raises a number of organisational issues and questions within special schools, where a high proportion, if not all pupils, have a statement of SEN. This section will explore some of the issues that have, so far, evolved within the focus schools. Three areas will be examined: professional attitudes towards transition planning; effects 'for' and 'upon' the focus schools; and organisational issues involving timing and logistical considerations.

5.1.1 Attitudes

Professional interviews indicated that the idea of formalising and focusing procedures for the concept of 'transition planning' was generally welcomed and valued (see also Russell, 1994; Fish and Evans, 1995; Wood and Trickey, 1996). It was seen as a positive development with potential advantages and opportunities for all parties:

> "I think the idea of making a plan about transition is first rate, it has to be."
> (Cedar Drive Head, March'95)

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However, there were also reservations and concerns. Resources and resource management were issues frequently raised by professionals from different agencies. For example, social services (children) within Authorities 2/3 noted their additional responsibilities but also their uncertainly about resources:

> " ... inevitably it creates an awful lot of work with very little new resources to cope with that, um, it's difficult at this stage to see what the outcome is going to be ..." (Children's Manager, February'95)

These feelings mirror concerns previously noted within the literature (Fish and Evans, 1995; Hornby, 1995; Pyke, 1995; Welding, 1996 and more recently DfEE, 1997). Furthermore, there are questions surrounding the legal standing and interpretation of the code. On one hand, professionals "must have regard to the code" (1994, p.i); on the other, the Code merely provides guidelines. Hence, there were fears that some professionals might not take transition plans seriously.

Amongst the focus schools here, transition planning was taken seriously. However, the significance and value attached to its introduction within the first review after a young person's 14th birthday was not consistent. Considerations of 'proximity' from school leaving were raised. On one hand, The Laurels Head expressed reservations, as he did not view the transition plan at 14 years as particularly significant or relevant for his school because, at The Laurels, the leaving age was predominately 19 rather than 16 years. Consequently, he felt that the time lapse between 14 and 19 was a major factor to be considered:

> "So year 10 it's really not that significant because of the fact that students generally stay for another 5 years, it's at 16 plus that we've noticed a bigger difference." (The Laurels Head, January'97)

On the other hand, he appreciated the importance of the concept and process of 'transition planning' and stressed the relevance of introducing transition plans at 14 years for young people who left school at 16. It was the blanket use of a specific age, namely 14 years for all schools that he questioned. The Head at Cedar Drive similarly raised this issue of 'proximity' from school leaving. He indicated that he might well have viewed the introduction of transition planning at 14 years differently, if his students left at 19:

> " ... I would feel that we probably had more time, so I would probably be less wound up about the actual plan, um and maybe a bit more relaxed about the whole thing..." (Cedar Drive Head, January'97)

Ideas surrounding the importance of transition planning at 14 years and the 'proximity' from school leaving were not however clear cut or consistent. At Oaksmere, the co-

ordinator similarly had students leaving at 19 years, but in contrast to The Laurels Head, she welcomed the introduction of transition planning at 14:

> "I've tried to bear in mind pupils of 12 and 13 in the annual reviews themselves and say...'I know it's a long way off but this is a new policy and it's really good because it gets you thinking well in advance'..." (Oaksmere co-ordinator, December'96)

It is important to place these diverging professional approaches in context and consider the school's different, pre-Code self-evaluations of their review procedures. For example, The Laurels' Head considered that his school already had a good post-16 review process which prepared students and their families for transition. The Oaksmere co-ordinator, however, acknowledged that in the past their review process had been ad hoc and disjointed. These different starting points may well influence how the Code of Practice's transition initiative at 14 years was perceived. Current interpretations are frequently a product of past evaluations: hence, the diversity of attitudes.

5.1.2   Effects For and Upon Focus Schools

In this section some of the effects 'for', and 'upon' the focus schools will be explored, in particular, those surrounding administration of the code and transition planning and also school processes.

5.1.2.1   School Administration

The increased administrative demands that the Code places upon schools have been well documented (Dyer, 1995; Hornby, 1995; Fish and Evans, 1995; Lewis et al, 1996; Welding, 1996). The focus schools clearly emphasised this as staff continually highlighted the problem of an increased administrative workload. However, this was not specifically related to the introduction of transition planning at 14-plus but was viewed as a general consequence of the Code's guidelines for annual reviews. These guidelines were felt to demand that schools collated, organised and distributed more information prior to and after review meetings. It is interesting to note that, although, the guidelines for the initial transition review after a young person's 14th birthday advocate that the LEA should invite the relevant parties to the meeting, it was still the individual schools who felt that they did the organising.

On one hand, the extra information was valued by schools but those who were actually organising the reviews felt that it brought them a great deal of extra work. In fact, two schools (Beechview and Oaksmere) noted increased levels of stress for staff (teaching

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and/or administrative). For example, the Oaksmere co-ordinator felt somewhat overwhelmed by the demands of annual reviews:

> "I mean if anybody said, 'what's on your mind at any one moment of the year?', I would say 'reviews'...." (December'96)

Within three schools (The Laurels, Ash-hill and Oaksmere) this administrative 'burden' had been partly addressed by employing extra staff (Lewis et al, 1996, p.106 also discuss extra staff). At The Laurels and Oaksmere non-teaching staff had been recruited to help organise and disseminate review information, and, at Ash-hill, a SEN co-ordinator (SENCO) had been appointed (a rather unusual step for a special school). Employing additional staff was viewed by these schools as an essential requirement if they were to cope with the demands of review administration. Henceforth, it was stressed at Oaksmere and The Laurels that review administration needed to be streamlined. It was also noted at Cedar Drive. In fact, the Head related this to a wider issue, namely, that the increasing administrative demands made upon teachers could take away valuable time from the very students they were seeking to help (see also Fish and Evans, 1995; Hornby, 1995; Lewis et al, 1996; Welding, 1996 and more recently DfEE, 1997). This was perceived as an ever-present danger but also one the Head sought to avoid:

> "... unless I were to devote myself entirely, sort of a day or two days a week throughout the year to, to annual reviews, I can't see how I could comply to the strict requirements of the Code of Practice and part of me is fairly bolshy, I'm not sure that it's necessary." (Cedar Drive Head, January'97)

This highlights conflicting demands made upon the Cedar Drive Head, both as an administrator and, as a caring head actively involved in school life. This is a wider tension that the Code can easily exacerbate.

5.1.2.2 School Processes

Four of the five schools highlighted specific school processes which they felt had altered or evolved as a result of the Code's review process or, more specifically, the initial transition review at 14-plus. For example, the Oaksmere co-ordinator felt that the Code's general guidelines on annual reviews had been used as an opportunity to reassess the whole school's annual review process. With regard to the initial transition review, both Beechview and Ash-hill suggested that the idea of planning at 14 had encouraged them to re-examine their timetables: in terms of either programme timing, such as careers programmes or, options/opportunities offered to students. Thus highlighting how the transition review can be a catalyst, encouraging changes within wider school processes.

Furthermore, staff at Ash-hill and Oaksmere felt that the introduction of transition planning at 14 had had an impact upon how staff generally viewed not only the concept of 'transition' but also the processes involved. Thus, they suggested that it had encouraged staff to be more aware of, and responsive to, transition preparations, as indicated by the Deputy at Ash-hill:

> "I think it's made a lot more staff aware ... aware of their responsibilities to the pupils and what we ought to be teaching these children in years 10 and 11. I mean as a result of this we've actually changed the way that we teach pupils of that age quite significantly so. *[later]* I think a lot of that has come about from transition planning..." (December'96)

The Code of Practice's guidelines have therefore had a number of important effects for the focus schools, both negative and positive. On one hand, all five schools highlighted the administrative effects of the Code's guidelines upon reviews in a negative and burdensome light. But on the other hand, four schools simultaneously indicated areas within which the introduction of transition reviews has had positive effects. However, it is not surprising that the one school, which did not clearly highlight positive effects, was The Laurels:

> "We have been involved in transition reviews for year 10 pupils statutory under the Code but really there has been little significant difference between pre and post the 1993 Act." (The Laurels Head, January'97)

Again, the importance of a school's prior evaluations of procedures is highlighted. Furthermore at Beechview, although the Head, Deputy and co-ordinator all noted that the Code may have had an effect upon school procedures, recent changes were not felt to be solely a result of the Code. It was rather part of a longer term, ongoing school led process of development which the Code had merely reinforced:

> "Um, where as I say for us it was just a natural progression. It was nice to see that we were already so much of the way there. We've just had to formalise it, you know write it down as it were." (Co-ordinator, November'96)

Wider school contexts and evaluations are thus very important to consider as they can and do play an important part within school perceptions and expectations of the initial implementation of transition reviews.

5.1.3 Timing and Logistical Considerations

5.1.3.1 Timing

The Code of Practice's guidelines indicate that:

> "the first annual review after the young person's 14th birthday and any subsequent annual reviews until the child leaves school should include a transition plan ..." (1994, 6:45, p.117)

It is important to note that the Code does not state a specific year within which transition reviews ought to be carried out but rather highlights a chronological age as the catalyst. Henceforth, either year 9 or year 10 could be a transition review year depending on when a young person's birthday fell (Wood and Trickey, 1996, p.121). However, for the majority of young people their 14th birthday falls within year 9 of their school career. One of the first things to note in exploring how the focus schools have approached the issue of 'when' to conduct initial transition reviews is that the schools chose a specific year within which to conduct reviews, either year 9 or year 10, rather than a combination of the two. In fact, two Heads (Cedar Drive and The Laurels) highlighted administrative efficiency and rationality as important considerations:

> "Yes, it was really just an administrative response to target a year group through that year group..." (The Laurels Head, January'97)

However, amongst the focus schools there was an authority difference. Within Authorities 2/3 the focus schools (Beechview, The Laurels and Cedar Drive) had, so far, conducted their initial transition reviews within year 10. In fact, an LEA official suggested that the authority had chosen year 10 rather than year 9. In contrast, Authority 1 schools (Ash-hill, Oaksmere) had conducted theirs within year 9. The latter, one could argue, adheres more strictly to the Code's guidelines. This was emphasised by the SENCO at Ash-hill:

> "The year 9's, that's the year when they have to do it. They say, officially in the Code of Practice, they say 'the first annual review after their 14th birthday'. We do all the transition plans for all of our year 9's..." (December'96)

On the other hand, the Oaksmere co-ordinator noted that the authority had not cast this in stone and thus some schools had chosen to delay their reviews until year 10. Consequently, although there was an authority difference within the focus schools there was still room for interpretation and difference.

This variation raises the question - 'why leave it until year 10?'. Two reasons were highlighted. The first was 'maturity'. Here, it was suggested that at year 9 the young

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people were too immature. Deferring the transition meeting for a year increased maturity and thus the level at which students could participate:

> Researcher: " 'Cos some do it in year 9?"
> Beechview Co-ordinator: "Um officially, it's, it's too early, they're so immature, it's totally meaningless" (November'96)

'Distance' from the actual transition was the second reason given and referred to the time lapse between the initial transition review and school leaving. Here, Cedar Drive and Beechview suggested that year 9 was viewed by their students as being an age away from leaving school.

Furthermore, the Cedar Drive Head felt that under the 1981 Education Act the old 13½ re-assessment had been too early. Consequently, if the initial transition review was conducted in year 9 then this, he felt, would be a retrograde step to 13½ rather than the Code of Practice's onus upon 14 years:

> " ... and I feel that if we were to do it in and as you rightly say for some students that could be in year 9, it would be like the old 13 plus." (January'97)

Advantages within delaying initial transition reviews until year 10 were also recognised in Authority 1 by the Ash-hill Deputy. In both interviews (1995 and 1996, prior to and after implementation) she highlighted reservations concerning year 9 and the fact that students were often both immature and unsure of their options/choices:

> "I don't think our children are ready to be thinking like that in year 9. I think we'd be far more successful with the children contributing to them in year 10 rather than year 9 ..." (1995) [and] "... with year 9 they really don't have any idea at all about what they're choices and what they're options are for them." (Ash-hill Deputy, December'96)

However, in 1996 the deputy was less emphatic in her criticisms. She was also aware that wider changes within school policies, such as, more target setting and self-evaluation at an earlier age could in time help students prepare for year 9 transition planning.

This demonstrates two important considerations: firstly, that these are tentative and early implementation assessments; and secondly, that the question of 'when' to conduct initial transition reviews is a continually debated area (see Wood and Trickey, 1996, p.121). The Deputy at Ash-hill has demonstrated this complexity, perceiving both the dangers of planning too early (see also Morningstar et al, 1996, p.257) and potential benefits of encouraging young people to become more involved from an earlier age. Furthermore, this latter idea raises a wider issue previously discussed by Tisdall (1996, p.30) and Russell (1996, p.126) - the importance of, and need to help students prepare to

become active, choice making participants well before transition planning. This has long term implications for schools and professionals surrounding 'how' and 'when' they begin to prepare students. Within the study a number of educational professionals were aware of this, especially the educational psychologist at Beechview:

> "So, if they're going to be asked at 14 to be involved in decision making they need to have experience of that sort of empowerment. So it needs to go back to a younger age..." (November'95)

This issue of involving young people will be discussed further in section three of this chapter.

5.1.3.2 Logistics

Logistically, all of the schools stressed the need for administrative efficiency and good management in order to organise transition reviews. The most common administrative procedure was to hold annual reviews on one morning each week, with initial transition reviews in a specific term or month each year. For example, Oaksmere conducted their transition reviews on Tuesday mornings during the summer term. However, one school (Cedar Drive) alternatively allocated two days to transition reviews within a set month. The administrative response was thus to allocate set days and set times to review meetings, including transition reviews. From the schools' perspective there were two advantages. Firstly, there were administrative benefits. A system of set times was felt to be the most efficient use of limited school time within a tight review schedule. Furthermore, spreading reviews throughout the year similarly enabled administration to be staggered. Secondly, from a logistical perspective, gathering together a range of professionals (same place, the same time) for an initial transition review was highlighted as extremely difficult:

> "Again, if you're dealing with that many people that in itself is like juggling with soot, trying to get everybody together." (Cedar Drive Head, January'97)

However, it was felt that there was more likelihood of busy professionals attending a transition review, if they not only knew the day and time well in advance but also if the slot was a regular one. Consequently, the focus schools stressed the importance of early planning and grouping reviews. On the other hand, one can see how Tisdall's criticism of FNA meetings as:

> " ... fundamentally structured around professionals - and their professional, bureaucratic and legal responsibilities - ..." (1996, p.29)

can also be applied to initial transition reviews.

On a rational, administrative level one can appreciate the necessity of such organisational planning, especially, in the context of an educational system which has recently faced numerous educational changes, without corresponding increases of resources or manpower. However, there is the danger of an approach similar to a production line, as discussed by Tisdall (1996, p.21-22). Thus, within initial transition reviews, there is a danger of processing transition plans en masse with little time to consider each young person's future or when would be the best time for each student to have their transition review and plan discussed. Furthermore, there is also a concern, as Wood and Trickey (1996, p.121) and Lewis et al (1996, p.108) emphasise, of "procedural aspects" dominating. Taken to its extreme, the key target becomes processing students through the transition review system. Ultimately, they highlight the danger that this can be focused upon getting the transition plan done, in terms of time and administration, rather than considering the processes involved for students moving towards adulthood.

On the other hand, it was clear that the focus schools did not see the transition review as an isolated, one off meeting but rather as part of a wider and deeper process (see section three of this chapter for a more detailed discussion). Furthermore, although the Deputy at Ash-hill recognised this administrative outlook, she was simultaneously trying to counter this within the school:

> " ...um, unfortunately what tends to happen is that at the moment it's very much thought of as a legal thing that we have to do. So we tend to think of it as another piece of paper we have to put together, but as I say ... we are attempting to make it as relevant a document to the children as possible..." (December'96)

However, the issue of individual timing needs remains. If transition reviews are conducted at a set time, this may suit some young people but it may not meet the individual needs of all. Once again, this factor was recognised by the Deputy at Ash-hill:

> "I think there have been mistakes made. Er perhaps some of the issues haven't been addressed early enough, perhaps, because we see in our calendar that, you know, year so and so will be in such and such a term. When really the needs of that individual we should have looked at them earlier but again we've recognised that." (December'96)

Trying to counter this the deputy stressed that they were striving to be as flexible and responsive to each student as possible. This recognition and goal is a positive one considering the very real structural and organisational constraints that schools face. Hence, one can appreciate that schools need to be efficient administratively, in order to cope with an unwieldy system. But one must not forget the importance of the transition plan and meeting each individual student's needs as it is 'their' plan. They are the most

important person. It seems that review tensions such as, administrative efficiency and production line fears will continue in the future, areas of debate little changed since Tisdall's (1996, pp.29-30) previous conclusions.

5.1.3.3 Parental Attendance

Potential problems with regard to parents attending review meetings during school hours has been noted by Tisdall (1996, p.21). One can immediately think of possible problems for parents with work or other commitments. In fact, two fathers within the sample criticised the timing of reviews and their inability to attend, due to work commitments. However, four schools' comments, challenged this, as they stressed that transition reviews had, so far, been well attended by parents. Furthermore, they also suggested that they were aware of, and as far as possible, responsive to parents' work commitments. High rates of attendance (at Oaksmere, Cedar Drive and Beechview) were attributed to parents recognising the importance of the transition review at 14 years. However, it is important to note (as The Laurels and Oaksmere acknowledged) that it was frequently only one parent who attended. This suggests that some parents have to make choices as to who takes time off from work.

In contrast, Ash-hill acknowledged that parental review attendance had been poor in the past. However, factors wider than work commitments were noted, such as, parental attitudes and the school's location - out of the city, at the top of a steep hill. The issue of location introduces a practical issuing concerning transport. Paradoxically, at Beechview they suggested that the 'distance' factor encouraged greater parental participation at transition reviews, because parents could not simply pop into school. However, this contrast is perhaps indicative of wider socio-economic differences between the two schools. Special schools with wide catchment areas can be problematic for parents lacking private transport.

5.2   Transition Plans

This section will focus more specifically upon the writing of transition plans, in particular, how they have been interpreted within the focus schools. Two specific issues will be discussed: looking ahead to the future and who writes the transition plan and does it matter?

5.2.1   The Transition Plan - Looking ahead to the future?

The importance of transition planning, especially early planning in a clear, coherent and comprehensive mannern has frequently been advocated within past literature,

particularly in the work of the CERI (1983, 1985, 1988) and Fish (1986, 1992). Within the Code's guidelines for transition plans, the importance of encouraging young people to consider long-term objectives is highlighted:

> "Transition should be seen as a continuum. Students should be encouraged to look to the future and plan how they will develop the academic, vocational, personal and social skills necessary to achieve their long-term objectives."
> (1994, 6:60, p.122)

This perspective reiterates the importance of planning not only for the next step but also longer term. Wood and Trickey (1996, p.120) suggest that there is a potential opportunity within the Code's approach for transition to be seen in a more broadly based perspective.

However, past analysis of transition planning meetings such as Tisdall's (1996/97, pp.6-7) study of FNAs within Scotland has highlighted a narrow approach to transition goals. Tisdall found that 'where next' predominated at the expense of wider goals such as employment, housing and leisure. Within the focus schools 'what' or 'where next' was indeed acknowledged as a key part of transition meetings. However, the Cedar Drive Head, whilst recognising an approach which focused primarily upon the last two years of school and the next step, was also vaguely critical of this. Comparing transition plans to individual action plans, he felt that transition plans had, so far, been a "missed opportunity" for more comprehensive planning:

> "I think the weakness of the transition plan is that it tends to focus on up to 16. It really is about 'what have we got to do between now and 16 when you go onto college or residential or what have you' ... I hope the Individual Action Planning that we do does go beyond that and does talk about a longer future, er longer term future and what might be needed to do that." (Cedar Drive Head, January'97)

Questions surrounding transition plans in comparison to other forms of 'planning' will be discussed in more detail later within this section. The important point to note here is the potentially narrow focus. On the other hand, the Cedar Drive Head was also aware of the problems frequently endemic within attempts to plan longer term. Looking ahead and planning in terms of the transition to adulthood was considered difficult as it was often viewed as gazing into an unknown and distant future. Staff at The Laurels and Ash-hill also shared this feeling. The key problem focused upon 'change': 'change' in terms of the provision of services available now and in the future, the latter being unknown; and 'change' in that young people can, and do, alter over time, both in terms of their disabilities and their ideas. This constant element of uncertainty does not encourage longer term planning:

"I mean the rate of change is such that it's quite, it's not easy to predict what is going to be available ... it's a difficulty that parents address with students and there aren't always answers, the long term vision doesn't often crop up at the transition review." (Cedar Drive Head, January'97)

However, just because this element of uncertainty existed this did not mean that the focus schools gave no consideration to the future in the longer term. In fact, the schools and their careers advisers recognised the importance and were all very aware of broader and longer term transition issues for families. Consequently, even though the primary focus was upon the next educational step, three schools (Ash-hill, Oaksmere and Beechview) highlighted that wider and longer term issues were sometimes raised and discussed at review meetings. For example, Ash-hill and Oaksmere noted the importance of discussing future living arrangements and, at Beechview, the social reintegration of students' back into their home communities was often raised. This was similarly illustrated within the transition reviews observed at Cedar Drive. Here, as previously noted, the head was aware of their narrow perspective and the meetings were indeed focused upon the next step. However, at three of the four reviews, broader, future employment goals and/or social independence skills were clearly discussed. On the other hand, the meetings only discussed these issues to a certain degree. Within a physically disabled student's review, although residential college and developing social independence skills was discussed, longer term issues around future living arrangements or provision was not introduced. Issues of time and the absence of social services may have been a factor. Overall, the general impression one is left with is that the transition meeting and the ensuing plan was viewed functionally. The *primary* aim was to explore the 'next step' and how to achieve this.

Different approaches towards transition planning at 14 years have been noted at Oaksmere and The Laurels, two relatively comparable special schools. These differences were re-emphasised as the Oaksmere's co-ordinator appeared more positive and enthusiastic than The Laurels' Head about encouraging parents to consider the next step at 14 years, even though it was five years away. The Laurels' Head, although keen to give parents information about potential opportunities at 19, felt that:

"Um, we haven't found parents wish to make any substantive enquiries at the age of 14. Um, they're quite happy to be guided by the school, by the careers service." (January'97)

Previously, it has been acknowledged that this difference in perspective could be influenced by each school's evaluation of their pre-Code review process. However, one should also consider each school's age range (Oaksmere serves young people from two to 19 years, whereas The Laurels serves young people from 11 years). Students at Oaksmere could therefore have remained in the same school for up to 17 years without

facing any substantial educational transitions. This can influence parents, especially their willingness to consider the future and thus change, as the Oaksmere co-ordinator highlighted:

> " ... it has always been difficult to impress upon parents that the future is never that far away and also sometimes I think it is something the parents don't want to face because a lot of them are in school from 2 right through until 19 ... and you get very comfortable ..." (December'95)

This may also help to explain why the Oaksmere co-ordinator was so keen to begin the process at 14 years. However, one should not forget that families are diverse, some are eager to explore the future longer term, whilst others prefer not to. However, planning for the future does not occur in a vacuum. Parents' perspectives and wider socio-economic factors influence it as the Head at Oaksmere stressed. Consequently, a family's social and economic circumstances can influence their ability to plan for the future.

5.2.2   Who writes the Transition Plan - Does it matter?

Within the Code's guidelines for the first review after a young person's 14th birthday the onus is upon the LEA taking a more active role. One duty is:

> "The LEA prepare the review report and the Transition Plan after the meeting ..." (1994, 6:44, p.117)

However, this appears to be an area in which there are differences between the authorities studied, with different interpretations of roles and responsibilities. For example, within the focus schools in Authorities 2/3 (Beechview, The Laurels and Cedar Drive) an LEA representative generally wrote the transition plan after the review from notes taken at the meeting. In contrast, within Authority 1's focus schools (Ash-hill and Oaksmere) a member of school staff took responsibility for writing the transition plan. 'Who' this person was varied between schools. However, the important point was that each school appeared to be taking initial responsibility for writing a plan and then sending it to the authority to be checked and accepted. A Deputy seconded to Authority 1's LEA to oversee the implementation of transition plans confirmed this.

Satisfaction with the current system of 'who' wrote the transition plan also differed. Within Authority 1, both Ash-hill and Oaksmere appeared to be satisfied with the school taking responsibility for initially writing the transition plan. In contrast, two schools within Authorities 2/3 (Cedar Drive and Beechview) highlighted a number of concerns surrounding the idea and practice of LEA representatives writing transition plans. However, before addressing these concerns, it is important to note two points.

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Firstly, that the concerns expressed by the Cedar Drive Head and Beechview co-ordinator were personal opinions and, hence, may not have been shared by all within their schools. Secondly, although expressing fears about some LEA representatives writing transition plans, they could also appreciate the administrative advantages, especially in terms of reducing the burden for school staff. This was also recognised by The Laurels Head.

In order to explore concerns surrounding 'who writes the transition plan?' two issues will be examined: firstly, knowledge of circumstances and delivery; and secondly, who 'owns' the transition plan?

5.2.2.1 Knowledge of Circumstances and Delivering Transition Plans

The practice of LEA representatives being responsible for the writing up of transition plans raised a shared concern for the Cedar Drive Head and co-ordinator at Beechview. For these there was a fear that some LEA representatives may be 'strangers' to students and their families. Hence, there was a perceived danger that some LEA representatives could lack both knowledge and understanding of a family's current circumstances:

> "And it seems to me that there is a real problem that, in that at a very critical point in the whole process, a very critical element of the whole process is actually taken out and given to someone else to do, somebody who doesn't know the student." (Cedar Drive Head, January'97)

The Head at Cedar Drive took this a step further noting that LEA representatives could also lack a knowledge of past events and experiences. He felt that it could potentially have a profound effect. The co-ordinator at Beechview voiced similar concerns:

> "Um, but a representative of the authority coming into a meeting having just read documents, perhaps met the parents and the child for the first time, it must be very difficult to go away and write something without knowing the child." (November'96)

Furthermore, this danger was unwittingly re-emphasised by an LEA representative within Authorities 2/3. During an interview she acknowledged that she often did not have enough time to look at students' files before attending their transition review.

Two further issues were raised as areas of concern: firstly, 'how' transition plans were written; and secondly, their timing and 'when' they were delivered. The Cedar Drive Head perceived the LEA representative as basically a 'scribe' at transition meetings, a person who wrote the minutes. Thus, he felt that the minutes produced were frequently a detached and superficial synopsis of the transition meeting, and did not really explore the wider and deeper issue of 'planning' for students:

"*[Transition plans]* don't in my opinion carry any insights into the needs and aspirations of the youngster. I mean it may say something like, 'she enjoys working with her hands and hopes one day to be er a mechanic or to be a nurse or something like that'. Um, but you don't by and large see the kind of informed comment that says, 'she enjoys working with her hands, er would like to be a mechanic and is planning to do the following long term steps to get there'. Um, it will be a report of what people say." (Cedar Drive Head, January'97)

Furthermore, although not specifically critical of LEA representatives writing transition plans, The Laurels Head and an Authority 2 educational psychologist both noted that written transition plans were frequently rather bland:

" ... they're *[transition plans]* a bit dry, the descriptions ... I don't feel that they capture the full range of issues to do with what's going to be around through transition beyond 16." (Educational psychologist, November'95)

In defence of LEA representatives, one official within Authorities 2/3 felt that, although her role at first had been merely writing notes, over time she had developed a more co-ordinating and productive role:

"... as I've become more experienced I've been able to have an actual input, to improve or direct or involve somebody else." (Pupil Support official, September'95)

The second issue focused upon 'when' transition plans were written up and dispatched. The co-ordinator at Beechview (a residential school dealing with a number of different LEAs) noted that from her experiences, the time different LEAs took to write up transition plans and despatch them varied enormously. Speaking in November 1996 she commented:

"I'm still waiting for June's, apart from the Authority 3 child, I have not seen those transition plans yet, from the June transition reviews, I've not had a copy of them."

This raises the issue of a bureaucratic and administrative 'time lag'.

However, the co-ordinator at Beechview was also aware that some LEA representatives would adopt a more personal approach:

" ... he *[representative]* used to come into lessons before and discuss what's going to happen. What sort of things, you know, should we write down about you and we did two or three weeks work together and we had some super transition plans ..." (November'96)

From this perspective, it is clear that the co-ordinator does not reject the idea of LEA representatives writing transition plans but is critical of 'distant' representatives.

However, one can see numerous bureaucratic obstacles within a more personal approach, such as time constraints.

Conversely, the Cedar Drive Head suggests diverting responsibility away from LEA representatives as 'authors', to place greater emphasis upon the student and 'knowing' professionals. However, in doing so he is aware of extra administration for the school:

> "Well yes, I like the idea of the LEA taking some of the responsibility for doing some of the processing ... But I have to say that I think that it would be better if the LEA said, 'we're going to take minutes of this meeting and the outcomes of the meeting and we're going to provide you with minutes for your record. But it's you, the school's responsibility, with the careers adviser and with the student first and foremost to actually now draw up an action plan'." (January'97)

5.2.2.2 Who 'Owns' the Transition Plan?

As we have seen, two educational professionals shared a number of concerns surrounding the danger of 'distant' and 'detached' LEA representatives writing transition plans. Taking this a step further, one can begin to question if distant LEA representatives can produce written transition plans that are personally relevant and meaningful to each student. This also raises the question of 'ownership' (Wood and Trickey, 1996, p.120 also emphasise the concept of 'ownership'). This concern was discussed within initial interviews and developed further a year later.

The issue of 'ownership' revolved around whether a student felt that they 'owned' their transition plan. This was most clearly explored by the Cedar Drive Head:

> " ...frankly I think it's not something that any body has any ownership of, it's just a record of the meeting ... it's not a document that a student and his parents or her parents or his or her carers will look at and say, 'yes, this is ours, we understand this, we know where it's come from' ..." (January'97)

A lack of 'ownership' for young people was also suggested by the Beechview co-ordinator when comparing transition plans with Careers Action Plans. Two issues were highlighted. The co-ordinator firstly noted the importance of students being involved within the process of Career Action Plans (a factor also stressed by the Cedar Drive Head). In particular, she noted the important symbolism of students signing 'their' own Career Action Plan. As far as the co-ordinator at Beechview was aware, students did not personally receive a copy of their transition plan but rather a copy was sent to their parents. This in turn raises questions about a formal recognition of the student's contribution and role within the process.

The second issue focused upon the potential effects of a 'time lag' for students and their families. The co-ordinator was sceptical about a lag between transition meetings and

receipt of transition plans raising fears about relevance and meaning. In contrast, the Careers Action Plan was perceived as a much more immediate and thus meaningful document for students:

> " ... the Careers Action Plan ... they have to sign it when they're talking to the careers adviser, it is theirs. Um, the transition plan there's somebody there from the authority who they don't know, they go away and write it and it could be many weeks later, it's totally meaningless for them." (Beechview Co-ordinator, November'96)

The co-ordinator's view was that if this time delay could be addressed and the process of producing transition plans quickened, this may help.

> "If it [transition plan] came ten days later, within a fortnight, I think it would be much more meaningful." (November'96)

Overall, it is clear that these two professionals would like to see their students having more 'ownership' of their transition plans especially 'felt ownership' that it was 'theirs'. However, they were also aware that this might be difficult to achieve within current procedures and structures.

This section has highlighted two important issues. Firstly, it was clear that transition meetings were used in a very functional manner as a time to plan for the 'next step'. However, some discussion of longer and broader transition issues were apparent, especially within the observed transition reviews at Cedar Drive. Within these meetings professionals did seem to be more willing to think about and discuss longer term issues compared to those reported by Tisdall (1996/97, pp.6-7). Secondly, the issue, 'who writes the transition plan?' has raised a number of concerns surrounding the Code's guidelines outlining LEA representatives responsibilities. This is a complex issue as the use of official representatives does highlight the significance attached to transition plans. However, the danger and potential effects of unknowing LEA representatives, interwoven with wider 'ownership' issues, need to be considered carefully within policy guidelines.

5.3 Involvement and Support

This section will discuss young people's and their families' role within transition reviews and the construction of transition plans. It will focus on - 'involvement' and 'support'. These concepts have in recent years gained a common currency. For instance, in the United Nations Convention on the rights of the child (especially Article 12, see Lansdown, 1995) and specific pieces of UK legislation (Children Act, 1989). They are also highlighted in studies exploring the transition towards adulthood for disabled young people (Hirst, 1985; Fish, 1986; McGinty and Fish, 1992; Thomson and Ward,

1994; Tisdall, 1996, 1996/97). Given this, one should not be surprised to find that these principles are highlighted within the Code of Practice's guidelines:

> "The views of young people themselves should be sought and recorded wherever possible in any assessment, reassessment or review during the years of transition." (1994, 6:59, p.122)

This section will firstly explore ideas and practices surrounding the concept of young people's 'involvement' and then move onto discuss a range of 'support' issues.

5.3.1 Involving Young People

5.3.1.1 A Broad Approach?

The focus schools emphasised the importance of taking a broad approach to involving young people. In general, they felt that they encouraged young people's involvement and awareness of transition by thinking about and discussing 'the future', over a period of time. In fact, all the focus schools emphasised that they tried to involve young people as far as possible. However, there were qualifications within this and ideas of 'appropriateness' were raised: these will be discussed later within this section.

The importance of encouraging young people to assess themselves or their skills was frequently highlighted. However, school-leaving age once again emerged as a significant difference between schools. At Oaksmere and The Laurels, leaving school preparations focused largely upon the post-16 period rather than from 14 years:

> " ... er careers lessons formally from 16, they do have provision on the timetable, they do have tutorials on their timetable with 16 plus staff. So there's the opportunity to talk about their work generally, school generally, how they feel and also introduce the future as well." (Oaksmere co-ordinator, December'96)

The Oaksmere co-ordinator may have taken a more positive approach to the idea of transition planning at 14 years compared to The Laurels Head, but this seemed to be in terms of parental involvement. Again, there appears to be an association between young people and their school leaving age (at Oaksmere and The Laurels 19 years). There also seemed to be an association with perceived 'severity' levels as young people with pronounced learning disabilities attended The Laurels and Oaksmere.

Amongst the schools (Ash-hill, Cedar Drive and Beechview) where a formal programme of leaving preparations began pre-16, the transition plan at 14-plus was viewed as part of a wider and deeper process of leaving school preparations. This was also emphasised by the careers adviser within Authorities 2/3 and an educational

psychologist. At Beechview and Cedar Drive, the importance of wider careers programmes and action planning (years 10 and 11) was stressed:

> " ... it's part of their careers programme, we do the transition plan in our careers programme in the last term and then we really start looking at what's available ..." (Beechview co-ordinator, November'96)

At Ash-hill, the SENCO saw the transition plan and process of planning in general, as part of the school's life skills programme:

> " ... it isn't done just once a year, bearing in mind even from year 7 the timetables geared round the life skills ... so the transition plan isn't the only focus, you know, this once a year thing, it's an emphasis all the year round. It is more integral within the school life than simply that." (December'96)

The important point to note is that for these schools the transition plan was regarded as part and parcel of a wider and deeper process - leaving school preparations and the movement to adult life. This may have been perceived in terms of life skill preparations, Individual Action Planning or Records of Achievement. But the philosophy appeared to be largely the same. The plans were much more than a detached and one off event:

> "... the review meeting is just one tiny speck of a whole process in time that goes on to do with the transition beyond school..." (Educational psychologist, Authority 2, November'95)

Furthermore, The Laurels Head may not prioritise the transition review at 14 years, but he was very clear that The Laurel's post-16 reviews were part of the broader transition planning process. A wider and deeper process was thus recognised, the main difference was that it was delayed until post-16.

Prioritising transition plans as part of a wider planning process simultaneously raised a further issue of concern for the Cedar Drive Head, surrounding the very concept of 'planning'. More specifically, he highlighted the different forms of 'planning' that young people can encounter during their final years at school (Individual Action Planning, careers planning and Records of Achievement). Consequently, he felt that the concept of 'planning' within transition plans needed to be managed carefully and implemented in order to avoid young people becoming "overburdened" or "confused":

> "I think that if you look at the whole concept of planning, there is every potential for students to be very confused ... *[later]* I mean professionals in a multi-disciplinary sense, we need to address transition planning in the context of all other planning that goes on at that time. Otherwise, I think students are going to sit there and look at the whole range of plans and think, 'well, what does all this mean?' " (Cedar Drive Head, January'97)

This is important to consider as it could have negative ramifications not only upon young people's involvement but also their very wish to participate.

5.3.1.2   Involvement and the Transition Review

In terms of 'involvement', both educational professionals and careers advisers emphasised that this was more than attending or not attending the transition meeting. Of course, involvement occurred at different levels and in different ways due to the varied nature of the special schools. For example, both the Oaksmere co-ordinator and Authority 1's careers adviser emphasised problems that they felt they encountered trying to access the ideas and feelings of students with pronounced learning disabilities. As a result of this the Oaksmere co-ordinator stressed the importance of practical experiences for students, drawing upon young people's reactions to different experiences:

> " ... to go on reaction to a placement, reaction to activities, that sort of thing, it's very, very difficult." (December'96)

Within past literature many theorists (Brisenden, 1987, 1989; Barnes, 1991; Mason and Rieser, 1994) have argued very lucidly that the ethos surrounding special schools is frequently paternalistic and unduly protective. Hence, it is perceived as a context that can have a profound effect upon young people's involvement within school processes. Within this study it appeared that the schools were at different stages in seeking to involve students. However, it is important to note that *all* the focus schools stressed that they sought to do this. Involvement was viewed as a constant process of development. None of the schools felt that they were complacent. In fact, they highlighted that improvements can always be made. The staff at Beechview, for instance, prided themselves upon prioritising students' involvement and stressed that they constantly worked towards this goal. Furthermore, the co-ordinator argued that it was potentially easier to involve students within the process of transition planning in a small special school rather than a large mainstream school with a few statemented pupils. Within special schools she felt that there was more time to prepare students because, as a year group, they all faced the same transition review process and time could be built into careers programmes (see Lewis et al, 1996, pp.107-108).

The idea of student participation as a developmental process was practically demonstrated by the Beechview co-ordinator. Within her initial interview (January 1996) she indicated that it would be a good idea if students had an opportunity to see more information that was written by other parties, prior to their transition review. Within the second interview (November 1996) this was being developed. The idea that a

young person has a basic right to be informed and involved was prioritised - *as far as possible*. There were important provisos:

> "I just think it's important that they do play a part. There are some that maybe I wouldn't show everything, some maybe I wouldn't show what their parents have written about them. I don't think that's fair ... but on the other hand, what they say *[i.e., prior to the transition review]* is seen by everyone." (Beechview Coordinator, November'96)

Exploring attendance policies at transition reviews has been clearly recognised as a limited indicator of students involvement; involvement can and does occur in many contexts and guises. Furthermore, as Tisdall concluded from her studies of inter-disciplinary meetings, merely having a policy of attendance does not guarantee that a young person is actually involved or participates:

> " ... it cannot be assumed that physically including young people in inter-disciplinary meetings about their post-school futures will actually involve and empower them." (Tisdall, 1996, p.31)

However, on the other hand, the issue of review attendance did raise some important differences between the focus schools and some interesting questions surrounding concepts of age and perceived severity levels. Within three focus schools (Beechview, Ash-hill, Cedar Drive) the importance of young people attending their 14-plus review was stressed as part of a wider and deeper school ethos of pupil involvement. This was clearly expressed by the Cedar Drive Head and the careers teacher with the suggestion of "ownership":

> "Oh yes, we ask them 'cos I think it's wrong, I'd be so annoyed if I thought there were a dozen people sitting round a table talking about my future and I wasn't there." (careers teacher, October'95)

However, subtle differences emerged within Ash-hill and Beechview, instances where it was not deemed *appropriate* for a young person to be present during specific periods of a meeting:

> "It's usually part of it, um what has happened is that um, I think it depends what the issues are for the young person. Some of them are very straightforward, the child is there all the time. If we feel or the parent has concerns that they want to raise and which they don't want the child to know about ... or the school has concerns that they want to raise with the parent. The child will come in towards the end of the meeting." (Ash-hill Deputy, December'96)

Issues of family dynamics and sensitivity were highlighted. However, it is clear that there was a subtle difference between the rights of young people and that of their parents. Here, the idea of a young person attending the whole of their review meeting was not viewed as an automatic or taken for granted right as it was for their parents.

In contrast, students at The Laurels and Oaksmere had not, so far, generally attended their initial transition reviews (14-plus). However, The Laurels Head stressed that attendance occurred within the post-16 department. But this too was conditional upon notions of *appropriateness*:

> "Not at 14, but students in post-16 provision will attend their reviews where appropriate. I mean for some students it would be inappropriate because er they're inability to be able to understand what was going on. I'm thinking of students who are profoundly handicapped but for the majority of post-16 students, yes, they will attend their reviews." (The Laurels Head, January'97)

Similarly, the idea of 'appropriateness' appeared to pervade many decisions at Oaksmere. Both in the past (co-ordinator suggested that young people's non-attendance at first round of initial transition interviews was due to disability severity) and also considerations for future years:

> " ... as I say in terms of actual formal meetings, I think I would be selective about who attended and also selective about which part of the meetings they were there at, at least to start with." (Oaksmere Co-ordinator, December'96)

At Oaksmere it appeared that there was not a past tradition of young people attending their reviews until the final year before school leaving. Furthermore, interwoven within notions of *appropriateness* there was a moral dimension for some teachers - the right of parents to talk freely to professionals at a meeting and a school's obligation to protect young people from hearing things which could be hurtful. In addition, the co-ordinator at Oaksmere feared being drawn into a situation where she was talking over the head of a young person and thus excluding them, although they were present:

> " ... there's that issue as well, talking about somebody when they're there, which it becomes when they're non-verbal. It becomes, talking about them a lot of the time and that is something we've always tried to avoid in school, that you don't discuss people over their heads because it's not fair..." (December'95)

Attendance was thus perceived as a complex issue. Ideas of *appropriateness* frequently interwove with 'severity' level evaluations and obligations to parents. Issues surrounding the concept of "competence" (see Franklin, 1995, pp.10-12; Lansdown, 1995, pp.20-23 for a discussion) will no doubt remain a controversial issue. However, one has to weigh these ideas and feelings with issues surrounding young people's rights, in particular, a young person's right to be present and to participate in *their* transition meeting and future life planning.

5.3.2 Providing Supporting

One of the general principles within the Code of Practice is to encourage and promote partnerships:

> "the knowledge, views and experience of parents are vital. Effective assessment and provision will be secured where there is the greatest possible degree of partnership between parents and their children and school, LEAs and other agencies." (1994, 1:2, p.2)

Here, two areas will be discussed: firstly, the issue of a supportive atmosphere within transition meetings, important for both young people and their parents; and secondly, providing support by keeping people informed.

5.3.2.1 A Supportive Context

The context of a review meeting both in a physical and a social sense plays an important role within the social interaction of those present, especially young people and their parents. Discussions within the focus schools raised two important issues: firstly, the notion of formal versus informal meetings; and secondly, the number of people attending. If one considers the ideal for a transition meeting, as suggested by the Code of Practice, the image is of a rather formal meeting with a range of professionals attending. Hence, the numbers involved could potentially be considerable. This could be extremely intimidating, especially for young people, as Tisdall (1996, p.20) has demonstrated.

Three focus schools (Cedar Drive, Oaksmere, The Laurels) noted this danger within transition reviews. They commented that reviews in general could be too formal and thus a potentially inhibiting and daunting prospect. The Authority 2 educational psychologist suggested that a room full of professionals "probably feels a bit de-skilling for a parent." Consequently, the importance of creating as informal an atmosphere as possible was emphasised. For example, the Cedar Drive Head was very aware of the importance of seating and his own role as an ally for parents:

> "I ... almost always sit myself alongside the parents so that they don't sit themselves facing everybody, so that they actually see themselves as part of the group, hopefully with me as an ally to try and make it comfortable." (January'97)

Furthermore, the question of 'who should attend?' was raised. The issue of 'unknowing' professionals writing transition plans has been discussed in the previous section. For parents, the importance of informed and known professionals was stressed by co-ordinators at Beechview and Oaksmere and the careers adviser within Authorities 2/3.

Indeed, the Oaksmere co-ordinator emphasised that she was reticent to invite professionals whom parents did not know. Past knowledge and understanding was felt to be very important:

> "I think the parent has got to trust the people who are in the room. I think that is vital and you usually find that ... if you feel comfortable in a meeting they're [parents] going to be honest and they're going to talk and they're going to tell you exactly what they feel. If they're not comfortable then forget it. That's why I feel there should only be people there who parents feel comfortable with, the more strangers you get in the room, the more difficult it is for them to talk..." (Oaksmere Co-ordinator, December'96)

The idea of having 'known' professionals raises some important ramifications for professionals - their workload, timetables and involvement, especially social workers. Indeed, the very idea may be unrealistic. Furthermore, even if it is achievable, would it always be desirable for parents and young people? For example, as parental interviews illustrated (see chapter six), parents held different attitudes towards, and expectations of, social services and their input. More specifically, some parents did not want social worker involvement.

Only having 'known' professionals also leads to the wider question of the number attending transition reviews. On one hand, the focus schools valued and welcomed varied professional involvement. On the other hand, the benefits of keeping meetings small enough to be manageable and not intimidating was recognised, as the Deputy at Ash-hill demonstrated:

> "I think a lot of them [pupils] would be intimidated, you know, at a meeting ... I think a large meeting where all the world and his wife might be there isn't the best place." (November'95)

This was also noted during observations of transition meetings at Cedar Drive. Even though all the professionals present, especially the Head, tried to put the young people at ease and create a relaxed atmosphere, three out of four remained very nervous and seemed daunted by the occasion.

5.3.2.2 Information

In terms of information, the focus schools appeared to value the Code's contribution to improving the degree of information available for both professionals and parents. Generally, it was felt that people were better informed prior to meetings. However, the achievement of this was felt to have been at the expense of an increased administrative burden for schools.

More information was being produced but was it accessible to parents? Two schools (Beechview and Oaksmere) considered the issue of professional jargon within reports (see Orlowska, 1995, pp.444-446 for a wider discussion of information accessibility problems). Both were aware of the importance of accessible information and simultaneously, the danger of professional jargon as a potential barrier. However, the co-ordinator at Beechview stressed that the information they presented was "fairly accessible" to parents. Her objective was to have informed rather than excluded parents:

" ... it is mainly the school report ... er, we do try to write it jargon free, the medical one tends to be a ticky box, that sort of thing ... so yes, it's fairly accessible the information going through. It has to be. Parents need as much access as possible. So we try to make our school reports nice and easy." (Beechview Co-ordinator, November'96)

On the other hand, there was still a recognition that jargon related misunderstandings can and do occur. Furthermore, the Oaksmere co-ordinator recognised that many teachers were frequently oblivious to this jargon. Hence, she suggested that there was a need for teachers to be more perceptive, to stand back and be aware of language used:

" ... I think professionals, teachers as well, get very used to the language that they use. They forget that it's jargon. They see it as a very everyday language really, it's only the parents or a lay person coming in that says 'I don't understand'..." (Oaksmere Co-ordinator, December'96)

In addition, one must also recognise the danger of information overload. This can be intimidating for parents, as one set within the study indicated (see chapter six). Hence, it is important for schools to consider 'how' they present information to parents.

One suggestion for how parents could perhaps get more information out of transition meetings was raised by the Cedar Drive Head. The Head was considering introducing a "prompt sheet" of questions that parents may like to ask. He saw this as a user friendly and practical tool - a list of possible probes. This, he felt could perhaps help parents to pursue a more informed and active role within the transition review and reviews generally:

" ... one of the things that I am proposing to do in the future is actually send a prompt sheet out to parents beforehand because I think there is some difficulty. They may come in and they're really not sure what they're saying." (January'97)

In a similar vein, two professionals (the Oaksmere co-ordinator and Authority 1's seconded Deputy) highlighted the importance of encouraging parents to become more informed and active rather than passive respondents. On one hand, they foresaw a potential to do this within initial transition reviews. They felt the reviews encouraged parents to think about the future and consider provision requirements at an early stage:

" ... it's parent power isn't it? If parents are forewarned and are prepared for the future and think about it early enough - what they want, what they perceive their son or daughter needs, may need in the future. Then you know, you can have a voice and it can be said in front of the LEA or whoever and hopefully change things in times to come." (Oaksmere co-ordinator, December'95)

On the other hand, they were also aware (especially the Oaksmere co-ordinator, post transition review implementation) of the danger of raising parents hopes and/or future expectations to 'unrealistic' levels:

" ... it may be disadvantageous if we go down, if we become idealistic ... we have to be careful and to say to them [parents] 'you mightn't get all of them'. But if we know what you want, what the ideal picture is, then we can help you get as many of those elements as you can. There is a danger there and we've got to be very careful." (Oaksmere co-ordinator, December'96)

Overall, three points are important: firstly, the idea that information can be a source of power and thus empowerment for parents, as discussed by Orlowska (1995, p.444). This stresses the importance of information for parents, especially during the transition period when key decisions are discussed. Secondly, the fact that some professionals were encouraging parents to be active and thinking actors. They were thus recognising and valuing the contribution that parents can make. The third and final issue raised was the importance of 'realism'. The Oaksmere co-ordinator and seconded Deputy were both wary of nurturing 'unrealistic' parental expectations. What counted as 'realism' by professionals was an important consideration within Tisdall's reviews (1996, p.24). Furthermore, as we shall see in chapters six and seven it was also an important concern for the study's parents.

In terms of young people being informed, the importance of providing access to, and accessible information has been discussed in relation to careers and Personal and Social Education. In effect, the schools highlighting a broader approach. However, one professional (Educational psychologist, Authority 2) felt that there was still a great deal of work to be done within this area, especially in terms of 'when' to provide information for young people. Flynn and Ward (1991, pp.133-134) have highlighted the importance of preparing people, helping them to take a more active role; the educational psychologist similarly recognised this:

"I think an enormous amount more work is needed on looking ahead to what decisions pupils are going to be asked to make and then thinking about what information they'll need to make those decisions. ... I think there's an enormous amount of work that should go on there, but time again will be the restriction on that, I think." (November'95)

The twin themes of 'participation' and 'support' have raised a number of important but complex issues. Within the focus schools it was clear that they valued and strove towards the idea of 'participation'. However, considerations of 'age' and 'severity' of disabilities were frequently raised, focusing around notions of *appropriateness* and *competence*. Some educational professionals felt clear moral obligations, both to parents – their ability to speak openly - and to students, sometimes it was felt students needed to be shielded from information that they might find hurtful or not understand. Participation is undoubtedly a complex area, especially within such a varied sample of focus schools. Levels of participation will of course vary. However, one must not loose sight of the basic right for young people to be present at their own review meeting, especially as it is *their* future being discussed (see Franklin, 1995; Lansdown, 1995 for a discussion on children's rights). Disabled young people are in many ways a 'vulnerable' social group (see Coles, 1995). They face an inequitable and disabling society. However, feelings for a need to 'protect' young people can easily lead, as social model theorists (Brisenden, 1987, 1989; Barnes, 1991; Mason and Rieser, 1994) argue, to paternalism even exclusion, although it may be well meant. The second theme of 'support' has similarly raised a number of issues surrounding information accessibility and the 'appropriate' context and composition of meetings. Providing accessible information in a relaxed and open context is an important objective. However, transition reviews were sometimes felt and seen to fall short of this. On one hand, professionals were often aware of this but, on the other, some of the issues Tisdall (1996, p.20) raised, surrounding an inhibiting context remained.

5.4 Multi-Disciplinary Working

The Code's guidelines for the first transition review clearly focus upon encouraging and developing multi-disciplinary working, in the pursuit of a transition plan which is both comprehensive and coherent. Past research and experience suggests a note of caution. Professional inter-agency working is frequently an aspired to ideal but practically difficult to achieve (Bradley et al, 1994; Means and Smith, 1994; Fish and Evans, 1995). This section will explore how the focus schools feel the idea of inter-agency co-operation is working in practice and examine some of the issues raised by the schools.

Amongst the focus schools, there was a lack of consensus concerning general evaluations of change perceived to have evolved from the Code of Practice and the introduction of transition reviews. For example, the Oaksmere co-ordinator presented a positive evaluation of the potential of the transition review to improve and develop inter-agency working, whereas at Beechview, the Head and co-ordinator did not see a great deal of change. Beneath these two extremes it is important to understand each

school's initial premise for evaluation. The Oaksmere co-ordinator assessed previous inter-agency review collaboration as poor:

> "I think it's *[multi-disciplinary working]* getting better. I think it's getting better and I think the transition planning will help that ... I think it was more or less non-existent in the past." (December'96)

In contrast at Beechview, the Head highlighted how the school already had a well-developed inter-agency network:

> " ... we already involved parents, we already had joint review meetings with all agencies involved with young people and the Code of Practice has merely formalised that for all schools." (June'95)

However, there was also a rather more sceptical or perhaps 'realistic' suggestion. It was felt that the notion of actually gathering together all professionals who are, or could be, invited to a transition review was an ideal rather than practically achievable. Both the Deputy at Ash-hill and the co-ordinator at Beechview shared this feeling:

> " ... with the best will in the world I don't really think there is any way that you'd get that number of people there." (Beechview co-ordinator, November'96)

To unpack these general evaluations of inter-agency working two themes will be explored: Firstly, the co-ordination and co-operation of professionals, such as careers advisers, social workers and medical professionals; and secondly, the idea of coherence, joint reviews and sharing information.

5.4.1 Co-ordination and Co-operation of Professionals

5.4.1.1 Careers Advisers

The focus schools' initial response to their careers service's involvement during this period of preparation was a positive one. Careers advisers were generally valued and their input welcomed during the transition review. Furthermore, the careers service was involved within all the schools during the transition period. However, there was a degree of variation in the form that this involvement took.

The Code advises that:

> "the LEA must invite the careers service to be represented at the review meeting, to enable all opportunities for further education, careers and occupational training to be given serious consideration." (1994, 6:44, p.117)

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However, Oaksmere and The Laurels highlighted that their careers adviser had not actually attended initial transition reviews. At The Laurels, the Head stressed that this was a joint decision and that both he and the careers adviser judged actual attendance as not the best use of the careers adviser's time. This again illustrates the Head's lack of prioritisation for the reviews at 14 years:

> "I decided with the careers officer that it would be more important if she met with the families and the students outside that review meeting rather than just coming to the review ... she doesn't come to the transition meetings because we found that it wasn't probably the best use of her time." (The Laurels Head, January'97)

The Laurel's careers adviser re-emphasised the importance of being flexible to school-leaving ages and the needs of young people and their parents:

> "... for many youngsters at The Laurels to have it at year 10 ... you're talking about so far ahead that it's really complying with the Act for the Act's sake..." (Careers adviser, Authorities 2/3, November'95)

In contrast, the co-ordinator at Oaksmere highlighted that it had been the careers adviser's rather than the school's decision not to attend:

> " ... the careers service were invited but at this stage he didn't feel he needed to come..." (December'96)

Indeed, the careers adviser within Authority 1 noted the general procedure in which all year 9 pupils met an adviser, a report was written and then forwarded to their meeting:

> "What I have said within the careers service is that we should participate in the transition plan but not necessarily attend all annual reviews. That is purely from a time point of view." (Careers adviser, Authority 1, June'95)

These two schools and their respective careers advisers views, illustrate how attendance at the initial transition review was negotiated or forfeited in return for alternative modes of involvement. Furthermore, this personal interpretation of the Code's guidelines appeared to be interwoven with the fact that young people usually left Oaksmere and The Laurels at the age of 19 years. However, Oaksmere had only conducted one set of transition reviews. The co-ordinator acknowledged that the practice was tentative and subject to review.

5.4.1.2   Social Services

In Tisdall's study of FNA meetings within Scotland, "the lack of social work contribution" was felt to be "notable" (1996/97, p.9). In this study, a principle officer (1995) within Authorities 2/3 emphasised that social services would attend/had attended

the initial transition reviews of young people viewed as 'disabled', under current disability legislation or, as a 'child in need' (Children Act, 1989). Within Authority 1, the official policy appeared to divide statemented young people into three groups. These were: young people who are 'looked after', i.e. in receipt of local authority care, either residential or respite; those who are 'known' to social services as an active case but not 'looked after'; and those who are not 'known' to social services. Social services policy was generally to attend the transition reviews of 'looked after' young people but not those of young people 'not known'. Decisions seemed to be negotiated on those young people 'known' to social services but not 'looked after'.

On the other hand, focus school assessments of social services attendance were not so clear cut. In the past, general attendance within school reviews was often felt to have been erratic. Furthermore, current patterns of attendance were still felt to be somewhat patchy. The importance of being 'known', highlighted within the above social service policies, was re-emphasised by the schools. Indeed, four schools noted that if a young person had a 'named' social worker, a specific contact with social services, then they would be more likely to attend that transition review:

> "They *[social services]* are always invited um the one's with specific social workers usually do. The generic social workers, the learning disabilities team we actually inform the line manager for that local team who may or may not send anybody." (Beechview co-ordinator, January'96)

Furthermore, both Beechview and The Laurels felt that geographical distance could also be an important factor:

> " ... some pupils who maybe live eight to 10 miles from school, they're support is provided from an office some considerable distance away ... Now that presents issues in terms of their ability to have a social worker attend meetings..." (The Laurels Head, January'97)

Issues of time and distance were thus raised as important considerations. These factors are particularly pertinent to special schools as they traditionally have large and widespread catchment areas (see Barnes, 1991, pp.42-43).

On one hand, the schools were sympathetic to, and understanding of, problems that social services faced. In fact, they were quick to suggest that in many instances social workers often wished to attend, but were prevented due to pressures of work and heavy case loads:

> " ... social services, if, again if there's no, if they're not in attendance it's because of the pressure of their work not because they're not willing to participate..." (Ash-hill Deputy, December'96)

The co-ordinator at Beechview also felt that the issue of prioritisation could emerge:

> " ... but it's like everybody else, they're *[social workers]* rushed off they're feet, they intend to come in and then they're in court, there's a child abuse case, something more important comes up, you know, I don't envy them that job one little bit." (November'96)

Furthermore, it was also recognised by three of the focus schools that a social worker's presence was not always necessary for every young person.

On the other hand, there was a general feeling that more participation from social services would have been welcomed their input was valued. This was most clearly expressed at Oaksmere and The Laurels:

> "I still don't get the level of support that I would want from community services ... I would like to see closer involvement from community services." (The Laurels Head, January'97)

This is not unsurprising as Oaksmere and The Laurels families frequently looked towards and prioritised the future involvement of community services.

However, within the focus schools there were certain expectations for involvement. For the co-ordinators at Beechview and Oaksmere, the idea of an 'unknown' social worker (for Beechview, a personal rather than educational social worker) simply turning up to a young person's review was seen as potentially both inhibiting for parents and generally unhelpful. In the latter case, a lack of prior knowledge regarding a family's circumstances was felt to introduce the danger of 'unrealistic' or unhelpful comments:

> " ... as I say it's odd social workers who come in and perhaps they're line manager told them, 'we've got a child coming back in our area from school, you must go' and they've got no idea." (Beechview co-ordinator, November'96)

This should not detract from the potential benefits of inter-agency collaboration as a goal for professionals. But it does, again, highlight the complexity and difficulties involved in trying to forge good inter-agency reviews within which participants feel relaxed and informed.

The Laurels Head emphasised the benefits of Authorities 2/3's recent policy, introducing social service transition officers (see chapter four for a discussion of their role and different age remits). He felt that Authority 3's transition officer had, so far, provided an important positive contribution to post-16 reviews at The Laurels, and more generally, to helping co-ordinate the move from child to adult services:

"The reviews for students post-16 provision has probably better support from community services ... through people like the transition officer who's worked with the school, worked with the students..." (The Laurels Head, January'97)

However, this evaluation was again premised upon a prioritisation of 16-plus rather than 14-plus transition reviews. It is also important to note that Authority 3's transition officer did not usually get involved within pre-16 reviews. Hence, he had not been involved within transition reviews at Cedar Drive, where young people leave at 16 years. This age variation once again emphasises different professional interpretations of the transition period and the diversity in provision that this can cause.

5.4.1.3 Medical Input

Within the sphere of medical inter-agency working, three schools (Beechview, Cedar Drive and Oaksmere) recognised the benefits of having 'on site' professionals. This was seen to encourage not only a working relationship between medical professionals and educationalists but also to foster a closer relationship between medical professionals and students. Furthermore, 'on-site' professionals were felt to be able to attend reviews, as and when required. This was exemplified within the reviews observed at Cedar Drive and Oaksmere. All review meetings observed were well attended by 'on-site' professionals, especially the nurse and physiotherapist.

In contrast, it seemed that visiting professionals did not always attend review meetings. For example at Ash-hill, it appeared that medical professionals who visited the school frequently often sent a report rather than attended reviews:

"I mean the speech therapists, the doctor, the medical they all prepare written reports, they don't attend because of pressure of time. They don't attend the reviews but they always submit for the review..." (Ash-hill deputy, December'96)

The school seemed happy with this as an alternative because it gave some professional input. One can appreciate professionals, whether medical or social services, sending in reports rather than attending reviews, due to the aforementioned time and resource restraints. However, the participatory and discursive elements within a face to face meeting are lost, important elements when a young person's future is being discussed.

5.4.2 Issues Surrounding Coherence

5.4.2.1 Concurrent Assessments and Joint Reviews

The second theme considered is the idea of fostering a more 'coherent' approach to the transition of young people. Within the Code's guidelines for the initial transition review,

professionals, especially social services, are encouraged to consider combining young people's assessments, whenever possible:

> "The LEA ... must invite the social services department to attend the review so that any parallel assessments under the Disabled Persons Act (1986); the NHS and Community Care Act 1990; and the Chronically Sick and Disabled Persons Act 1970 can contribute to and draw information from the review process." (1994, 6:44, p.117)

This discussion of inter-agency working will explore concurrent assessments with regard to the Disabled Persons Act (1986), as this was the Act most frequently discussed. Two issues will be explored: firstly, interpretations of the 1986 Act and the Code's (1994) guidelines; and secondly, the practicalities of combining assessments.

Within sections 5 and 6 of the Disabled Persons Act (1986) the onus is upon LEAs seeking information from social services, whether or not a statemented young person is considered 'disabled' under the terms of the National Assistance Act (1948). LEAs are initially advised to seek this information at the earliest of the following:

> "(i). the time when they institute the first annual review of the statement following the child's fourteenth birthday, and

> (ii). any time following after that birthday when they institute a re-assessment of his educational needs ..." (1986, Part 1, section 5 (1))

Within the 1986 Act it is clear that social services are required to give an opinion at the time of the review after a young person's 14th birthday. But it does not specifically state that the officer should be present at that meeting to give the 'opinion'. However, the Code's guidelines more clearly suggest the idea of social services actually attending the first review after a young person's 14th birthday, in order to carry out, in parallel, the 1986 Act's assessment. Hence, within the 1986 Act and the Code's guidelines there is some ambiguity. This can leave room for different professional interpretations and prioritisations, especially if one considers the Code's status - professionals "have a statutory duty to have regard to" it (1994, Foreword, p.ii). "Regard" can be an evasive term.

Interviews with principle officers (1995) indicated that the focus authorities did not view the giving of an 'opinion' as an event that should occur within school review meetings. It was separate. In fact, the principle officer within Authorities 2/3 was very clear in her own mind that it was a detached "paper exercise", between the LEA and social services, one which did not involve the school, parents or young person. In addition she also stressed the fact that social services were not actually required, by the 1986 Act, to meet the young person:

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"Now, we can't go out and visit everybody and it's not appropriate that we do, 'cos it is a paper exercise. This is no requirement to go out and do it, there's no requirement to inform the individual or the parents..." (Principle Officer, Authorities 2/3, November'95)

Furthermore, how information was sought in order to give an 'opinion' similarly differed. Both principle officers (Authority 1, Authorities 2/3) acknowledged that information gathering had been erratic in the past (see Maddon, 1993 for a general discussion of problems within sections 5 and 6 of the 1986 Act). However, Authority 1's principle officer suggested information had been sought directly from schools, whereas Authority 2/3's principle officer sought information directly from the educational authority. The Laurels Head reiterated this:

"Well, I've never had anything to do with the '86 Act because how it's generally been um managed has been between officers of the LEA and officers of social services..." (January'97)

There was also vagueness and uncertainty about this procedure amongst some of the staff who organised transition reviews within three of the focus schools. The Cedar Drive Head and co-ordinators at Oaksmere and Beechview seemed unclear as to what exactly happened and how, or even if, 1986 Act assessments were conducted. However, it must be noted that, at Beechview and Oaksmere, co-ordinators rather than heads were specifically asked about the process at 14 years. The above conclusion does not refer to the Heads' knowledge of the process. It is perhaps not surprising that co-ordinators were vague about parallel 1986 Act assessments, given the procedures of social services. More importantly, it appears that the opportunity for a concurrent assessment at 14 years was not being utilised.

However, the timing of transition reviews within Authorities 2/3 is an important consideration. Transition reviews being conducted in year 10 (The Laurels, Cedar Drive and Beechview) means that many young people are 15 years at the time of their initial transition review. Hence, they are potentially beyond the remit of the 1986 Act's social services assessment at 14 years. This does not encourage a parallel assessment. Indeed, the timing of transition reviews in Authorities 2/3 led the principle officer to interpret the 1986 Act's role within these reviews rather differently. 'Opinion' giving and transition reviews were interwoven. Schools would use decisions made by social services prior to transition reviews as a guide when deciding which professionals to invite to a young people's transition review. This was the ideal, although she also acknowledged that it had not yet occurred:

"... schools would get the notification list and from that they could then identify those young people when they were holding a transition plan, at that meeting at 14, they could go into a process which invited the key agencies and they knew which ones to do that for. Unfortunately, it hasn't worked because the information is inaccurate" (Principle Officer, Authorities 2/3, November'95)

The 'opinion' giving assessment was a prelude to the transition review rather than occurring simultaneously. However, it was left rather unclear if the interpretation of the 1986 Act was at 14 years, because, within a draft protocol document produced (1994) the guiding age for the education department to notify social services was young people over the age of 13 years. Indeed, ambiguity seemed to pervade sections 5 and 6 of the 1986 Act. This made it difficult to explore.

Within Authority 1, the 1986 Act's social services led reviews, prior to 'disabled' young people leaving school were called 'Tom Clark' reviews. Within the study, knowledge of the 1986 Act was by no means consistent. For example, the Oaksmere co-ordinator may have been vague about 'opinion' giving at 14 years but she was very clear of social services role within 'Tom Clark' reviews. Furthermore, she felt that in the past, 'Tom Clark' reviews had been detached and distant from previous school reviews. In fact, she hoped that the Code's initial transition review would encourage more continuous and coherent social services involvement from 14 years to the school leaving ('Tom Clark') review:

"I think that's where transition planning's going to help because hopefully people involved in the Tom Clark reviews [social services] will have been involved much earlier on in the transition planning process ... At the moment it's almost as if the annual review process stops, they take over and there's not sort of, it doesn't compliment each other if you like." (Oaksmere Co-ordinator, December'96)

From a social services perspective, Authority 1's principle officer similarly acknowledged that 'Tom Clark' reviews had previously been ad-hoc and uncoordinated. On the other hand, a social work manager from a local CLDT felt that they had worked well in the past interpretations of their success varied. However, there was a shared belief that they could be improved and it is at this point, i.e., prior to school leaving rather than the initial transition review, that Authority 1 professionals talked of a parallel assessment. More specifically, they supported combining the last, school transition review with the 1986 Act social services' assessment:

" ... what we're going to try and do is dovetail the final school leavers transition plan with the Tom Clark review so that we don't have two meetings." (CLDT social work manager, Authority 1, December'95)

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On one level, it was recognised that merging the two reviews was both a rational and progressive act, providing an opportunity to share information and develop a single comprehensive, future plan. However, both Authority 1's social service professionals could see potential practical problems, such as, how to merge the two. The principle officer felt that there was a danger of ending up with two separately chaired sessions within the one meeting:

> " ... the sort of pessimistic part of myself thinks that we will do our assessment with our assessment instruments and the school will do whatever assessment they're wanting, but how we're ever going to get a united assessment I'm not sure ..." (October'95)

This would somewhat contradict the idea and purpose of holding a joint review. It was, however, a valid concern. Within the focus schools, The Laurels Head noted (1997) that he had been holding joint reviews, whenever possible, for the last 18 months, i.e. after the introduction of the Code of Practice. However, it appeared that these had evolved into two, somewhat separate reviews within the one meeting. More specifically, there was an educationally chaired agenda and then a social services agenda, where clear agency differences persisted. In fact, The Laurels Head saw this as an important factor to retain, i.e. a distinction between agencies. On the other hand, The Laurels Head also illustrated the practical advantages of merging two reviews as foreseen by Authority 1 professionals. Indeed, he highlighted the practical benefits of joint reviews both in terms of time and resource efficiency and effectiveness:

> "... it seemed wasteful in time, and parents, I would have imagined would have resented having to turn up at two review meetings within such as short space of time, so it seemed to be the natural thing to do." (The Laurels Head, January'97)

Furthermore, it is interesting to note that the focus of attention was upon time and resources rather than any potential advantages for young people, such as non-repetition of reviews. The idea of uniting the last school transition review and the 1986 Act social services led assessment was clearly an accepted idea within Authority 1. It was seen as a logical step that the Code of Practice encouraged. How it will actually develop remains to be seen, especially as the whole area of inter-agency working contains so many 'ifs' and 'buts'.

5.4.2.2 Forwarding Information

The final issue to be considered is the passing on of information, i.e. young peoples' latest review statement and transition plan, to their 'next step', post-school leaving. The co-ordinator at Oaksmere perceived the Code's guidelines as potentially advantageous, an opportunity to pass on, within the transition plan, essential information concerning a

student's needs to their next step. This was viewed as particularly relevant to young people with pronounced disabilities. However, the co-ordinator was also aware that, on a personal level, the administrative burden of this would fall upon her.

Furthermore, Beechview and Cedar Drive suggested that not all colleges/placements asked for a young person's transition plan. The co-ordinator at Beechview suggested that residential colleges did, but not all-local day colleges. Furthermore, the Cedar Drive Head noted a general reluctance by some to accept and value anything other than traditional measures of achievement:

> "... I think that raises questions about how the community, both the education community and the employment community actually views records of achievement. I've been heavily and centrally involved in that issue and I'm still a bit disappointed." (January'97)

This section has discussed two broad and complex themes: professional collaboration; and the pursuit of greater coherence. With regard to professional collaboration, it was clear that, on the whole, the focus schools would welcome greater collaboration and participation from social services at transition reviews. However, the all too familiar problems of over burdened social workers, in terms of workloads and time commitments were simultaneously recognised by schools. In terms of coherence, it was clear that efforts were being made to work more coherently, with the pursuit of joint educational and social service reviews. However, one of the clearest things to emerge was the lack of clarity concerning the development of concurrent assessments, such as those under the 1986 Act. Inter-agency working was a clearly valued and respected policy amongst the focus schools. It was one they were all keen to highlight that they were striving to achieve; however, problems and frustrations remained.

Conclusion

This chapter has explored the initial implementation of the Code's transition review at 14 years and the writing of a transition plan. The ideas and experiences of five different schools have been examined. Consequently, this is a predominately school based perspective. Young people and their family's perceptions will be explored within chapter six. The ideas and experiences emerging from the implementation of transition reviews and their plans has highlighted a range of important issues and questions which need be considered. These cover six key areas:

1. The idea of a multi-disciplinary transition plan to prepare for a young person's future was clearly welcomed and valued by all the focus schools. However, school organisers viewed the administrative demands placed upon them as burdensome (see also Dyer, 1995; Hornby, 1995; Fish and Evans, 1995; Lewis et al, 1996; Welding,

1996). In fact, this problem has recently been acknowledged by the Government within their Green Paper (1997, p.32, no.2). How far these issues will be addressed remains to be seen.

2. On one hand, the question - 'when to conduct transition reviews?' - clearly illustrated the importance of professional, organisational and logistical considerations. This was similarly demonstrated by Tisdall's study of FNAs within Scotland: "... meetings were fundamentally structured around professionals – and their bureaucratic and legal responsibilities - ..." (1996, p.29). On the other hand, school organisers also held very clear ideas concerning the 'best time' to conduct transition reviews for students. These were frequently premised upon ideas of young people's 'maturity' and their 'proximity' from school leaving.

3. The question 'who should write the transition plan?' has highlighted the importance of different interpretations between authorities and schools. The Code's guidelines advocate that LEAs should prepare transition plans. However, this situation raised a number of questions and issues for two focus school professionals within Authorities 2/3. Important considerations included some LEA representatives lacking detailed knowledge of young people and their family's circumstances, and how this effected their ability to deliver informed and meaningful transition plans. Other questions surrounded the 'ownership' of plans.

4. Participation as a concept and goal for young people was generally valued and pursued by all the focus schools. However, within this, differences emerged, frequently focused upon school based perceptions of 'appropriateness', according to judgements of 'age' and 'severity' of disability. These school ideas were often complex. Indeed, the level and form of participation inevitably varies amongst disabled young people. However, the issue of a young person's basic right to be present at their review meeting when 'their' future is discussed was emphasised (see Franklin, 1995; Lansdown, 1995 re children's rights).

5. Developing supportive and relaxed transition review meetings was frequently viewed as an important concern. However, it also raised some important questions, such as, 'who?' and 'how many?' should attend. These are issues that Tisdall (1996, p.20) has similarly discussed.

6. Interrelated to the above is the question of multi-disciplinary working, a concept and goal clearly valued by all the focus schools. However, in practice it appeared that social services participation was rather patchy and erratic. Whilst this was understood, it was also regretted as it inhibited the co-ordination of comprehensive

assessments and transition planning. Concurrent assessments and the 1986 Act proved difficult to explore due to different professional interpretations and levels of knowledge within the focus schools. However, the idea of joint, school transition reviews and 'Tom Clark' reviews was welcomed within Authority 1, even though they raised some practical and organisational issues of concern.

Chapter 6 - Leaving School Experiences: Young People And Their Parents

Introduction

Chapters four and five focused upon professional evaluations within institutional contexts. They examined policies and provisions provided within the focus schools when preparing young people and their parents for the transition from school and the movement towards adulthood. Within chapters six and seven the focus will turn to the personal evaluations and experiences of a sample of young people and their parents from the focus schools (see Table 15 and Table 16). These experiences were gleaned at two key points in time. The first was pre-school leaving with interviews taking place between April to July 1996, up to four months before the young people left school. The second was within the first 12 months of leaving school, either January to February or April 1997. As noted in chapter three, pre-school leaving interviews took the form of individual, in-depth recorded interviews. The second phase, post-school leaving interviews covered a representative sub-sample of eight young people and seven sets of parents. In addition, the second phase included telephone interviews with three young people and seven sets of parents, 10 to 12 months after their initial interviews. One family did not have a telephone, so an open-ended set of follow-up questions was sent. Due to a language barrier within one family (Fiona's), interviews were conducted with the young person's elder sister rather than her parents. One young person (Ellen) lived with foster parents whilst her parents were out of the country. Interviews were thus conducted with her foster parents. Interviewing the young people and their parents at two key points in time provides insights into the transition process, both in terms of leaving school and, more broadly, the movement towards adulthood. Furthermore, it also provides an ongoing assessment of the process of transition and its procedures rather than a static snapshot. The interviews provided an opportunity to draw upon the benefits of hindsight, develop comparisons and also explore any progress that was made as the young people left school and moved onto their next step. [See Appendix 1 for family pen portraits]

Authority 1 (Metropolitan)		Authority 2	Authority 3 (Unitary, detached from Authority 2 April'96)	
Oaksmere	**Ash-hill**	**Beechview**	**The Laurels**	**Cedar Drive**
*Susan *(19)*	*Laura *(18)*	*Ellen *(19)*	*Eric *(19)*	Bob *(16)*
Jason *(19)*		*Ian *(18)*	Julie *(19)*	*Luke *(16)*
		Louise *(18)*	*Janet *(19)*	Geoffrey *(16)*
		Lisa *(18)*		
		Linda *(17)*		
		*Charisa *(16)*		

* Young people reinterviewed face to face.

Table 15: Young People Interviewed (Age at School Leaving)

Oaksmere	Ash-hill	Beechview	The Laurels	Cedar Drive
*Susan's Mother	Laura's Father	*Ellen's Foster Mother	*Eric's Parents	Bob's Parents
Jason's Mother	Steven's Mother	*Ian's Father	Julie's Father	*Luke's Parents
Fiona's Sister		Louise's Mother	*Janet's Parents	Geoffrey's Mother
		Lisa's Parents		
		Linda's Parents		
		*Charisa's Parents		

* Parents reinterviewed face to face.

Table 16: Parents Interviewed

This chapter will continue to explore and evaluate institutional and professional policies, practices and provisions during the process of leaving school. It will be divided into four broad sections: firstly, leaving school - feelings and expectations; secondly, evaluations of school preparations, particularly, information and support; thirdly, young people and their parents' participation within the leaving process; and finally, health and social service transitions. The first three sections will focus upon young people's and their parents' experiences of transition in terms of leaving school preparations. The fourth and final section will broaden the analysis to explore welfare transitions: more specifically, the role, support and type of service provided by health and social service professionals as the young people prepare to leave school and move onto adult services. Chapter six's four broad section headings also provide an opportunity to consider four of McGinty and Fish's (1992, pp.92-99) evaluatory transition criteria, namely: the

availability of information; participation and choice making; family involvement; and the issue of coherence.

6.1 Leaving School: Feelings and Expectations

The transition from school can be approached and experienced in many different ways and from numerous perspectives. Within this section the importance of feelings towards, and young people's differing approaches to, the prospect of leaving school and the transition to their next step will be explored. More specifically, two areas will be discussed: firstly, leaving school and feelings about 'moving on'; and secondly, the young people's hopes and expectations for, and initial outcomes from, specific school leaving preparations and their next step transitions.

6.1.1 Leaving School Feelings

.Leaving school and moving on can be an emotional time for both young people and their parents, especially for young people who are leaving a school which they have attended for many years. This was clearly the case for young people at Oaksmere, all of whom were 19 years old and had attended from the age of four or five years. Hence, their experiences of different forms of provision were almost non-existent. Consequently, it is important to stop and consider the feelings of both young people and their parents as they take this crucial step within the life-course.

6.1.1.1 Young People's Feelings

The prospect of leaving school frequently raised mixed emotions. For many, these involved sadness when looking back, but happiness when looking forward to the next step. Feelings of sadness were expressed in terms of 'loss'. Seven young people highlighted feelings of regret at the thought of loosing valued social relationships, especially those of peers and school staff:

> **Janet**: "Me friends won't be there" (The Laurels, Pre-school leaving)
> **Charisa**: "Lose the staff" (Beechview, Pre-school leaving)

For these young people, leaving school raised important questions concerning, feelings and fears of losing emotional support and security. Leaving friends and teachers can be a traumatic experience. Thus, it is not surprising that one of the young people (Luke) expressed his feelings in terms of fear and anxiety:

> **Luke**: "Worried and (pauses)"
> **Researcher**: "What are you worried about, is there anything in particular?"
> **Luke**: "Well, about, about um leaving all the teachers and that." (Cedar Drive, Pre-school leaving)

On the other hand, in a similar vein to Hirst's (1985, pp.143-144) study of physically disabled school leavers, feelings of happiness at the prospect of leaving school were articulated by the majority. These were expressed in many different forms. Two young people's (Laura and Geoffrey) immediate response was to view leaving school as a welcome break and rest from life's routine - a holiday. Taking a somewhat longer-term approach, some associated 'moving on' with 'progress' (Luke, Ellen and Ian). Here, leaving school was clearly more than a few weeks 'holiday'. However, leaving school feelings were not by any means always straightforward. Laura felt confusion and conflicting emotions, pushed and pulled in different directions:

> **Laura**: "I don't want to leave school but on the other hand, I do wanna leave school" (Ash-hill, Pre-school leaving)

The five young people who communicated with the aid of symbols appeared, on one level to have rather more straightforward emotions. For example, four chose the 'happy' face and one, the 'OK' face to describe their feelings towards leaving school. It was thus generally viewed and approached in a positive manner. However, one cannot presume that the young people had not enjoyed school. They made it clear with the 'happy' face that they had and did. Furthermore, the idea that their emotions were more clear cut and straightforward may well have been a result of communication difficulties (see chapter three). However, the young people's parents expressed different interpretations of the depth of feeling that they perceived their son or daughter to hold. On one hand, two sets of parents (Julie and Eric's) rejected the idea of their son or daughter having complex emotions and a clear understanding of the situation. Indeed, their feelings were presented as rather one-dimensional. Eric's mother said for instance:

> **Eric's Mother**: "He knows he's leaving school and he wants to go to college, but I don't honestly, honestly think that he's aware of what it really, really means..." (The Laurels, Pre-school leaving)

Conversely, two other sets of parents (Susan and Jason's) suggested that their son or daughter's feelings had greater depth. Susan's mother suggested that her daughter had experienced a degree of understanding on leaving school, noting her sadness and reasoning:

> **Susan's Mother**: "Well, she said she was sad, you know about leavin' you know, she said everyone's goin' to miss her" (Oaksmere, Pre-school leaving)

This interpretation of Susan's feelings initially stands in contrast to Susan's own expression, as she pointed to the 'happy' face. However, this difference may be a result of Susan's interview taking place a few weeks after she had left school. During the interview, questions were located predominately within the present. Consequently, these were her current feelings rather than her feelings, perhaps, at the actual time of leaving school. Feelings can and frequently do change within short periods of time. However, this does re-emphasise an inherent methodological challenge: namely, trying to explore feelings that are frequently fluid and complex, with symbols, which are invariably somewhat summative and static.

6.1.1.2 Parents' Approaches

Within the sample the vast majority of parents viewed their son's or daughter's school positively, either for educational, social or care reasons. As a result of this, pre-school leaving, there was a general air of sadness amongst parents. Firstly, there was recognition that it was the end of an era; secondly, there were feelings of 'loss'. Within the former, three mothers from both authorities (Bob's, Geoffrey's and Susan's) highlighted that the end of school marked the closing of an important chapter within their own lives. This was succinctly summarised by Bob's mother as she attended her last harvest festival at Cedar Drive:

> **Bob's Mother**: '...harvest festival, October and I said 'well, that's the last one'..." (Pre-school leaving)

In a similar manner to the young people, parents from both authorities expressed feelings of 'loss'. However, approaches differed. For example, Fiona's family from Oaksmere focused upon the potential loss of care for Fiona, whereas Julie's father from The Laurels highlighted a social 'loss' for himself as a parent:

> **Julie's Father**: "I'm sorry to see her leave school. I've made lots of friends there as well; other parents and the staff. I consider them friends as well as professionals. So yeah, that's a bit of a wrench really but it's just progression, it has to happen." (The Laurels, Pre-school leaving)

On the other hand there was also an element of pragmatism and progression for Julie's father. It was accepted and acknowledged that leaving school was both an inevitable factor of life and also that it was time to move on from The Laurels:

> **Julie's Father**: "I think they've done a reasonable job as far as they can go. But I think Julie is on a bit of a plateau now... which is why I'm quite pleased it's time for a move to college, 'cos I feel that's what Julie needs, another stimulant to get her moving... I think they've done what they set out to do but they can only go so far." (Pre-school leaving)

Sentiments of pragmatism and/or progression were similarly recognised either pre or post-school leaving by six further sets of parents. Some parents took a very practical approach to leaving school. This was aided by the fact that many parents were extremely relieved that further or continuing education opportunities existed, there was something to move onto. For example, three sets of parents stressed that they wanted their son or daughter to remain in education for as long as possible, due to their belief that it was the best place for them. This feeling arose in part from wider parental concerns surrounding the issue of future post-education daytime activities. On the other hand, four sets of parents acknowledged with relief that there were 'some' options but they were rather more critical of them. In particular, they highlighted that these options were rather narrow and limited in scope. For example, Steven's mother, drawing upon past family experiences, was critical of what she considered to be inadequate provision of support for disabled young people within training schemes:

> **Steven's Mother**: " ...it's t' same with like training schemes, I mean they have someone like in charge of them, these training schemes but it's obvious that they don't have time, you know, to show them what to do. Er where my son was there was about 22 on t' scheme and there was only him with special needs and he just didn't have t' time to keep an eye on what were happening, bullying and what have you, just don't have t' time." (Ash-hill, Pre-school leaving)

However, in contrast, Ian's father was extremely positive about the support that his son had so far received whilst training on a Barnardos catering scheme:

> **Ian's Father**: "Well, it's actually geared for him, every individual at Barnados, the course is geared for them as we've found out... it's geared on a level for Ian, for specific individuals, he can go at his own speed, his own time." (Beechview, Post-school leaving)

This diversity amongst parental experiences re-emphasises the variability in quality within training schemes (see also chapter four). However, it must be recognised that the Barnardos scheme was predominately for young people with learning disabilities. Hence, there were elements within the scheme and associations of it being perceived as 'special' rather than mainstream.

6.1.2 Preparing For and Moving Onto the Next Step - Young People's Hopes, Expectations and Initial Outcomes

The significance of work experience and college link courses as important components within school leaving preparations was highlighted within chapter four. Amongst those who had had an opportunity to participate within work placements or college link courses, experiences were generally presented as pleasurable. Seven young people with pronounced disabilities, either physical or learning, did not undertake work experience.

Of those who did (nine), their enjoyment was clear. They frequently became animated during discussions. Furthermore, three young people were already looking forward to doing more work experience within their next step after leaving school. Only a small minority (two young people) mentioned in passing that their placements had, at times, been rather boring and repetitive. Work experience was thus viewed positively by the majority of the young people. This was similarly concluded within Knox and Parmenter's earlier Australian study (1990, p.53). In addition, out of the 13 young people who had attended college link courses only one young person (Ian) indicated that he had not really enjoyed the experience. Here, his negative feelings arose, in part, from the idea that college was too big for his liking. This emphasised the contrast in size to his small, special school. Armed with these positive experiences it is unsurprising that the majority of the sample was looking forward to their next step and presented the move in a positive manner. In fact, out of the 15 young people interviewed, only two appeared to harbour any doubts or uncertainties.

6.1.2.1 Valued Aspects and Future Expectations

Within the sample many different reasons were given by the young people as to why they valued their work experience, college links or next step choices. In the latter, there were also clear expectations. These can be grouped into three broad categories: educational; social; and "maturational" factors (Miller et al, 1991, p.18). The first revolved around ideas of doing new things, learning new skills or conversely continuing with familiar subjects. Four young people highlighted this as a reason why they valued the college link courses that they had undertaken and six looked forward to their next step as a potential learning opportunity. This was most clearly demonstrated by Janet and her expectations for residential college:

> **Researcher:** "What do you think will be the best thing about going to college?"
> **Janet:** "To learn" (The Laurels, Pre-school leaving)

The second category (social) encompassed opportunities to meet people and develop friendships. Amongst school leaving preparations, social opportunities evolving from work experience or college link courses were noted by three and six young people respectively. Within college links it was either the opportunity to see old friends who had previously left the focus schools, or, for two young people from Authority 1, an opportunity to meet and make new friends. This prioritisation of making 'new' friends re-emphasises the policy of special schools within Authority 1 sharing college links (see chapter four). On one hand, this policy presented the young people with an opportunity to extend their social network. However, it was largely limited to the special school sector. Similarly, three within their next step choices stressed developing friendships both old and new as an expectation. There was also excitement for five young people

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from Authorities 2/3 at the prospect of 'staying over' at residential college/school. A factor Luke clearly illustrated:

> **Luke:** "I haven't stayed overnight in a school before, it should be quite an experience." (Cedar Drive, Pre-school leaving)

Hence, Luke valued the social aspect of residential school. There were also wider associations of independence, namely staying away from home. Furthermore, Janet associated this with feeling 'more grown-up':

> **Researcher:** "Will you like the aspect of staying over night?"
> **Janet:** "It's more grown-up to go."(Pre-school leaving)

Janet's comments highlight important expectations. She associated staying overnight at residential college with being 'more grown-up' and 'adult'. These indicators suggest hopes for a changing status.

This links to the third and final factor, "maturational" issues, described by Miller et al (1991, p.18) as confidence boosting, feeling like an adult or providing opportunities for independence. On one hand, it must be acknowledged that "maturational" factors were not experienced or expected by all the young people. However, there was a small but significant number within the sample who did associate either college link courses, work placements or their next step option with increasing independence and a more independent status. This recognition and valuing of independent opportunities was expressed in terms of either felt experiences within college links (four) and work placements (three), or expecting potential opportunities within next step options (four). Two common themes were raised: firstly an opportunity to learn and develop independence skills, as Luke highlighted:

> **Luke:** "Because I can start new lessons about being independent." (Pre-school leaving)

or secondly to gain greater personal autonomy. This was clearly illustrated by Janet, via her work placement that had enabled her to practice independent travel skills:

> **Researcher:** "Who did you walk with?"
> **Janet:** "First I went with my teachers and then I went on my own."
> **Researcher:** "Oh yeah, and did you like going by yourself?"
> **Janet:** "Yeah."
> **Researcher:** "Why?"
> **Janet:** "It's more grown-up to go." (Pre-school leaving)

In addition, one could also argue that college links and work placements have important "maturational" associations as they theoretically provide an opportunity for young people to experience a temporary change of status: from being a 'pupil' at school, to

college and 'student' or work place and 'worker' status. However, one must recognise, as Todd (1995) argues, that these experiences were frequently highly managed and supervised or selective in view of who was considered 'appropriate'. In terms of actually recognising this association between specific school preparations and the transition to 'student' or 'worker' status, two young people come to the fore (Luke and Ian): in particular Luke, as he clearly recognised their potential value in aiding his transition from school to college or from school to work. This was expressed most forcefully with regard to work experience:

> **Luke**: "It give me some time to get out of the classroom environment and go into work surroundings and it teaches me about jobs outside the classroom." (Post-school leaving)

Luke was thus perceptive of the wider aims and implications of Cedar Drive's preparations. More specifically, he associated these preparations with 'moving on' into a more 'adult' world and thus by implication a changing social status. However, one must recognise that Luke stood somewhat alone within the sample of young people. The most common reaction was one premised upon enjoyment and thus a much more immediate level.

From a parental perspective, only four sets of parents made a point of noting the value of college links as a means of preparing for school leaving and moving towards 'adulthood'. However, work experience was more clearly valued (a similar finding to Gallivan-Fenlon's (1994, p.16) American study) and recognised as a potential preparational tool. Lisa's mother indicated the opportunities she felt work experience offered: for example, her daughter experiencing a 'real work setting' and developing social and independent 'adult' life skills:

> **Lisa's Mother**: "Well, she knows what it's going to be like when she goes t'work. When she does get a job and um mixing with normal people, grown-ups..." (Beechview, Pre-school leaving)

6.1.2.2 Initial Outcomes

Pre-school leaving the vast majority of young people thus viewed their impending transition from school and proposed next step positively. As we have seen, a small but significant number looked towards and valued the independence opportunities that they felt would ensue from moving onto college or training. Six to 12 months later, having made the transition from school, this feeling of optimism was still found to be strong, perhaps even stronger amongst some of the young people. For example, of the 11 reinterviewed, nine made it clear that they felt the next step was better than their old school. They did not want to go back, unless it was for a visit. Furthermore, of the eight

young people reinterviewed in-depth and face to face, five felt that they had become more independent since leaving school and moving onto their next step. Charisa, for example, stressed how residential college had encouraged her to do more things for herself:

> **Researcher**: "What do they encourage you to do at college?"
> **Charisa**: "To get myself undressed on the top half." (Beechview, Post-school leaving)

This was a change that was welcomed by these young people and was similarly reiterated by many of the parents. For example, of the 15 reinterviewed, 12 felt that their son or daughter had progressed since leaving school, whether educational, socially or in terms of independence.

This positive evaluation of the movement to college was not however shared by all. For two young people (Ellen and Laura) the transition to college had been a rather negative and unrewarding experience. Ellen, for example, pre-school leaving had been very optimistic and positive about the prospect of going to college and the independence that it may bring. However, when reinterviewed, it was clear that Ellen had found her special course within a local, mainstream college extremely difficult:

> **Ellen**: "I think some of the lessons are quite hard for me and I find it difficult to keep up." (Beechview, Post school leaving)

This led to plans for Ellen to leave the course after one rather than the customary two years. Feeling comfortable and at ease with a chosen college course is thus an important consideration within the transition from school. Ellen's transition is, of course, only one young person's personal experiences. However, the importance of being comfortable and at ease does raise wider questions and issues, such as: 'support', professional advice, courses available to disabled young people, other people's expectations and, perhaps most importantly, ideas of 'appropriateness'.

This sub-section has demonstrated that the majority of the sample clearly valued their post school, 'next-step' option, as a positive and progressive step. They valued college links and work experience opportunities more than the small number of physically disabled young people who had undertaken them in Hirst's (1985, p.145) earlier study. Indeed, both specific school leaving preparations and next step options were valued for the educational, social or "maturational" opportunities that they presented or which they may procure in the future. More specifically, "maturational" factors were closely interwoven for a number of the young people with expectations of opportunities for greater personal self-development, especially increasing independence and autonomy. Taking this a step further, recognising and appreciating the wider aims of school leaving

preparations and their association with a more 'adult' environment and a changing social status was not a typical response amongst the young people. However, Luke's perceptions, although a minority insights should not be ignored as they highlight Cedar Drive's wider preparational aims.

6.2 Evaluating Information and Support

Within this section the focus turns to the young people's and their parents ideas, experiences and expectations of advice and support received during leaving school preparations. Here, a key question is - did the young people and their families feel that they were, or had been, well supported and advised? Beginning to unpack this, one needs to consider 'what' sort of advice and support was received, wanted or indeed expected by the young people and their families. This is an extremely broad area. Consequently, this analysis will concentrate upon two specific spheres: firstly, the focus schools, their general leaving preparations and support mechanisms; and secondly, the careers service, its role within the focus schools and advice/support provided.

6.2.1 Focus School Preparations

6.2.1.1 Timing of School Leaving Preparations

The timing of school leaving preparations is an important issue. As we shall see, inappropriate timing can cause additional stress and anxiety within what is an already stressful time. In fact, parental concerns evolving from "last minute transition planning" have been highlighted by Gallivan-Fenlon (1994, p.16). Within this study, parents highlighted a range of opinions. Some parents were ambivalent, whereas others expressed a more forceful opinion. For example, a number of parents felt that their school had got the timing right. Susan's mother indicated her satisfaction:

> **Susan's Mother**: "No, it's about the right time, a year or so when they leave, you say, 'well, you've only got one more year'." (Oaksmere, Pre-school leaving)

This was later reinforced by the fact that Susan had indeed gained a place at the college of her choice. Practical success thus helped to some guide parents' evaluations.

In contrast, a significant number of parents (six) were more critical of their school's timing and felt that earlier preparations would have been advantageous. This was most clearly demonstrated in the case of Janet. Between leaving The Laurels and starting at Willow Lodge, a residential college, Janet had experienced a three to four month 'gap' at home. This 'gap' was blamed upon a late application to college where there was an 18-month waiting list. Within both interviews Janet's parents were critical of the timing

of The Laurel's school leaving preparations. More specifically, they felt that this 'gap' could have been avoided if preparations had been undertaken earlier:

> **Janet's Mother**: "Janet's name should have been on that list for college 12 months earlier and we wouldn't have had this three or four months gap, you know, she could have gone six months before. It was bad planning on someone's part ... um we don't know what's the right time to sort of start approaching places like Willow Lodge, um, initially it should have been school." (The Laurels, Post school leaving)

In fact, the importance of early investigations was stressed by three sets of parents from Authorities 2/3 (Julie, Eric and Charisa's). All three were looking towards residential college as the next step option. Indeed, these parents emphasised that they had started investigations prior to their school's preparations. Furthermore, they advised other parents to do the same, i.e. begin the process as early as possible.

On the other hand, early preparations cannot and do not thwart the anxiety that bureaucratic delays and decision making can bring. Chapter four raised the issue of late funding notification (FEFC) bringing additional anxiety for parents. Within the sample, two of the above parents (Charisa and Eric's) confirmed this:

> **Charisa's Father**: "Yeah, it was a real sort of eleventh hour"
> **Researcher**: "How did that make you feel?"
> **Charisa's Father**: "... I must admit it was hard, it was getting a bit of a knife edge situation but when we got it, um, the funding it was straightforward then..." (Beechview, Post school leaving)

This emphasises that school-leaving preparations operate within a much wider socio-economic sphere. Parents as individual actors may start the process early but ultimately they can become powerless within wider institutional and bureaucratic procedures.

6.2.1.2 Accessing Information

The importance of accessible information has been frequently raised within the literature (McGinty and Fish, 1992; and Gallivan-Fenlon, 1994; Orlowska, 1995). Before one can explore how parents regarded the information that was available to them it is important to examine how parents perceived their own role within the leaving process. This influenced how parents approached the collation of information. Amongst parents there were two broad approaches. Those parents who perceived their role as 'active' highlighted the importance of seeking out information themselves. Those who perceived their role as more 'reactive' were in turn more prepared to be professionally guided. Obviously, some parents exhibited elements of both roles; however, there was a broad divide between these two sets of parents. For example, within pre-school leaving

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interviews five parents from Authorities 2/3 highlighted an active and enquiring role. Geoffrey's mother, in particular, attached almost a sense of 'duty':

> **Researcher**: "How did you find out what there was really, you know, what was available for Geoffrey?"
> **Geoffrey's Mother**: "I worked very hard on it..." (Cedar Drive, Pre-school leaving)

Furthermore, it is unsurprising that three of these 'active' parents were Charisa's, Eric's and Julie's who had begun preparations at an early stage.

In contrast, the remaining 12 sets of parents took, to varying degrees, a more reactive role. They looked to the school for their information and guidance (see also Gallivan-Fenlon, 1994, p.18). Four out of five parents from Authority 1 adopted this approach. Here, it was clearly regarded as the schools' role to provide information for parents rather than for parents to actively seek it out for themselves. Underpinning this approach there was a strong belief in the efficacy of professional knowledge. Pre-school leaving Fiona's sister demonstrated this:

> **Fiona's Sister**: " ... it was them [the school] who suggested the King Street centre, that it was the most suitable for her, so, and they pointed out all, the facilities that would be there for her. So we're quite pleased with the way that they've kind of directed us to making that decision." (Oaksmere, Pre-school leaving)

Different parental approaches were demonstrated most clearly at Oaksmere and The Laurels, two relatively comparable schools within contrasting authorities. At Oaksmere (Authority 1) parents appeared to be more dependent upon the school for information, whereas two parents from The Laurels (Authority 3) viewed their role as much more active and independent. Within this school and authority difference one must consider the role of residential college. Parents from Authority 1 did not regard this an option. Conversely, parents at The Laurels did. One could also consider class differences. As we saw in chapter four, the Head at Oaksmere highlighted the poverty of many families within his school, whereas the Head at The Laurels noted a much more diverse socio-economic school population. Socio-economic differences can impact upon parental role perceptions and, hence, attitudes and action taken, from knowledge and confidence levels to more practical aspects such as, the ability to visit geographically disperse colleges. On the other hand, role perceptions were not always static. For example, during a telephone reinterview, Fiona's family had started to reassess their 'reactive' role and foresaw a more 'active' role in the future as their confidence and knowledge increased.

The above parental perceptions obviously filtered down into how parents both accessed information and evaluated what they received. Pre-school leaving, the most frequently mentioned source of information (10 parents) was the focus schools. Here, parents generally felt that their school had provided good or adequate post-school information within an informal and relaxed atmosphere. As one would expect, parents who took a more 'reactive' role, such as those from Oaksmere School, highlighted this area and felt that the information provided had been valuable.

On the other hand, a small but diverse range of parents from both authorities (five) felt, to varying degrees, that their schools could have provided more information prior to choice making. They felt ill informed and thus unprepared. Two general problems were highlighted: the time involved; and accessing information. Amongst these parents it is interesting but not unsurprising to note that three took a more 'active' role. Within the former problem, two sets of parents (Julie and Charisa's) felt that the time and effort involved in seeking out information had personally been a burden upon them. The second problem was knowing 'where' and 'how' to tap into information. Two sets of parents (Geoffrey and Luke's) stressed that they would have liked more information upon post-school options to be collated together. For Luke's mother this conclusion emerged retrospectively as she looked back upon the information Cedar Drive had provided during the preparational period. Ultimately, she felt it had been rather ad-hoc:

> **Luke's Mother:** " ... you hear things through the grapevine and you realise that you might have had a bigger choice than you were actually given. I think someone ought to get their act together and get it all, you know, all of the colleges, all of these special schools, all of these units which are throughout the country and you have a list of what is available throughout the country, rather than what you're told and then may be later find out that there was something else somewhere else but you didn't know." (Post school leaving)

Geoffrey's mother from Cedar Drive similarly raised this idea of a centralised list:

> **Geoffrey's Mother:** "Just, I would think more information in directory form, not just little, you know, thousands of leaflets in file boxes and you don't know where to start." (Pre-school leaving)

For these two Cedar Drive parents a more centralised system of information was seen as advantageous. On the other hand, this needs to be balanced against the danger of overloading parents with too much information. For example, Charisa's parents had initially looked at a directory of colleges and felt overawed. The need to clarify 'where to' seek out information and present this is an accessible, collated but not overpowering form is an important issue to consider (see also Orlowska, 1995, pp.444-446 for a discussion of information accessing problems).

This assessment has so far focused upon 'formal' sources of information. However, 'informal' sources can and do play an important role, as Geoffrey's mother noted. Talking to other parents, especially, those who have already experienced leaving special schools was emphasised. In fact, one set of parents from The Laurels (Eric's) felt that this was an area which could be developed and used more productively to inform parents. For example, having an evening when past students and parents came to share their experiences and knowledge:

> **Eric's Father**: "Possibly invite some parents of children who had already left back because we actually know somebody and we contacted them, but again, we did that off our own back." *[Later]* "I'm sure a lot of parents don't get the advantage of that, 'cos they just don't know, they don't know anybody to ask." (The Laurels, Pre-school leaving)

6.2.1.3 School Support

Information was by no means the only recognised form of support during this period. The importance of personal support emerged as a valued factor for both parents and young people within pre-school leaving interviews (see also Whitney-Thomas and Hanley-Maxwell, 1996, p.83). This support frequently took the form of a key person with whom they identified, they could talk to or with whom they were comfortable. At The Laurels and Oaksmere, class teachers were central. Here, both young people and their parents emphasised that the person with whom they could talk, gain advice and support was 'their' class teacher. For those attending Beechview, Ash-hill or Cedar Drive where numerous teachers were involved within school leaving preparations, it was either form tutors or careers teachers who emerged as key contacts. For the vast majority of parents, assessments were positive. In fact, only one parent from Ash-hill felt that the school careers teacher did not always have enough time for parents. However, this highlights a wider issue, namely workloads and responsibilities. Furthermore, the careers teacher at Ash-hill himself recognised this as a potential issue - having too much to do and too little time to do it within.

In addition, although the sample had only one ethnic minority family (Fiona's), the potential importance and value of an interpreter during leaving preparations was noted by Fiona's sister. Here, an interpreter was viewed as essential when English was a family's second language:

> **Fiona's Sister**: "Well, it's the um, interpreter there ... basically, yeah, she's been the, she's been the enormous help ... because I mean, obviously um, I can't be there all the time when they *[parents]* go to meetings and she has been a great help." (Pre-school leaving)

In all five schools the 'open door' policy was generally viewed positively by parents. In fact, the vast majority of parents felt that they could either just ring up the school or pop in any time they wanted. However, in terms of school-home contact at Beechview (a residential school, Monday to Friday) there was a rather more mixed response from parents. Within residential schools there is, as Barnes (1991, pp.42-43) and Fish and Evans (1995, p.79) have noted, the ever-present danger that geographical distance can reduce contact between home and school. Of the six parents interviewed at Beechview, two (Linda and Charisa's) felt that, especially in the past, there had been a lack of school-home contact. On the other hand, this was felt to be improving, as Linda's father demonstrated:

> **Linda's Father**: "Yeah, a lot of information don't come home as what's happened, but it's just getting back to that now, I think it is, 'cos they've just started ringing us and such..." (Pre-school leaving)

Exploring parents' evaluations of school support during leaving preparations has highlighted the importance of initially understanding parents' perceptions of their own role during this period. Parents' ideas can and do have an important effect upon 'how' they evaluate their school's preparations, especially experiences and expectations of information and support. Within the sample many parents were generally satisfied with the support provided. However, a significant number of parents felt that the timing of next step preparations was an issue of concern. This re-emphasises the importance of early preparations as noted in past literature (Hirst, 1985; Fish, 1986; McGinty and Fish, 1992; Blalock and Patton, 1996). Furthermore, the issue of accessible information produced two parental suggestions, emphasising the importance of 'how' information was presented to parents and 'by whom'.

6.2.2 The Careers Service

6.2.2.1 Young People's Perceptions

Information on young people's perceptions of the careers service is largely based upon pre-school leaving interviews. However, further advice at college was expected and welcomed by a number of the young people and their parents.

The importance attached to the role of the careers adviser varied. For those who communicated with the aid of symbols, knowledge of their school's allocated careers adviser seemed rather vague. When future choices and sources of advice were discussed it was their class teacher who seemed the most prominent. This mirrors a tendency at The Laurels and Oaksmere to place relatively less emphasis upon careers advisers meeting young people individually (see chapter four). However, one must remember

that communication was dependent upon symbols and the young people's familiarity with some symbols may have been a factor within their choice.

Of those who verbally answered questions, six out of nine young people within Authorities 2/3 not only remembered meeting their careers adviser but also viewed that meeting(s) as an important opportunity to talk about the next step and leaving school. Careers advisers within Authorities 2/3 were recognised as both familiar and significant professionals within school leaving preparations. In fact, they were valued for both their knowledge (four young people) (see also Armstrong and Davies, 1995, p.73) and, on a personal level, as someone they could talk to and who listened to them (five young people). Indeed, three of these (Luke, Ian and Lisa) prioritised the careers adviser as one, if not the most, helpful person in aiding them to think about leaving school. Lisa explained:

> **Researcher**: "Who do you think's been the most helpful person when you've been thinking about leaving Beechview?"
> **Lisa**: "Careers adviser." (Beechview, Pre-school leaving)

In stark contrast to this, the one young person who verbally answered questions within Authority 1 (Laura) appeared to be much more vague:

> **Researcher**: "Do you have a careers adviser who comes into the school, you know, someone who's not actually a teacher at the school but comes and talks about careers?"
> **Laura**: "I think so"
> **Researcher**: "Have you seen this person at all?"
> **Laura**: "No"
> **Researcher**: "Have they ever come and talked to the class at all?"
> **Laura**: "Not that I know of, no"
> **Researcher**: "Would you have liked to have spoken to the careers person?"
> **Laura**: "Yeah"
> **Researcher**: "Why?"
> **Laura**: (pauses) "To see what kind of jobs they can offer to us." (Ash-hill, Pre-school leaving)

The above conversation suggests that Laura perceived a potential value in meeting the careers adviser. But the fact that Laura cannot remember seeing her careers adviser or being given an opportunity to do so raises questions about both careers service provision and its impact upon young people. However, one cannot really make comparisons to the young people within Authorities 2/3 or to careers service provision, as only one young person verbally answered questions within Authority 1. Laura could have been a-typical of her fellow peers at Ash-hill School. Furthermore, as we saw in chapter four, the careers co-ordinator at Ash-hill presented a very different perspective. He emphasised the school's close links with the careers service and regular

opportunities for the young people to see the careers adviser. Consequently, we thus have two very different perspectives and interpretations of the same school leaving process. Two parents from Ash-hill further exemplified this conclusion. Laura's father, similarly suggesting that he had not seen a careers adviser at school, whereas Steven's mother recounted attending a careers evening at Ash-hill with the careers adviser present. However, the important point to note is that there was a young person who felt she lacked both information on the careers service and personal contact with a careers adviser.

6.2.2.2 Parental Evaluations

For the majority of parents, the careers service had played a role within school leaving discussions. In fact three quarters of parents talked specifically and clearly of having had contact with a careers adviser at one point or another. However, evaluations of this input, its degree or direction varied. Parental evaluations were frequently not clear cut bur rather ambiguous or double edged. For example, seven sets of parents expressed concerns or criticisms. On the other hand, a number of these parents were full of praise for the careers service. Positive evaluations (for six sets of parents) focused upon advice that had been received. For example, Ian's father viewed the careers adviser as both an important and pro-active source of help:

> **Ian's Father:** "The careers adviser as far as I was concerned, was extremely good." (Beechview, Pre-school leaving)

On the other hand, a number of criticisms and concerns were simultaneously raised by some of the parents. These can be divided into two broad issues: 'quality' and 'quantity'. The former (quality) was highlighted by three sets of parents (Julie, Steven and Luke's). For example, Luke's mother was concerned that her son had sometimes received 'unrealistic' information that she felt was not always 'appropriate':

> **Luke's Mother:** " ... but from what Luke has brought back from the careers fairs that he's been to, the exhibitions, I wasn't overly impressed with it, 'cos they were giving him information on careers really which are way beyond what he's capable of." (Cedar Drive, Pre-school leaving)

This was felt to be dangerous as it could lead to 'unrealistic' hopes and aspirations. Brogan and Jennings (1993, pp.79-80) have also raised this issue. Two sets of parents (Charisa's and Lisa's) highlighted the issue of 'quantity'. Here, it was suggested that they would have welcomed either more information or more time from careers advisers. 'More' rather than less was seen as advantageous. For example, Charisa's parents stressed that they would have liked more information, including information from the careers service at an earlier stage:

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> **Charisa's Mother**: "I just think it would have been nice to have something, you know, at the beginning, sort of last year, you know. We could have talked to someone about careers and what was available, maybe we just started a bit too soon and got going on our own..." (Beechview, Pre-school leaving)

This suggestion, as we saw in the previous section, links into their wider concern for early school leaving preparations.

The above parents may have wished for specific improvements in order to procure what they felt would be a more supportive service. However, the basic role and input of careers advisers within school leaving preparations was recognised and valued. There was a general desire for careers advisers to be involved. However, this was not always the case for every parent. This was most clearly demonstrated by two parents at Oaksmere (Susan and Jason's). In fact, a contrasting approach between parents was most apparent between those at The Laurels and Oaksmere, two comparable schools with similar careers service input. At The Laurels (Authority 3) parents recognised the role of the careers adviser within leaving school preparations. Eric's parents demonstrated this:

> **Eric's Father**: "I mean her *[careers adviser]* role has really been in helping us to find the right sort of college for Eric..."
> **Eric's Mother**: "Yes, it's via her that the funding goes..." (The Laurels, Pre-school leaving)

In contrast, at Oaksmere (Authority 1) Susan's and Jason's mother did not appear to see a great deal of point in the careers service being involved. In fact, Susan's mother suggested that she felt the careers service's input was not of great importance as Oaksmere and its teachers could provide all the information that she required. When asked if she felt that more careers input would have been beneficial, she replied:

> **Susan's Mother**: "Well, it wouldn't 'cos the teachers talked to me anyhow, so that was just as good." (Oaksmere, Pre-school leaving)

This approach adopted by Susan's mother re-emphasises, as Gallivan-Fenlon (1994, p.18) has noted, the important role that school can, and does, play within parents' lives. In addition, it is interesting to note that both Susan's and Jason's mothers adopted a 'reactive' parental role, whereas, two out of three parents at The Laurels pursued a more 'active' role. Furthermore, within this different approach one must also recognise the role of residential college. At The Laurels, the careers adviser becomes practically involved in residential college funding applications (FEFC). Conversely, residential college applications are extremely infrequent at Oaksmere and so the careers adviser is less involved in funding issues. This perhaps helps us to begin to understand the differing parental attitudes towards careers advisers at The Laurels and Oaksmere.

Experiences and evaluations of both the careers service and careers advisers can and did vary enormously. When many young people discussed their careers adviser within Authorities 2/3, it was clear that they had played an active role within school leaving preparations and that a significant number of them valued their input and advice. Similarly, for those parents who welcomed the careers adviser's input, it was their knowledge base that was valued. However, not all parents recognised or valued the role that careers advisers could play within leaving preparations. Furthermore, a small minority of young people could not remember seeing their careers adviser. This indicates that, in comparison to earlier studies, such as Anderson and Clark's (1982) study of physically disabled young people, careers advisers have clearly made significant inroads into special schools and their leaving programmes. But there are still many areas where improvements can be made. This was demonstrated within issues of 'quality' and 'quantity' and more broadly in terms of status and perceived relevance.

6.3 Participation And Feeling Involved

Generally, the idea and importance of young people and parents participating within decision making has gained common currency and legitimacy. In fact, these two concepts lie at the heart of many diverse acts (The Disabled Persons Act, 1986; The Children Act, 1989; The NHS and Community Care Act, 1990; The Education Act, 1993 and its associated Code of Practice, 1994) and raise wider questions surrounding the whole issue of 'rights' and 'citizenship'. Past transition studies (especially McGinty and Fish, 1992, pp.92-99) have also recognised and emphasised its importance. Here, 'participation' and 'involvement' will be explored through two specific areas: school meetings, especially leavers meetings; and the choice making process, in particular, choosing a next step option. The third and final area within this section will draw upon and bring together parents' ideas and experiences in order to explore 'how' the transition process has been approached and evaluated by them. It will thus raise the question of "transition management" (Tisdall, 1996/97, pp.10-11).

6.3.1 School Based Meetings

Here, it must be noted that when the young people and their parents were talking about school meetings, there was a great deal of diversity concerning exactly which meetings they were talking about. Some talked generally about annual reviews, whereas others talked specifically about meetings concerned with leaving school. However, even within these, there appeared to be three further differences: general school leaving meetings; transition planning meetings, re the Code of Practice (1994); and social services led meetings, re The Disabled Persons Act (1986). This in itself is indicative of the many

different meetings that statemented young people can face when leaving school (see also Coles, 1995). This makes generalisations and comparisons difficult. However, a number of themes and issues surrounding participation and involvement emerged. These will be explored via the young people's and their parents' recent experiences. The final part of this sub-section will focus more specifically upon experiences of participation and feeling involved within transition planning meetings, re the Code of Practice (1994).

6.3.1.1 Young People's Involvement and Participation

Young people's involvement within meetings can be explored on many different levels, from physically attending meetings to playing an active and central role. Tisdall (1996, p.31) has argued that young people's attendance does not automatically lead to their involvement. This of course is very true. However, attending a meeting can be a first step, especially, when this is not the usual procedure. Within this study, attendance at school meetings appeared to be the norm within the upper years of three of the focus schools (Ash-hill, Cedar Drive and Beechview). In contrast, at Oaksmere and The Laurels, schools where the young people had more pronounced learning disabilities, this was more ad-hoc and largely related to disability levels (see also chapters four and five).

Knowledge about and feelings towards school meetings was rather difficult to probe, especially, for those young people who communicated with the aid of symbols (five). However, three young people appeared to be clear in their own minds that they had attended school meetings. Of these, two, (Eric and Susan) indicated that they had felt happy, whereas, the other young person (Jason) "felt sad". However, it was unclear why he "felt sad". Amongst the wider sample there was a range of responses. For example, four young people clearly related school meetings to issues surrounding their future. Luke, recognising his last meeting as an opportunity to think about and plan for the future demonstrated this:

> **Luke**: "It was good 'cos we had a chat about what was available when I leave, like one choice was [unitary city] college and the other choice was Beechview." (Cedar Drive, Pre-school leaving)

Conversely, other young people were more vague. Three in particular gave no real recognition that future planning issues had been involved. In fact, they were often rather bored, as Laura noted:

> **Researcher**: "How do you find those meetings?"
> **Laura**: (pauses) "A bit boring but it's all right" (Ash-hill, Pre-school leaving)

Feelings towards school leaving meetings have been explored by Morningstar et al (1995) and Tisdall (1996, 1996/97). Morningstar et al's American study of young people with learning disabilities (p.255) suggested that the vast majority of their sample held negative views, with only a very small minority recognising any meaning to the meetings. In a similar vein to Tisdall's study of Scottish young people with recorded 'SEN' (1996/97, p.8) within this study there was a mixture of satisfaction and dissatisfaction; some of the young people here held non-committal or negative views. On the other hand, a small but significant number of young people held positive views. However, as both Morningstar et al and Tisdall highlight non-committal or negative attitudes, their existence in this study amongst some of the young people once again raises important questions about the role and nature of planning meetings and their function within the Code of Practice (1994). Furthermore, this re-emphasises the fact that schools continually face a challenge in trying to ensure transition-planning meetings appear and are perceived as relevant by all young people. Chapter five demonstrated that some teachers are already very aware of this.

The young people were asked about their own role within school meetings. On one level, three young people (out of five) who communicated with the aid of symbols indicated and felt that professionals had talked to them - but 'how much' and their role within these meetings was unclear. Furthermore, one young person (Julie) responded by associating school meetings with something separate from her - 'for others'. Of course, one could question if Julie actually understood what I was asking. However, feelings of distance were clear from her response:

> **Researcher**: "When Dad used to come to school to talk to Mr. Jones and Mr. Atkins did you used to talk with them?"
> **Julie**: "I'm not allowed to go to the staff room."
> **Researcher**: "They went to the staff room, did they?"
> **Julie**: "I'm not allowed to."
> [Later] **Researcher**: "Do you go to any other meetings with Dad to see people?"
> **Julie**: "Mr. Jones and Mr. Atkins won't let me, Miss Kent won't let me go into the staff room." (The Laurels, Pre-school leaving)

On the other hand, amongst the wider sample, eight out of ten felt that they had been asked questions and/or had had their opinions sought by professionals. However, beneath this there are two issues to be considered: context formality and degree of input. Three young people (Geoffrey, Ellen and Louise) suggested that the context of school meetings did, or could, make them nervous. Geoffrey explained:

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> Researcher: "And what's it like going to those meetings?"
> Geoffrey: "All right."
> Researcher: "What makes it OK?"
> Geoffrey: "Um (pauses) sometimes you feel nervous."
> Researcher: "Yeah, what makes you feel nervous about it?"
> Geoffrey: "What they're going to ask me and stuff like that." (Cedar Drive, Pre-school leaving)

Of course there is a personal element here. Other young people stated very clearly that they did not feel intimidated. However, when four transition planning meetings were attended at Cedar Drive, it was very clear that the young people were nervous. Three appeared intimidated by the context of the meeting, a factor the head himself acknowledged. Hence, the important point to note is that the context of these meetings 'is' or 'can be' "intimidating" for young people. This was also highlighted by Tisdall (1996, pp.20-21; 1996/97, pp.8-9). Furthermore, interpretations of the same context can, and do, vary. For example, Geoffrey and his mother gave a very different interpretation of the same meeting. One cannot presume that just because a parent perceives the context as relaxed, his/her son or daughter does as well. It is also interesting to note that when asked – "Who did most of the talking at these meetings?" only two young people (Lisa and Luke) put themselves at the top of the list. The others prioritised either professionals or their parents. Thus, the young people placed themselves at the margins rather than centre stage.

From a broader perspective, the majority of parents were generally satisfied that the school had involved their son or daughter within leaving preparations. However, this was often accompanied by the ambiguous and selective phrase, 'as far as possible'. On the other hand, four parents were rather more critical as they looked back over the years. Janet's father, for example, felt that his daughter could have been more involved during annual reviews:

> Janet's Father: "And again, we sit round at these assessment meetings, appraisal meetings, nobody talks to Janet, or very rarely, it's just a little pleasantry here and there on the side, an acknowledgement that she's there. But nobody sits down face to face with Janet and says 'what do you want? Where do you see yourself going?' " (The Laurels, Pre-school leaving)

6.3.1.2 Parents' Perceptions

School meetings were generally viewed positively by the majority of parents' (14). In fact, only one set of parents indicated that they hardly ever attended annual reviews. However, two fathers stressed that the timing of reviews, i.e. during school hours, meant that only one parent attended, usually their wives. In terms of parental participation, the majority, once again, felt that they had been involved within school meetings. More

specifically, parents felt that professionals had included them, they had been asked questions and felt about to comment. In fact, many parents considered it to be an open atmosphere.

On the other hand, two sets of parents (Lisa's and Bob's) stressed that they had not felt actively involved within leaving school meetings. Before exploring these parents' perceptions it is important to note their pre-school leaving context. Both sets of parents were not happy with the post-school options suggested within their school-leaving meeting. Consequently, this may have coloured their interpretation. However, their comments raise important questions and issues. For example, Lisa's parents felt that the professionals present did not want to listen to them as parents. The atmosphere was viewed as 'closed' rather than 'open'.

> **Lisa's Mother**: " ... when I went to this meetin' ... he *[careers adviser]* seemed as if he was pushin' her *[Lisa]* all t' time, it's what he wants, you know, not what we wanted, what he wants, oh yeah." (Beechview, Pre-school leaving)

This raises issues around the professional management of meetings, as Tisdall (1996, pp.29-31; 1996/97, pp.10-11) has previously discussed. Bob's parents also felt somewhat excluded and unable to participate because they felt uninformed and lacking in knowledge:

> **Bob's Father**: "I didn't think it was really all that helpful because um ...There was nothing really we could have put in because we didn't know anything ... you know, even if we'd gone, just got some leaflets, you know, that we could have looked through..." (Cedar Drive, Pre-school leaving)

This re-emphasises the importance of information for parents and highlights Orlowska's (1995, p.444) suggestion that information can be an important source of power.

In addition, one set of parents (Janet's) were rather sceptical of the very context of annual reviews and statementing. They highlighted its bureaucratised, rubber stamping nature and thus detachment:

> **Janet's Father**: " ... this army of bureaucrats that send you forty page statements which virtually are the same each year..." (The Laurels, Pre-school leaving)

This general comment links into wider concerns surrounding Code of Practice (1994) transition reviews (see chapter five - Lewis et al, 1996; Wood and Trickey, 1996), more specifically, the potential danger that they will become bureaucratised administrations.

6.3.1.3 Transition Planning Meetings

As a result of these concerns it is important to consider personal experiences of transition planning meetings, re the Code of Practice (1994). Due to the diverse age range of the young people within the sample (15 – 19 years), at the time of interviewing many of the young people and their families had clearly missed the introduction of transition plans at 14 years within the Code of Practice (1994). However, four families at two of the schools (Cedar Drive and Beechview) had experienced transition planning via the Code the previous year. Within this sub-section these four families' experiences will be explored and discussed. This is a small and specific sub-sample: hence, it is by no means representative. However, it does provide an alternative perspective to professional interpretations and raises a number of important issues.

Amongst the four young people who had experienced a Code of Practice transition planning meeting (where a transition plan was drawn up) three (Geoffrey, Bob and Charisa) were extremely vague about their meeting and the writing up of a transition plan. Within pre-school leaving interviews, only one young person (Luke) recognised that it had been a special meeting and related it to future planning. On reinterviewing Luke and Charisa eight to nine months later, a similar pattern emerged. Charisa had no recollection of seeing a transition plan, whereas Luke knew that he had written, future plans within his Record of Achievement but was unsure of the specifics:

> **Researcher:** "Can you remember if these ideas were sent to you on a piece of paper and you had a look at them?"
> **Luke:** "Yeah, it was in my red book [Record of Achievement] I got on my last day"
> [Later] **Researcher:** "What was it actually called that you had, did it have a name on it?"
> **Luke:** "Can't remember" (Cedar Drive, Post-school leaving)

It was therefore a little unclear which plan he was talking about - a Transition or a Careers Action Plan. There seemed to be some confusion. In fact, Luke's parents felt that the transition plan had not really made much impact upon their son:

> **Researcher:** "I was just wondering how you felt it was for Luke?"
> **Luke's Mother:** "I don't really thing he thought much about it, it was just words to him." (Post-school leaving)

This re-emphasises some of the concerns that the Cedar Drive Head demonstrated in chapter five. These young people did not regard participation within the drawing up of a transition plan as a memorable experience. However, one must not forget the time lapse between writing the plan and the interviews.

Pre-school leaving interviews with parents also indicated some diversity in knowledge of transition plans. On one hand, all four parents were aware that it was a special leaving school meeting. Parents may have been only vaguely aware of the Code of Practice but they recognised the importance of their leavers meeting. On the other hand, only two sets of parents (Luke and Geoffrey's) could remember seeing a transition plan. Furthermore, it is important to note Luke's parents' approach and attitude towards their transition plan. It was viewed as mainly a professional 'next step' document; a tool for professionals to use in the passing on of information to the next step:

> **Researcher**: "Do you think it *[the transition plan]* was a useful thing to do, for young people and yourselves or do you think it wasn't much different from the annual review?"
> **Luke's Mother**: "It wasn't much different, apart from it being, it just gave them *[school and professionals]* a plan to pass onto Beechview. Sort of like, this is the end of what we've done and this is what we think Luke wants to continue in the future, so we'll be able to pass that on, it was just a tying up thing." (Post-school leaving)

Thus, there was no real sense of it being 'their' plan, something that they owned. It was rather detached and mainly for the use of others. This parental perception does not appear to be in tune with the Code of Practice's wider policy objectives but it does somewhat mirror the Cedar Drive Head's fears about a lack of 'ownership' for parents and young people.

This sub-section has demonstrated that, on one level, many of the young people and their parents felt involved within school meetings. However, on another level, 'feeling involved' is a relative concept hence, there were differences. Viewing the young people's participation, one can conclude in a similar manner to Tisdall (1996, p.17). Young people may be attending their meetings, they may be asked questions and expected to provide an input. Some may clearly feel at ease doing this. But there are certain situations when some may experience fear, even feelings of exclusion. Similarly, the power of professionals to 'manage' meetings was highlighted by two sets of parents. Thus feelings more akin to disempowerment rather than empowerment were also present.

6.3.2   Who Makes The 'Next Step' Choice?

Before exploring how young people and their parents viewed their role and input within the choice making process, it is important to recognise that choice making does not occur in a social and economic vacuum. Young people and their parents may participate and feel that they are making a choice but wider factors were frequently involved. For example, three issues were mentioned: the management and presentation of

information; practical issues; and economic factors. Within the first, one should consider 'what' information was presented to families and 'how' it was presented. For example, there was a difference between authorities with regard to the use of residential college. Within the focus schools in Authorities 2/3, it was presented as a positive option, whereas in Authority 1 it was not really discussed. Parents, of course, cannot be seen as merely puppets pulled and pushed by schools. Some were active, enquiring and challenging of professional ideas. However, other parents, as we have seen, were more dependent upon their schools and adopted a 'reactive' and sometimes deferential role. Louise's mother suggested that 'they' as teachers knew best:

> **Louise's Mother**: "I mean they *[professionals]* advise you, we just go along, they're the experts and if they think that that's the best option for her then we'll go along with it." (Beechview, Pre-school leaving)

In addition, practical issues, such as college provision in terms of physical access or personal support, were important within the choices of four sets of parents. The third issue of economics concerns the importance of financial considerations, as discussed in chapter four. More specifically, benefits can, and do, influence parental attitudes to a son or daughter living away from home. This was similarly demonstrated by one mother (Eric's) drawing upon her knowledge of other families and their decisions:

> **Eric's Mother**: "Yes, it's a lot of money that goes, one week you get it and the next week it's not there, so yes ... and I should think for some parents they would really struggle without it. Um, I have heard that some parents won't let their children go away for that very reason." (The Laurels, Post-school leaving)

Furthermore, one mother from Ash-hill (Steven's) raised the inflexibility of the benefit system and the uncertainty that this can bring as an important consideration. This has been well documented within the literature (see Beyer and Kilsby, 1996, 1997; Thomson and Ward, 1994). Here, the importance of 'cost benefit' analysis was raised. Perceptions of an unaccommodating benefit system and its ensuing economic dangers had led Steven's mother to reject training schemes as a post-school option for her son. Consequently, economic considerations and evaluations of the benefit system were indeed important.

6.3.2.1 Young People's Perceptions

The importance of wider socio-economic factors has been demonstrated. On the other hand, one should not forget the importance of individual actor's perceptions of their own role within the choice making process. For those young people who communicated via symbols (five) it was difficult to ascertain their level of participation and input. However, three sets of parents (Linda, Susan and Jason's) stressed that they had been

consulted and all five young people indicated that they were pleased with their proposed 'next step'. Of course, there is a difference between being 'pleased with' and actually 'choosing' one's 'next step'. Within the wider sample (ten), eight young people felt that they had participated in choosing their 'next step'. However, the degree of perceived input varied. For example, six of the eight stressed that it was 'they' who had made the choice, indicating that they were aware of alternative options. More specifically, they clearly valued the opportunity to have input and felt proud that it was 'their' choice, as Bob illustrated:

> **Researcher**: "I wondered who helped you choose Beechview, who helped you make the decision?"
> **Bob**: "I made it myself virtually."
> [Later] **Researcher**: "Was it a hard decision to make?"
> **Bob**: "Yes, it was a bit, deciding between Beechview and Manor House." (Cedar Drive, Pre-school leaving)

On the other hand, it must be noted that these choices were all within a very narrow 'special' sphere. Two young people (Geoffrey and Laura) stood apart, as they were less enthusiastic about their own input within the choice making process. The reasons given highlighted either strong parental ideas (Geoffrey) or a lack of personal direction concerning the future (Laura).

Amongst the young people who felt that they had had input, two factors appeared to underpin their feelings of 'being involved'. Firstly, it was important to them to be asked (four young people), in particular, to be given an opportunity to say what they wanted. Secondly, tangible symbols were valued. For example, Luke and Ian welcomed professionals writing things down, replying or looking at them when they spoke:

> **Researcher**: "What made you think she *[careers adviser]* listened to what you said?"
> **Luke**: "She looks at me and she writes on the board." (Cedar Drive, Pre-school leaving)
> **Ian**: "He look at you when you're talking to him." (Beechview, Pre-school leaving)

On the other hand, there were times during the interviews when three young people (Ian, Janet, Geoffrey) suggested that school staff did not always listen to them.

Furthermore, perceptions of the same situation can and do differ. For example two young people (Lisa and Ellen) perceived their role and input within the choice making process very differently to that of their parents/foster parents. Pre-school leaving, both young people suggested that they were 'in control' and 'active' participants. However, their parents/foster parents presented a rather different picture. For example, Lisa's father actually interjected within his daughter's interview and contradicted her

suggestion that she was going to the local college. In addition, Ellen's foster mother emphasised that it was Ellen's parents rather than Ellen, who were making the decision. Here, we have two examples of differing interpretations of who is making the 'next step' choice. This raises important questions concerning perceptions of control as each party felt that they were 'in control'. However, the actual outcomes may be quite different. Lisa did go onto the local college of her choice. On the other hand, Ellen had later come to acknowledge her parents' 'active' role in choosing her college course and work experience and thus her own relative 'powerlessness':

> **Ellen**: " ... they *[her parents]* think, they think they know what's best for me and they always think all the time, they always give me the wrong job which I don't like."
> **Researcher**: "Yeah, what sort of things?"
> **Ellen**: "Like that catering job at the um snack bar ... it was their idea of giving me the job in the first place and that's why I don't like it." (Beechview, Post-school leaving)

Perceptions of one's role within the decision making process are thus a complex area. However, it is clear that a significant number of the young people felt that they had been actively involved within the decision making process of their 'next step' and were proud of this fact. On one hand this appears very positive. However, one must not forget that perceptions of input are relative and can depend upon one's expectations and previous experiences of choice making or personal autonomy. Within past studies such as Hirst and Baldwin (1994) and Flynn and Hirst (1992) it has been suggested that disabled young people frequently experience less autonomy than their peers in general, a factor which may well influence perceptions of input.

6.3.2.2 Parents' Perceptions

Amongst parents there was a range of views as regards their role, perceived input and its importance within the choice making process. More specifically, there was a broad division between parents who felt that they were either 'in control' or had a significant degree of input and parents who felt 'less in control' or 'less influential'. Six sets of parents stressed that they had felt 'in control' of the choice making process. Here, the linking factor was parental attitudes - 'how' parents perceived their own role or that of their son or daughter rather than wider authority differences. For four sets of parents this control was linked to a perception that they really needed to make the decision for their son or daughter: it was in 'their best interests'. Julie's father suggested:

> **Julie's Father**: "I think, talking about Julie's future, obviously she's got a bearing on her own future but I don't think she's mentally aware enough to make a subjective decision. ... so I think you've got to take decisions for her." (The Laurels, Pre-school leaving)

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This perception of control was interwoven with ideas about ability to make important decisions. For the other three families it was associated with disability levels.

On the other hand, seven sets of parents expressed feelings of having 'less control' compared to those above. However, four of these parents viewed this positively. For example, Ian's father prioritised his son as an important decision-maker:

> **Researcher**: "Who sort of made the decision to go to on the catering course?"
> **Ian's Father**: "Ian, it has been Ian's, all we've done, we've just followed him through and we've just been behind him. Then we've let him make the decisions ... but if you can't make a decision at 18, he's not ever going to make that decision." (Beechview, Pre-school leaving)

In contrast, two sets of parents (Bob and Lisa's) viewed their perceived 'lack of control' in a more negative manner. This evolved from their experiences of school meetings and professional dominance or management.

Parental evaluations of participation and input within 'next step' choice making emerged from different parental perceptions of roles, whether; their son or daughter, their own, or that of professionals. It is clear that not all parents wanted to control the decision making process, whereas others expected to be active and influential. Ideas of 'responsibility' were also important and what a 'responsible' parent should do.

6.3.3 Approaching The Transition - Parental Perspectives

Drawing these experiences and previous parental evaluations of school leaving preparations together, parental attitudes and approaches to the transition from school and future planning will be discussed. Officially, the Code of Practice (1994) advocates long term planning. However, a somewhat shorter-term approach was frequently adopted within transition meetings (see chapter five). Within this sample, some parents advocated a 'next step' perspective, whereas others looked longer term. At this point the analysis will focus upon the ideas and expectations of two contrasting sets of parents (Luke's and Janet's) as they raise a number of important issues.

Within both interviews Luke's parents stressed that the transition from school for their son should be approached from a 'next step' perspective. This conviction was premised upon the idea that Luke's future potential and progress could not, and should not, be pre-empted. Consequently, it was felt to be foolish and perhaps dangerous to try and plan too far ahead:

Luke's Father: "I just don't, I don't think it's worth even trying to think that far ahead really. Almost from when he's born it's been a case of taking every day as it comes in all honesty and not trying to look too far ahead ... so what will happen in five years time is in the lap of the gods really, can't say, just accept it." (Cedar Drive, Post-school leaving)

At this stage it was thus seen as important to discuss Luke's 'next step' with the careers adviser but it was far too early to plan for a 'career'. There was a perception of distinct phases. In this way, his parents seemed to associate with an approach which Tisdall has depicted as "... smooth processing from provision to provision", embodying the "professional management" of the "transitional problem" (Tisdall, 1996/97, p.10). There was also an assumption by other parents, such as Susan's mother, that school would only look to the 'next step' as this was viewed as its basic remit. This approach demonstrates the importance of boundary perceptions and the phased nature of transition.

In contrast, Janet's parents stressed that the transition from school should be approached and explored via a longer-term perspective. In fact, within both interviews Janet's parents were critical of what they perceived to have been a short term and narrow perception of Janet's future:

Janet's Mother: "All that's been talked about really is, that she can stop in education until she's 25, everybody's plans seemed to be aimed at that, don't they?"
Janet's Father: "Stop in here until 25 and then worry about it when it happens."
Janet's Mother: "It's just the next step, what's going to happen then, you know, and when it gets to the end of that step, we'll take it onto the next one." (The Laurels, Pre-school leaving)

As an alternative it was stressed that they would have liked a perspective, which looked beyond further education to wider areas and opportunities:

Janet's Father: "There needs to be a plan laid out years in advance with check point along that." (Post-school leaving)

In particular, the felt absence of a discussion surrounding the concept of 'careers' in its broadest sense was noted. However, it must be acknowledged that the co-ordinator at The Laurels felt that they did address a number of wider issues such as residential college and young people moving away from the parental home.

As an ideal, Janet's parents suggested an approach within which professionals began to look at opportunities at an earlier stage and also began to discuss together these openings, where they might lead and how to prepare for them:

Janet's Father: " ... it would lay out a career path for that particular person as an individual with their relative strengths and weaknesses taken into account and all the services, education, social services, whatever. Parents are brought into it and follow it through and targets are set ... and a review, a timetable could be laid out and reviewed periodically along the way to see if you've attained those targets..." (Pre-school leaving)

Janet's parents are in some ways advocating as Tisdall has discussed, a "broader view of the 'transitional problem' " (1996/97, p.10). For Tisdall, the key to this is empowering the young person. However, this was not as central within Janet's parents analysis; improved multi-disciplinary working was their key concern. In fact, Janet's father made several pleas for more multi-disciplinary networking and longer term, professional future planning. These suggestions evolved as a result of personal review experiences before the Code of Practice (1994) was implemented. However, it is interesting to note that many of Janet's father's 'wishes' have in fact become official policy suggestions within the Code of Practice, particularly, transition reviews. Other parents may have considered some aspects of school leaving from a longer-term perspective. For example, residential college, particularly, future living arrangements was raised by a number of parents, especially from The Laurels. And for others (Louise and Lisa's) 'more' and 'earlier' information on longer-term future options was noted. However, it was Janet's parents who were the most clear and forceful in their criticisms and suggestions. Hence, they stood somewhat apart within the sample, and in some ways their comments were a minority view.

From this brief analysis of approaching the transition it is clear that not all parents wanted or advocated the same approach to transition planning, but had different expectations and objectives. The importance of 'planning' was generally stressed but perceptions of 'when' and 'how' planning should take place varied between parents.

6.4 Health and Social Service Transitions

This fourth and final section will broaden the analysis to explore welfare transitions. The previous three sections have discussed the transition largely in educational terms focusing upon leaving school preparations. Within this section, health and social service provisions will be discussed as the young people both leave school and move onto their 'next step' and transfer into adult services. The importance of service 'coherence' and 'continuity' during this transition period has been highlighted (McGinty and Fish, 1992, pp.97-98). Conversely, past studies of young people with many different impairments (Brimblecombe et al, 1986; Fish, 1986; Bax et al, 1988; Bax, 1990; Hirst et al, 1991; Thomson and Ward, 1994) have illustrated problems of 'incoherence' and 'discontinuity'. Within chapter four, professionals provided a lucid account of service

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provisions in both authorities. However, perceptions and evaluations of provision can and do vary. Hence, it is important to explore the service ideas and experiences of young people and their parents, in order to develop a comprehensive assessment. However, due to the sheer scope of health and social service provisions, only three areas will be explored: firstly, post-school health services and support; secondly, social worker involvement; and, finally, information surrounding social security benefits.

6.4.1 Service Provision - Health and Support Services

6.4.1.1 Young People's Ideas

Within the sample there were a small number of young people who prioritised their health needs. However, service provision in general was a rather abstract and uninteresting concept to many of the young people. This has also been noted by Hirst and Baldwin (1994, p.104) and Fiedler and Johns (1997, p.47 – reporting on a transition project in Sheffield). Discussing services with the young people who communicated with the aid of symbols, current provision was the main focus. Pre-school leaving, three young people indicated that they enjoyed working with school medical staff. One (Jason) was more non-committal. However, there was generally little sadness at the prospect of leaving school medical staff. Six to eight months later, two young people (Susan and Eric) were reinterviewed and both indicated that physiotherapy or speech therapy had continued at college and that they were enjoying the service.

Within the wider sample, four young people highlighted that they had received physiotherapy at school. Indeed, three of them (Luke, Bob and Charisa) prioritised physiotherapy within their next step. These three young people seemed to be very aware of their physical needs and the importance of physiotherapy continuity, as Charisa explained:

> **Researcher**: "What's the best thing you think will be about going to college?"
> **Charisa**: "I can have phsyio and things." (Beechview, Pre-school leaving)

Eight to 12 months later, all three were quite happy with the physiotherapy they were receiving. In fact, Charisa suggested she enjoyed it more at college than at school:

> **Researcher**: "Do you think you have more or less physio now than you did at school?"
> **Charisa**: "Just the same."
> **Researcher**: "And which do you like best do you think - physio at college or physio at school?"
> **Charisa**: "College." (Post-school leaving)

However, Charisa was also aware that her parents were disappointed with the lack of speech therapy at college. Furthermore, she felt that speech therapy would be advantageous to her.

6.4.1.2 Parents' Ideas and Experiences

Speech therapy as an area of limited provision has been noted within past literature (Bax et al, 1988; Hirst et al, 1991; Ward et al, 1991; Hirst and Baldwin, 1994; Ward et al, 1994). Within this study, of the parents who did discuss speech therapy (six sets), half similarly highlighted experiences of limited provision. For the three families who had or did receive speech therapy (Eric, Susan and Ian) this was a valued service. However, future provision was not always a certainty, as Ian's father demonstrated:

> **Researcher:** "... do you think he will have speech therapy, how do you think it will pan out in the future?"
> **Ian's Father:** "I haven't got a clue, I couldn't tell you. I don't even know how long that it's going to go on for, 'cos I do know that they are cuttin' back, so I just don't know." (Beechview, Post-school leaving)

Physiotherapy provision within the next step was considered by half of the sample of parents (eight). In anticipating this provision, five sets of parents expressed feelings of optimism as they believed physiotherapy would continue to be provided. In fact, 'on site' physiotherapy provision was an important consideration within the next step choice for two sets of parents (Bob and Charisa's). It was clearly valued and prioritised, as Bob's mother highlighted:

> **Researcher:** "Do you think that there will be quite good services for him there *[next step]*?"
> **Bob's Mother:** "Yes I do, that's what we checked out on, the physio." (Cedar Drive, Pre-school leaving)

In contrast, for three families (Fiona, Linda and Lisa) there was a sense of uncertainty. More specifically, they were unsure of the provision that would be provided - 'when', 'where' or 'how' much. Lisa's father was the most emphatic, suggesting that he just did not know:

> **Researcher:** "When she leaves Beechview obviously she'll be leaving the school physio and the nurse then, I just wondered what happens about physio?"
> **Lisa's Father:** "Nobody knows, I don't know, I can tell you nobody's contacted us yet." (Beechview, Pre-school leaving)

In chapter four, the Oaksmere physiotherapist within Authority 1 presented a bleak assessment of provision, particularly for young people with learning disabilities who chose to go to day college. Amongst the three young people from Oaksmere it is rather difficult to compare their situation with the physiotherapist's assessment, because only

one chose a day college. The other two attended a continuing educational centre with 'on-site' provision. However, it must be noted that parents generally presented a rather more positive picture of provision compared to that of the physiotherapist at Oaksmere. In fact, of the seven sets of parents reinterviewed who wanted physiotherapy, only one (Susan's mother) was vague about the specifics of her daughter's provision at college. On the other hand, this was the mother of the young person from Oaksmere who had moved to day college. There is thus some ambiguity surrounding this issue of physiotherapy provision at day college. This is an area, which could be further explored, in future research.

The remaining parents (six) were all clear that their son or daughter was receiving physiotherapy within their next step, and were generally pleased with the provision. In fact, two (Luke and Charisa's) noted the benefits of 'on-site' provision. For example, Luke's mother felt there was a degree of continuity:

> **Luke's Mother**: "I know the physio from Cedar Drive sent a sheet through of what she'd been doing, so I'm assuming that they're following that and Luke's not said anything different and he's now gone swimming on a Tuesday to college. No, I think it's the same, maybe better, I don't know." (Cedar Drive, Post-school leaving)

However, there were still some areas of concern for Luke and Charisa's parents. This was demonstrated within their assessment of transferring information between schools. Luke's mother in particular, felt that this had been rather ad-hoc:

> **Luke's Mother**: "Um, there are still a couple of things that I feel they ought to have known but they didn't know, like the fact that Luke had a raise on his shoe. They didn't know anything about that or they didn't appear to anyway." [later] "There's a little bit of a lack of communication sometimes, but again you don't know how much they've said to Luke, um that he's not said to us." (Post-school leaving)

Although presented as a teething problem, the very fact that this was noted suggests that the coherent transfer of information between institutions could be improved.

Choosing a next step with 'on-site' service provisions, in many ways, postpones parents moving from a model of school service 'dependency' to greater 'independence' (see also chapter four). For example, of the seven sets of parents reinterviewed post-school leaving, those whose son or daughter had moved on to residential school/college did not really feel that their level of service support had changed, as there was still 'on-site' support and contact. In contrast, those whose son or daughter had moved on to a day option (Susan, Ian and Ellen's foster mother) recognised that post school, the onus was now 'more' upon them initiating contact with services. In a manner similar to Swain

and Thirlaway's observations (1994, p.170) Susan's mother lamented the loss of school support and guidance:

> **Susan's Mother**: " ... if there's anything wrong with the wheelchair or anything wrong with her boots I could just go to school but there's none of that now. But they said, they told me at school that, that still carries on at college when she's there, but then she's only there for two years, what happens when she leaves college?" (Oaksmere, Post-school leaving)

In contrast, Ian's father whilst lamenting the passing of school support was more confident at the prospect of accessing services:

> **Ian's Father**: " ... because all the advice is there, all you've got to do is ask for it..." [later] " ...so it's just a matter of asking and if you don't ask, you don't get, it's as simple as that." (Beechview, Post-school leaving)

Here, there is a presumption that everyone can just ask or knows how to ask, the importance of parents being assertive is emphasised. Ellen's foster mother reiterated this idea:

> **Ellen's Foster Mother**: "You've got to shout, if you don't shout you're left aside and nobody will bother." (Beech-view, Post-school leaving)

In addition, Susan's mother's comments raise the issue of service provision in the longer term. For Susan's mother it was service provision, post-education that was viewed as the time of great change rather than service provision on leaving school:

> **Researcher**: "Do you think there's been a change in services since she's left Oaksmere school?"
> **Susan's Mother**: "Not at the moment, it's when, it's actually when she leaves college, that's when the time will be." (Post-school leaving)

Hirst and Baldwin (1994), Ward et al (1991, 1994) and Thomson and Ward (1994) have highlighted this parental concern for provision, post-education. Within this study, a fear of future, reduced service provision was raised as an area of concern by six sets of parents. More specifically, there was a fear of less health and support services when a son or daughter moved onto adult services. Of course, the degree of concern varied. For example, from Charisa's parents, who, although pleasantly surprised by the involvement of the adult community physiotherapist during their daughter's college holidays, still feared that post-college, provision would be less. To Eric's mother who was much more emphatic. In fact, she described the movement from child to adult services in terms of a "big door closing":

Eric's Mother: " ...um there's such a lot for the children and when they get to 18 it's like a big door closing and you've got this long adulthood, you know, stretching ahead of them with very little input, very, very little..." (The Laurels, Post-school leaving)

'Continuity' and 'coherence' are also important considerations when a young person moves from paediatric services to adult specialists. Chapter four demonstrated that this was an area of concern for some professionals. Within this sample there was diversity, as some young people had not yet transferred from paediatrics, whereas others had. Amongst those who had transferred there were further differences. Some parents (Jason, Lisa and Bob's) seemed unperturbed by this change and did not view it as particularly significant. In contrast, two sets of parents (Julie and Steven's) questioned service continuity. In particular, Julie's father stressed that the neurology service they received within adult services was less coherent and personal than the paediatric service:

Julie's Father: "Er a retrograde step ... you're more of a number there and you know, you're churned round in the big machine..." [later] "A doctor, you see them twice and then they've moved on, next time you see someone else..." (The Laurels, Pre-school leaving)

These criticisms re-emphasise concerns raised both within chapter four and past literature (Hirst et al, 1991; Hirst and Baldwin, 1994; Begum and Fletcher, 1995; Johns and Fiedler, 1995). However, it is important to remember that not all parents expressed concern about the move to adult services or a fear of reduced provision in the longer term. Within the sample, the medical requirements of the young people varied considerably and this was partly mirrored in the diversity of parental experiences and their evaluation of health services.

6.4.2 Social Worker Support

Within the sample, there were many differences amongst families in terms of past support received from social workers. These differences did not seem to apply to any particular policies or patterns of provision between authorities but were rather ad-hoc and associated with parents' personal experiences and individual social workers. For example, only half of families whose son or daughter had more pronounced disabilities had a social worker. Although this is a small sample of families this is in contrast to past findings (Hirst et al, 1991, p.146; Flynn and Hirst, 1992, p.50; and Hirst and Baldwin, 1994, p.103) where young people with pronounced disabilities were highly likely to have a social worker. Of course, as we shall see, this may have been the decision of parents. Furthermore, as young people approached school leaving, still only a small minority received contact from a social worker.

Parents' expectations of social worker support during this transition period also differed, and frequently seemed based upon past experiences with some more optimistic than others. Pre-school leaving, six sets of parents were quite optimistic about social worker input. For two sets of parents (Bob and Fiona's) there was a sense of anticipation as they had recently been introduced or promised an opportunity to see a social worker.

> **Bob's Mother**: "I got some forms from the DLA and I didn't know where to start ... so I rang Doctor Brown ... he said, 'I'll get you a social worker'. He said, 'you haven't got one and you've missed out on a lot of things'. So she *[social worker]* came to see me and she's beautiful." (Cedar Drive, Pre-school leaving)

A year later, both families were generally pleased with the input they had so far received. The remaining parents (four) based their 'optimism' upon past experiences of being well served.

In contrast, a more sceptical approach was adopted by seven sets of parents. For four of these parents, scepticism arose from past personal experiences of being poorly served, as Lisa's father highlighted:

> **Lisa's Father**: "We never see a social worker from one month to another, last time we had a social worker to do with any of them was nine years ago." (Beechview, Pre-school leaving)

Conversely, the other sceptical parents (three) were more reticent to accept social worker support even if it was available because they viewed it as a sign of being unable to cope. There was still a strong association of social workers with stigma, as Charisa's father recognised:

> **Charisa's Father**: " ... it's maybe the stigma that everyone sort of conjures up, what social workers are all about..." (Beechview, Pre-school leaving)

Chapter four discussed the post of transition officers within Authorities 2/3. From a professional perspective the post was largely welcomed however, amongst parents, especially those at The Laurels, there was a mixed reaction. It was generally recognised that transition officers served the transition years. More importantly, that they filled a service 'gap' between child and adult services, as Julie's father explained:

> **Julie's Father**: "I felt that the children's services felt, 'well, it's adult services problem is that'. But adult services never seemed to pick up the reckoning slip until Tom *[transition officer]* was appointed. It was obviously that gap there, which was why they appointed Tom and his sole responsibility is the 18 to 25 year old band." (The Laurels, Pre-school leaving)

On the other hand, Eric's mother was also aware of inherent contradictions. Personally, the transition officer may be supportive and active but this does not detract from the fact

that, whilst smoothing the transition path, services and support were in fact being withdrawn as her son moved to adulthood:

> **Eric's Mother**: "They have a scheme now where they have like an intermediate social worker who deals with the 16 to 18 years olds and I think that's supposed to ease this transition but I don't think it actually makes a scrap of difference really. ... at the end of the day, you know, at the close of the day, no matter how well you prepare it, the outcome is just the same. You know, you're still sort of closing the door, no matter how gently you close it, it still shuts, bangs behind you..." (Post-school leaving)

Thus, Eric's mother viewed the transition officer's role as limited. Wider questions of resource availability and participation within adult services were recognised as important by her.

Furthermore, it is also important to consider the issue of resources in terms of post-school social service support for statemented young people who do not meet the strict criteria of 'disabled' within the Disabled Persons Act (1986). A danger of young people slipping through the service net has been previously noted (see chapter two – Armstrong and Davies, 1995, p.71 and Thomson and Ward, 1994, pp.89-90). Within this study, one parent in particular, Steven's mother (Ash-hill school) was both aware of, and concerned by, a lack of post-school community support "for kids with special needs". Drawing upon the experiences of her son's friend she felt that there was a need for more co-ordinated support networks within the community. For example, "drop in centres" where young people could find both support and advice:

> **Researcher**: "What sort of things would you like to see?"
> **Steven's Mother**: "Err drop in centres for kids with special needs an' that, I don't think there's a lot goin' for them..." (Pre-school leaving)

These concerns reiterate the importance, as Ward et al (1991) and Thomson and Ward (1994) have demonstrated, for more support and guidance to be available to young people striving to live independently. This will be discussed further in chapter seven.

6.4.3   Benefits and the Provision of Information

Anderson and Clarke's (1982) earlier study of physically disabled young people highlighted that many had a limited knowledge of the benefit system and benefits they received. Within this sample of young people there was a similar situation. Many talked of having money to spend, mostly 'pocket' money, but only two (Laura and Ian) were clearly aware of their benefits. Thus, even though the young people were at least 16 years and so eligible to claim benefits within their own right (see Hirst and Baldwin, 1994, pp. 39), parent's ideas and experiences will be explored. Within parental

discussions questions focused upon the provision of information rather than benefit levels or perceptions of adequacy.

Discussions revealed that the study's families recognised three potential sources of information about benefits: professionals; their school; and informal networking. Professionals, especially social workers, were recognised by six sets of parents as a 'potential' source of information. But only two parents (Bob's and Ian's) appeared to have actually received information directly from a social worker. In contrast, relatively more parents had received information from either their school (four sets) or informally from talking to friends or other parents on the "grapevine" (five sets). Louise and Luke's parents illustrated this:

> **Louise's Mother**: "Well, we were actually advised by the school what to apply for ..." (Beechview, Pre-school leaving)

> **Luke's Father**: "The problem is the benefits officers never tell anyone about the benefits that can be paid, you just find out on the grapevine." (Cedar Drive, Post-school leaving)

This feeling of dissatisfaction which Luke's father expressed was a shared one. Indeed, a significant number of parents raised concerns and criticisms about the provision of benefit information. More specifically, half the parents within the different authorities raised its inaccessibility. A key concern was getting to know about your entitlements; Luke's father felt that it had been almost a matter of luck:

> **Luke's Father**: "As I say it's been on the grape vine, nobody has come to us from the DHSS or social workers or any organisation ... it's definitely you find out about it and then make a telephone enquiry..." (Post-school leaving)

It was suggested that the Department of Social Security or other professionals should provide more direct information concerning entitlements. Janet's father felt that parents would then no longer have to rely upon an ad-hoc informal network:

> **Janet's Father**: "... there is no statement or letter that comes to you and says, 'you are the parents of a handicapped child, you are entitled, providing they fit into this criteria to claim this' ... um there's no clear, concise set of guidelines for you and nobody says, other than other parents who have gone through the mill and found out themselves..." (The Laurels, Pre-school leaving)

This is an important issue as it re-emphasises many of the points that Thomson and Ward (1994, pp.90-91) raised within their study, especially that information about benefits is often regarded as confusing or absent. Within this study, it was clear that 'when' professional advice had been received, parents valued it. Furthermore, the focus schools were also recognised as an important source of information. Thomson and Ward suggest that it is the role and responsibility of social workers to provide more direct

information. Furthermore, they suggest that appropriate benefit information should be written into young people's Record of Needs (Statement in England and Wales) and continually updated. Recognising the importance of social workers and schools is thus not new. But it could be developed and formalised further by the focus schools, via the Code of Practice (1994) when writing transition plans. However, social services attendance at these can and does vary, as chapter five demonstrated.

It is also important to consider how the process of gaining information and applying for benefits can be a complicated and difficult process for young people with learning disabilities to negotiate. Ian's father was very aware of this and suggested that getting rid of jargonistic and confusing language would help young people with learning disabilities:

> **Ian's Father:** " ... by putting it into plain text rather than half of the jargon that they put into leaflets, you don't understand anyway..." (Beechview, Post-school leaving)

This is obviously important if disabled young people are to be encouraged and helped to take financial control within their lives.

Section four has explored welfare transitions. Within the sample there were many different parental experiences in terms of health and social services support, perhaps only to be expected from a small, diverse sample. Therapy services, in particular physiotherapy, were an important concern for a small but significant number of the young people and many of their parents. Assessing provision post-school, both the young people and their parents were generally satisfied. However, a significant number of the young people had moved onto other forms of 'on-site' provision. Hence, the transition to adult, community-based services had not yet occurred. When the time comes to leave education, the situation may be a less positive one, as Ward et al (1991), Ward and Thomson (1994) and Hirst and Baldwin (1994) have demonstrated. Indeed, a fear of reduced service provision in the future was very real for a number of parents. This raises concerns surrounding 'coherence' and 'continuity'. Furthermore, there is also the issue of feeling informed; many parents clearly did not feel adequately informed in terms of benefit entitlements.

Conclusion

Chapter six has moved the focus of analysis from professional evaluations of institutional practices, provisions and policies to explore young people and their parents' experiences and personal evaluations. Four areas have been examined: leaving school feelings and experiences; evaluations of school preparations; involvement and

participation within the process; and finally, health and social service transitions. The first three sections focused largely upon educational transitions and the final section broadened the analysis to explore welfare transitions. Amongst the sample there was a range of experiences; however, there were also many shared ideas and recurring themes. These can be summarised as follows:

Approaching The Transition

Leaving school and moving on was generally approached in a positive manner by many of the young people. Some sadness was expressed but there was also a great deal of post school optimism. Furthermore, eight to 12 months later, the majority were enjoying their next step. For a small but significant number this enjoyment partly evolved from feeling more independent at college or training. A sense of progress and development was thus important. From a parental perspective, initially there was a shared sense of relief that there was something for their son or daughter to move onto. However, beneath this, parents' approaches to the transition from school and perceptions of the future differed. Many wanted to pursue a step by step approach but some were more willing to take a longer-term approach, moving beyond the 'next step'. Official policy directives (Code of Practice, 1994) may advocate longer term planning. However, the depth and diversity of parents' emotions about school leaving and 'the future' highlights the complexity of this objective. Hence, the importance of professionals being aware of and responsive to the different needs of parents is emphasised.

Participation and Involvement

The importance of 'empowering' young people to take a more active role within their transition has been well documented by Tisdall (1994, 1996, 1996/97). Within this study a significant number of the young people indicated that they 'felt' involved within the decision of their 'next step'. Amongst parents, the majority also felt that they had been involved and that their opinions had been sought. However, 'feeling involved' and evaluating one's decision-making role as decisive are different things. This was demonstrated by the different interpretations that emerged between some young people and their parents. Parents themselves also differed in their interpretations of feeling 'in control'. This was frequently interwoven with the role that they expected or wanted to take within the decision-making process and their perception of professionals' role and that of their son or daughter. School meetings may have been viewed positively by many young people and their parents. However, they frequently seemed to be areas imbibed with ambiguity. Furthermore, within discussions it was clear that there were some important issues surrounding the very context and process of school meetings, which is a cause for concern. Tisdall (1996, 1996/97) has also noted similar areas of

concern within her study of school leavers meetings within Scotland. Ultimately, it is important to recognise that even though a significant number of young people and their parents felt 'active' participants they are in fact making a choice from a very narrow and specific set of 'special options'.

Information

Amongst the majority of parents it was clear that *more* information would have been welcomed during this transition period. This was especially true for those parents who perceived their role as more 'active' and information seeking. In particular, the importance of both 'early' and 'accessible' information concerning 'next step' options was stressed. For some parents this arose from negative or confusing personal experiences. Furthermore, it was also clear that a significant number of parents (half) felt uninformed with regard to benefits. Information was viewed as ad-hoc and too informal. Consequently, there were two 'felt' needs. The first 'felt' need was for the presentation of 'next step' information *earlier* and in a more collated, easy to manage form; and the second was for benefit information to be presented in a more direct and accessible manner to parents.

Service Continuity

Within welfare transitions, it was clear that many of the families had only just or were about to embark upon the transition from 'child' to 'adult' services. Hence, their assessments were initial ones. With regard to therapy service provision, especially physiotherapy, those who required it were receiving a service. Furthermore, young people and their parents were, on the whole, satisfied with the service they were receiving, especially when provision was 'on-site'. However, the 'future', especially post-education in 'adult' services was an important area of concern. There was a fear that greater changes might occur post-education rather than post-school leaving. Ward et al (1991), Thomson and Ward (1994), and Hirst and Baldwin (1994) have also discussed this. Hence, a small but significant number of parents (a third) raised questions and concerns about both the level and continuity of service provision. At this initial stage of transition to adulthood it was clear that the provision of 'on-site' services had postponed service transitions for some families. In the short term, this may have benefits for families but longer-term, the issue of reduced levels of service input within adult community based services remains a very real issue.

Chapter 7 – 'Adulthood'?

Introduction

The previous chapter began to explore some of the status transitions young people can experience during the leaving school process, especially within college link courses and work experience placements. Chapter seven will explore further and in greater depth the idea of a changing status, more specifically, the transition from 'child' to 'adult' status. However, before beginning to explore 'adulthood' and the transition to 'adult' status it is important to be clear how these concepts have been perceived (see chapter two). Past literature, exploring the general concept of 'youth' (Wallace, 1988; Jones and Wallace, 1992; Jones, 1995; and Coles, 1995) has depicted and described it as three main institutional status transitions upon which young people at different points in time embark. These are the school to work transition, the housing transition and the domestic transition. The focus has been upon both public and private institutions. Literature surrounding transition studies for disabled young people has further discussed and debated the concept of 'adulthood' (CERI, 1983, 1985; Fish, 1986; Ward et al, 1991, Hirst and Baldwin, 1994, Thomson and Ward, 1994). More specifically, it has searched to define and develop a set of 'markers' which encapsulate the concept of 'adult' status and can thus be used as a means to gauge disabled young people's movement towards 'adulthood'. A number of markers have been suggested. These frequently cover four main areas: living independently and/or personal autonomy; employment and/or economic independence; social participation and/or adult role taking; and post-secondary education (Fish, 1986, p7; Thomson and Ward, 1994, p.17). Furthermore, within this chapter, the importance of 'citizenship', as noted by Tisdall (1994, 1996/97) is recognised as a foundation stone within the concept of 'adulthood' and 'adult' status.

A key finding within many past studies (CERI, 1983, 1985; Fish, 1986; Ward et al, 1991; Flynn and Hirst, 1992; Hirst and Baldwin, 1994; Davies and Jenkins, 1993, forthcoming) has been that the transition to adult status for disabled young people is frequently "prolonged", sometimes never really achieved. This can be demonstrated with reference to both the three institutional transitions and, more generally, social independence and participation. Within this study, two young people stood apart from

the rest in the sense that they had already begun to make a number of significant steps towards greater personal independence and 'adulthood'. Although far from typical of the sample as a whole, these two young people provide an opportunity to begin to explore the transition to 'adulthood' and the significant transition steps embarked upon post-school. Furthermore, they provide a means through which to compare and contrast post-school situations and the transition to 'adulthood' as experienced by the wider sample of young people and their parents.

This chapter will be divided into three sections. The first section will explore and discuss the two case studies. The second section will use the case studies as a touchstone to the wider sample, in order to explore the three institutional status transitions and raise issues of comparison and contrast. Within the third and final section the analysis will be broadened. Issues surrounding social participation and community involvement will be examined.

7.1 Two Case Studies

Within this study two young people (Ian and Laura) from different authorities made a number of positive and far-reaching steps towards greater personal independence. Gaining greater independence is not an easy task, especially when there are physical, social and environmental barriers (CERI, 1988, p.19; Hirst et al, 1991, pp.139-143). The two case studies are not intended to be representative. However, their individual biographies provide an opportunity to begin to unpack and explore some of the key variables, which have been important factors in two young lives. Within the following analysis it is clear that structural factors can and have played an important part, even though some factors may be biographically unique. Ian and Laura were not merely puppets but rather active agents making clear decisions, which have an important bearing upon their progression towards greater independence.

7.1.1 Beginning The Transition To Adulthood - Ian

At the time of our initial meeting Ian was 18 years old and lived with his parents, brother and two sisters in a village within Authority 2. Ian had just left Beechview School having attended their post-16 independence course for the last two years as a weekly boarder. In fact, Ian had left Beechview in June rather than July as an opportunity to attend a highly respected 'special' training course within catering had arisen.

Post-school leaving it was clear that many changes had already taken place and were furthermore planned to take place within Ian's progression towards greater

independence. More specifically, in terms of timing, Ian's initial transition to living independently of his parents appeared to be largely a planned and gradual development. For example, within initial interviews both Ian and his father talked of planning for, looking towards and discussing with professionals how Ian would leave home:

> **Researcher**: "Do you have a social worker?"
> **Ian**: "Er yeah"
> **Researcher**: "And what's he like?"
> **Ian**: "He's all right, he's got me movin' in me own flat."

> **Ian's Father**: "As they *[professionals]* said, he'd come through a transitional period of being on his own at Beechview, now was the time to put him in a bedsit to come through the next stage ... so it was something we got to, we had to. Well, we'd been thinking about it for 18 months since it was, since the idea was first brought up." (Beechview, Initial interview)

Seven months later, Ian had recently made the move from his parents' home and was now living as a lodger with a landlady in his home town. Ian had thus begun a housing transition (Jones, 1995): more specifically, he had embarked upon a "housing career" (Wallace, 1988, p.28; Coles, 1995, pp.8-9). Within his new status as a lodger, the situation seemed to be that Ian's landlady would do his washing and ironing if he needed it. Thus, on one hand, there was an element of care and support available. Ian's father suggested that this depended on how much his son wanted or required it. On the other hand, there was also scope for greater independence. The transition to more independent living was thus a phased one. Furthermore, the present situation was not seen as static or fixed. For example, both Ian and his father made it clear that they were looking forward to and planning for the next step, i.e. a council flat:

> **Ian**: "I've got my name down for a council house."

> **Ian's Father**: "Eventually we're hoping he'll move into his own flat which will gain him his full independence." (Initial interview)

Prior to embarking upon this housing transition, Ian foresaw two key changes within his life, which he valued: having his own front door key:

> **Ian**: "Um, I can go out myself and have a key"
> **Researcher**: "... so you're going to have your own key?"
> **Ian**: "Yeah"
> **Researcher**: "And how do you feel about that?"
> **Ian**: "I'm happy and help me feel older" (Initial interview)

and having friends round whenever he wanted:

> **Researcher:** "Is there anything that you think you'll do when you live by yourself that you can't do here?"
> **Ian:** "Um, not really, I can have some of my friends round" (Second interview)

Similarly, after moving into his own room Ian reiterated that he welcomed his new found independence and enjoyed the two changes that he had previously noted, especially the potential to do what he wanted, when he wanted. The important factor was thus his ability to make his own choices and begin to take control of his life:

> **Researcher:** "What's been really good about living by yourself?"
> **Ian:** "Got my own house keys and that."
>   "I can have a couple of me mates in at night time." *[Later]* "Can have some cans of beer on me own."
> **Researcher:** "... and do you like doing that?"
> **Ian:** "Er, I haven't done it yet but sometime I want it." (Second interview)

Having one's own front door key is symbolic of a degree of autonomy, a symbol which suggests that one is independent of, rather than, dependent upon others. The importance of having a door key has been previously noted within Hirst and Baldwin's (1994, p.16) and Davies and Jenkins' (1993) studies.

Furthermore, it was also apparent that Ian had gained greater independence within other areas of daily living, such as financial management and independent travel. For example, Ian now both collected and managed his own benefits. In fact, his father stressed that he had encouraged and aided his son to take greater control because he prioritised financial management skills:

> **Ian's Father:** "Oh yeah, he does everything for himself now. At one time I used to go down and pick it *[his benefits]* up for him and deliver it to him, but I've now stopped doin' that ... he didn't like it to start with but er I think he quite likes it now because he goes up, draws his money and does what he wants with it and nobody interferes with him." (Second interview)

In terms of independent travel, within both interviews, Ian indicated that he travelled on the bus independently. In addition, he also indicated that he was currently saving for a motorbike, although he had failed his driving test twice:

> **Researcher:** "Is there anything that makes you feel grown-up?"
> **Ian:** "Er not really. Motor biking."
> *[Later]* **Researcher:** "Do you think you might get one?"
> **Ian:** "Yeah"
> **Researcher:** "When do you think you might get one?"
> **Ian:** "When I've got enough money for one." (Second interview)

Both a car and a motorbike are significant symbols of adulthood as they enhance a young person's personal freedom and autonomy, thus mirroring the general movement from childhood dependence to greater adult independence.

Within the sphere of a school to work transition it was clear that Ian valued and aspired to the idea of 'having a job'. On leaving school he had moved to a specialist Barnardos training scheme within catering. Ian clearly valued the scheme as he had definite aspirations to become a chef. To be sure, the transition was phased and gradual from school to work via training. However, Ian was undertaking a transition which many young people experience, due to the extension of education and training as the youth labour market has declined (Jones and Wallace, 1992; Coles, 1995). Past studies (Ward et al, 1991; Hirst and Baldwin, 1994) suggest a rather negative scenario for many disabled young people with extended or prolonged transitions. However, Ian already had a weekend job in the kitchens of a local pub, which provided him with invaluable work experience and the status of a 'part-time worker'. Furthermore, Ian had a very positive future outlook. He certainly expected to find work as a chef:

> **Researcher:** "... have you thought what you might like to do afterwards?"
> **Ian:** "Yeah, move to me own hotel"
> **Researcher:** "Move to a hotel ... and what would you like to do there?"
> **Ian:** "Cooking" (Initial Interview)

Ian did not perceive any future problems in getting a job; there was no discussed recognition that his learning disabilities may create problems or difficulties. Indeed, he was very optimistic, emphasising the value of his training course and that family connections (his brother was also a chef) would help:

> **Researcher:** "Do you think that it will be easy or difficult to get a job like that?"
> **Ian:** "If you works with Barnados they move you on and that [and] When I finish, when I get er a form sayin' I'm passed all my things."
> **Researcher:** "Yeah, do you think anything else will make it easier to get a job?"
> **Ian:** "Er, my brother help."
> **Researcher:** "Why, how will he help?"
> **Ian:** "He work in a hotel" (Second interview)

Within Ian's social life there were indications that some progress had been made towards more independent social participation, especially in terms of moving away from parental supervision. For example, Ian stressed that he enjoyed going down the pub without his parents, i.e. unsupervised. Here, going 'down the pub' was valued as an adult thing to do, especially having a beer. Going 'down the pub' has also been noted as an important social symbol of adulthood in other studies (Davies and Jenkins, 1993). On the other hand, Ian still attended 'special', segregated clubs and activities, although Ian

and his father interpreted this very differently. Within both interviews Ian's father felt that:

> **Ian's Father:** " ... he's a complete and utter loner."

Whereas, Ian presented a much more positive interpretation:

> **Researcher:** "Do you have many friends?"
> **Ian:** "Yes, I've got lots of friends." (Initial interview)

However, Ian's move out of the parental home had left his father with a dilemma. Should he intervene within his son's social life, organise activities and thus foster greater community participation or should he step back and accept his son's social choices:

> **Ian's Father:** "... he's still a lot on his own, which is what we're trying now to see if we can integrate him shall we say, so that he does mix." *[But later]* "... if he wants to do things on his own, well, I've got to respect that, it's unfortunate but I'm not going to push myself or Ian into anything that he doesn't want to do." (Second Interview)

These conflicting emotions seem to mirror a dilemma noted by Thorin et al:

> "Wanting to maximize the young adult's growth and potential and wanting to accept the young adult as he or she is." (1996, p.119)

Ian's father's prioritisation of social participation and community involvement raises wider and deeper questions concerning the social ramifications of moving from 'special', segregated education into adulthood. Brisenden (1987) has clearly highlighted, from personal experience, the socially isolating nature of special education. Ian's father similarly suggested that his son's years within special education have had a profound and ongoing effect upon his ability to socialise with non-disabled peers:

> **Ian's Father:** "... I think, as I said at the beginning a lot of it was due mainly to him being in a special needs school all the time. If he hadn't been in a special needs school, which is, well it's unfortunate that it's happened but er, I think he might, if from the beginning they'd actually mixed mainstream with special needs, he would have, er um mixed together you know ..." *[and]* "... he's not very good with, er shall I say mainstream people." (Initial interview)

However, it must be noted that Ian's father did not completely reject special education: he wished for modifications and closer alliances with mainstream education rather than its abolition.

Within this case study it is clear that there are a number of factors that Ian valued within his transition to adulthood. These can be summarised as: living more independently

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with the freedom to come and go as and when he pleased; financial independence; moving towards greater independent travel; and finally, working at weekends in a 'real' job. These factors were also shared by his father and were encapsulated by his future hopes highlighting the ongoing nature of his son's transition:

> **Ian's Father**: "Well, mainly for him to get his flat, for him to settle down, once he's finished his training get a decent job and just basically get on with his life, the same as everyone else does." (Second Interview)

Here, the importance of Ian having an independent future was clear. Parents of young people with learning disabilities similarly shared these sentiments within Lehman and Barker's American study (1995).

7.1.2 Laura

Laura was 18 years old at our initial meeting and lived in Authority 1 with her parents and younger brother and sister. She was preparing to leave Ash-hill school after having spent three years within their sixth form. Her younger brother was also about to leave school, as he was 16.

Pre-school leaving Laura had been vague and undecided in her future plans and career aspirations. Going to college to do a catering course was mentioned but merely in passing. Laura thus stood in contrast to Ian's clear pre-school leaving aspirations and plans. Laura had not thought ahead to the idea of 'having a job', let alone a specific type of job:

> **Researcher**: "... have you sort of got any long term plans, like what to do when you leave school, you know in terms of jobs or things?"
> **Laura**: "Um, I haven't thought about that yet." *[Later]* "I don't know haven't got that far yet?" (Pre-school leaving)

Post-school leaving, Laura initially moved to a local day college on a catering course. However, she only pursued this for a couple of days and then decided to leave, highlighting concerns surrounding the college, her course and perceived levels of support:

> **Researcher**: "And what was difficult about it?" *[the course]*
> **Laura**: (pauses) "The writing, 'cos I can't write very well, so that were it, I left it."
> **Researcher**: "Did anyone help you there at all?"
> **Laura**: "Well, there was a little but not a lot 'cos they had to do other work, you see, so I left? (Post-school leaving)

After this initial post-school set back Laura's life had taken a new direction as she embarked upon a "housing career" (Wallace, 1988; Coles, 1995; Jones, 1995). In contrast to Ian's housing transition, Laura's appeared to be less pre-planned and relatively quicker. Neither Laura nor her father, pre-school leaving, gave any indication of plans to leave the parental home or for Laura to move in with her boyfriend. In fact, when Laura discussed her relationship with her boyfriend she presented a situation where there was an absence of regular contact:

> **Researcher**: "... have you got a boyfriend?"
> **Laura**: "Well, yeah but he don't come down to see me, so bugger him." (Ash-hill, Pre-school leaving)

However, when reinterviewed, post-school leaving things had changed markedly for Laura. Within the space of eight months between the two interviews, Laura had left home and moved to her partner's house, located within the same street as her parents. It seemed quite an abrupt transition, as did her account:

> **Laura**: "... he asked me to move in with him, so I did do." (Post-school leaving)

Laura's housing transition also appeared to be quicker and less phased than Ian's. Part and parcel of Laura's housing transition also entailed the beginnings of a "domestic career" as she had moved from her "family of origin" towards a potential "family of destination" when she formed a partnership and created a joint household with her boyfriend (Wallace, 1988. p.25; Coles, 1995, p.8; and Jones, 1995, p.21). In terms of the future, Laura was also looking ahead as she was planning to get married within the next couple of years when she and her boyfriend had saved enough money:

> **Laura**: "I'd like to get married and that but we have to wait you see until we've got the money and that..." (Post-school leaving)

Marriage was thus an important aspiration for Laura; it was social recognition of her relationship with her boyfriend. However, it was perceived as an ultimate goal to be achieved after cohabitation and Laura seemed happy with this. A similar perception of marriage was found amongst some of the young people within Wallace's study (1988, p.30) and their transition to adulthood.

Within her domestic transition Laura had adopted the role of a carer as her partner was physically disabled following an accident at work. The adoption of a caring role was traditional and gendered - the female homemaker and carer rather than breadwinner. Laura's father, pre-school indicated that he was a little concerned about his daughter's 'vulnerability' and thus her need for protection. Consequently, one could argue that Laura's transition was also a relatively 'safe' one as she had moved from the care and protection of her parents to the care and protection of her boyfriend. However, this may

be a rather narrow interpretation. Indeed, Laura's adoption of a 'caring' role is almost a reversal of society's usual perception of young people with learning disabilities as being the 'cared for'. In Laura's case it was she who was doing the 'caring for'. She was undertaking the general care of her partner and the household tasks, such as cooking, cleaning and washing rather than being 'cared for' by others. Furthermore, she was very proud of her role and the tasks that she did:

> **Laura**: "Yeah, and look after me boyfriend..." *[later]* "I do cleaning up in here and do washing up and wash clothes and that, 'cos me Mum used to wash clothes for me but now I can do it for myself now."(Post-school leaving)

Laura and her partner's relationship also seemed to embody elements of reciprocal 'care', which took different forms. For example, Laura looked for help towards achieving greater independence from the support and encouragement of her partner. This was demonstrated in terms of financial management. She indicated that this was an area she found difficult but felt that progress was being made with the support of her boyfriend:

> **Researcher**: "... how do you find managing your money now...?"
> **Laura**: "It's a bit hard but my boyfriend helps me a little bit." (Post-school leaving)

Hence, 'caring' provided an important sense of self-worth and a recognised role for Laura. It was an important symbol endowed with both responsibility and associations of 'adulthood'.

However, Laura's 'domestic career' has simultaneously had important ramifications upon the traditional school to work transition. Laura has adopted a caring role as an alternative to a job within the labour market. Thus, in contrast to Ian's post-school transition of school to training and aspirations of subsequent progression to employment, Laura has pursued a transition essentially from school to the domestic sphere:

> **Laura**: "I've been looking after me boyfriend, see 'cos he's disabled, that's why I can't work, you see." (Post-school leaving)

Caring within the home frequently receives less social status than a 'job' within the labour market. On a more positive note, Laura's role as a carer was, however, socially and financially recognised by the social security system, via her receipt of invalid care allowance. It was thus a small but significant step towards, and symbol of, "social citizenship" (Jones and Wallace, 1992). However, there was a gendered dimension to this "social citizenship", a situation which Jones and Wallace (1992, p.49) depict as

"social citizenship by proxy?" i.e., gaining 'social citizenship' indirectly - via another, in this case, Laura's male partner.

Within the social sphere Laura had made some progress towards more independent social participation however, elements of a rather limited social life and community participation remained. Pre-school leaving, Laura's social life appeared to be home oriented, focused largely upon listening to music and watching television. On the whole Laura appeared to be satisfied with this however, she did express a desire to visit a night-club in town. Eight months later, having made both a domestic and housing transition Laura's social life was still predominately home oriented. It was focused upon a small sphere of people rather than wider community participation within 'adult' settings, such as pubs and night-clubs. On the other hand, one must appreciate the different context of her home oriented social life, the important difference being it was in her 'own' home rather than that of her parents under their supervision. Furthermore, Laura's social life was largely home centred due to financial constraints, 'going out' was seen as a luxury rather than a necessity and thus not prioritised:

> **Researcher:** "Do you go to night-clubs now?"
> **Laura:** "I would like to (pauses) but not really"
> **Researcher:** "Why not really, do you think?"
> **Laura:** "We haven't the money, we haven't got the spare money to spend on booze." (Post-school leaving)

This situation not only highlights the wider issue of poverty whilst on benefits (Walker and Walker, 1991; Barnes, 1991; Berthoud, 1995) but also the fact that Laura is having to make some very 'adult' decisions and priortisations in order to live independently with her partner.

The key factors Laura valued within her transition to 'adult' status were focused very clearly upon the domestic sphere. For example, having both her 'own' home to look after and a role within society, namely as her boyfriend's 'carer'. These gave Laura both a socially recognised 'adult' role and 'adult' responsibilities. Furthermore, Laura also valued being part of a 'couple', sharing her life and leisure with another hence, her prioritisation to look longer-term towards marriage.

7.1.3   Issues Arising

Within Ian and Laura's initial steps towards living independently of their parents one factor, which is immediately apparent, is the gendered nature of the two transitions. Laura's transition to adult status was clearly guided by her domestic transition within which domesticity and a domestic role were central; two roles traditionally viewed as

'appropriate' and 'acceptable' for young females. Furthermore, this was a situation which Flynn and Hirst similarly found and feared for young women with learning disabilities. They suggested:

> "Within the study sample, it is clear that young men were a more privileged group with women apparently destined for domestic seclusion." (1992, p.70)

Within Ian's transition to 'adulthood', a domestic transition had not yet played any significant role. Ian valued his housing transition and living independently of his parents but had no plans to live with a partner. Furthermore, although Ian had yet to gain economic independence this was very clearly his goal. His school to work transition may be prolonged but was still of paramount importance.

In addition to this underlying gendered dimension one can also decipher four specific areas which have played a significant role: firstly, professional input and prior planning; secondly, material and economic factors; thirdly, familial support; and finally, the personal input of each young person. Of course, these four are by no means 'the' or even 'a' comprehensive list of factors but were rather the important ones that came to the fore at this point in time. Furthermore, they demonstrate the importance of a diverse range of variables and factors within each young person's transition.

The main area of contrast between Ian and Laura's transitions was clearly the role and degree of professional input and the planning involved prior to, and during the transition to living independently of one's parents. For example, both pre and post home leaving, Ian's father, and to a lesser degree Ian himself, emphasised the importance and input of professionals, in particular their social worker. The social worker was viewed as a key player within transition preparations, someone to access services, advise and guide them. In addition, Ian's father stressed the importance of what he felt had been good communication and teamwork amongst the different professionals, without which he suggested his son's leaving home could not have occurred:

> **Ian's Father:** "... it was a team effort by everyone really, 'cos we knew, the school knew, I knew, social services knew that when Ian left Beechview School it was going to be hard, so it was literally a team effort from everyone." (Second Interview)

Furthermore, both Ian and his father noted that planning had taken place over a long period of time. For example, during pre-school leaving interviews Ian's father indicated that the idea had first been suggested some 18 months ago. In terms of the process of planning, Ian seemed to feel both in control of, and prepared for, the transition. He acknowledged the important role that Beechview's independence course had played in

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preparing him for independent living and also the opportunity to visit and get to know his landlady before making a decision to move.

Laura's transition from the familial home stands in contrast to Ian's. Professional involvement was not discussed within Laura's interviews; there appeared to be an absence of professional input and planning. Laura's housing and domestic transitions seem to have evolved independently rather than being professionally planned and organised. Thus highlighting how transitions are not always planned but rather can just occur due to personal factors and events.

On one level, Ian and Laura's transitions appear to be very different however, there were many important areas of similarity, such as: material and economic factors; familial support; and the personal input of each young person.

The material context within which disabled young people live can aid or hamper the transition to adulthood. This was clearly demonstrated within the study. Here, both Ian and Laura had an opportunity to move into housing which they considered to be 'appropriate'. However, for other young people, especially those with more pronounced disabilities, both physical and learning, this can prove to be rather more problematic. For example, both Morris (1993b) and Thomson and Ward (1994, pp.81-82) have noted a dearth of available and appropriate accommodation for disabled people. Furthermore, both Ian and his father prioritised the importance of a 'good' training scheme. However, underlying Ian's post school move to the Barnardos catering scheme, one must recognise an element of luck. Training schemes, as noted in chapters four and six, can and do vary both in quality and the degree of support provided. Thus, in one sense Ian was lucky he was in the right place at the right time.

In terms of economic factors, young people need an adequate financial income or resources to enable them to move out of the parental home. Here, the role of benefits was an important factor for both Ian and Laura. For Ian, a mixture of housing benefit and disability benefits helped to top up his training allowance. This training allowance, although criticised by both father and son for being low, was together with other benefits an important financial factor. For Laura, the importance of her partner's disability benefits within the household income and, via his disability, her receipt of invalid care allowance was paramount. Hence, social security benefits in one form or another helped to make it financially more feasible for both young people to leave the parental home and live more independently.

On a more personal level the importance of having contact and communication with parents was also important for both young people. This support was aided by the fact

that both Ian and Laura lived relatively near their parents, visiting as and when they wanted, and therefore receiving support practically, socially and/or emotionally. Morningstar et al (1996) and Blalock and Patton (1996) have previously noted the importance of parental support and involvement during the transition years. Although they had both left the parental home it was clear that Ian and Laura still relied upon their families and were by no means completely independent of them. This stage of semi independence from families has previously been noted by other studies with more general populations (Wallace, 1988; Jones, 1995).

Family relationships are frequently complicated they can also be influenced by external factors. Ian's father's assessment of the role of family dynamics and residential education demonstrated this. Post-school leaving, he suggested that there was a general tension between Ian and the family. He felt that over the years this had been exacerbated by residential education as Ian had become detached and thus almost a stranger within his own family:

> **Ian's Father**: "... being in residential care for two years, so he didn't know what it was going to be like coming home to the family. So although he came home for weekends I don't think the weekend is long enough for them to get back in the swing..." *[and]* "... in some senses we were like strangers to him..." (Second Interview)

This highlights the potential for residential education having negative ramifications upon family relationships and fostering distance between family members (see Barnes, 1991, p.42). Tension may have existed within Ian's family but his father was still aware of the importance of family support, both practically and emotionally, supporting Ian whilst at the same time 'letting go'. Here, the importance of giving young people more freedom and responsibilities in order to prepare them for adulthood was highlighted. This was clearly demonstrated by the pro-active but gradual preparational role that Ian's father had adopted:

> **Ian's Father**: "... he wanted his independence so much that I thought if he wants his independence I'm going to back off into the background, everything that we used to do for him we slowly broke off and left it for him to do more and more, we was there to assist." (Second Interview)

However, there were also elements of a more radical 'sink or swim' approach, especially in terms of independent travel. For example, Ian was taken to his training course the first few times and then encouraged to go on the bus alone:

> **Ian's Father**: "... as I say, we could've molly coddled him and kept running backwards and forwards and doin' everything for him but we didn't think that would have helped him in t' long run. So I got up one morning and said, 'that's it, you're on your own'." (Initial interview)

The idea of parents stepping back and "letting go" is complex and can be a very emotional issue (see Richardson and Ritchie, 1989; Richardson, 1989; and Swain and Thirlaway, 1994). 'Risk' as an area of concern was frequently expressed. Ian's father was aware of the issue of 'risk' but he was also perceptive to the important learning experience that came from his son being allowed to take risks and experience the direct consequences of his own actions, i.e., to learn from his own mistakes:

> **Ian's Father**: "And I reckon if they're going to make a mistake, let them do it ... because if you don't make mistakes they're not goin' to learn." (Initial Interview)

This leads to the final area, Ian and Laura's personal input, as both were active within the decision to leave the family home. Laura had decided to accept her boyfriend's offer to move in with him and Ian had chosen to accept a room with his landlady after an initial visit. This demonstrates how both Laura and Ian were active agents in developing their own careers. Although their initial steps towards greater independence took place within a very specific, social and economic context of external structures and guiding forces, the potential for individual agency cannot and should not be ignored or dismissed.

Within this analysis of two case studies the importance of trying to unpack initial, 'successful' transition steps in order to explore some of the underlying factors has been highlighted. Four factors have been discussed: professional input; young people's aspirations; the material context - opportunities and structures; and finally, family support and a willingness to "let go". The complex and multi-layered nature of individual transition contexts has also been demonstrated. For example, Ian's transition encompassed social, professional, economic and personal factors. This complexity has previously been noted by Chadsey-Rusch et al (1991, p.31) re-emphasising the fact that a young person's transition cannot be viewed as dependent upon one particular thing or person but rather many interrelated and interacting variables. Hence, Chadsey-Rusch et al suggest conceptualising transition via, as Haney (1988) has suggested, "an ecological perspective". One where:

> "... positive transition outcomes should be viewed as the result of dynamic interactions between youths and their environments." (Chadsey-Rusch et al, 1991, p.31)

Initial steps towards the transition to adulthood are also very personal and thus unique. However by exploring individual biographies important lessons can be learnt and wider associations drawn. Policies of good practice can be developed as the literature suggests (Fish, 1986; McGinty and Fish, 1992; Ward et al, 1991; Thomson and Ward, 1994; Fiedler and Johns, 1997). Ian's initial steps for example, have demonstrated that a well-

planned transition with multi-disciplinary support and co-operation was highly valued by Ian's father. This is something, which is highlighted as a key policy objective within recent legislation and Codes of practice (The Disabled Persons Act, 1986; The Children Act, 1989; The NHS and Community Care Act; and The Code of Practice, 1994).

7.2 Institutional Status Transitions

Section one explored two case studies; Ian and Laura were however, atypical of the wider sample. Within this section the above case studies will be compared to the rest of the sample in order to discuss the three traditional institutional status transitions (school to work; housing; and domestic). Comparisons and contrasts will thus be explored not only between the case studies and the wider sample, but also amongst the sample itself. For many of the young people 'tangible' transitions such as Ian and Laura's had yet to be embarked upon. However, a significant number of the young people held clear aspirations to at least one of the three traditional 'adult' status transitions.

7.2.1 'Work' - Aspirations and Perceptions

The concept of 'work' is frequently equated to paid employment, i.e. notions of 'having a job'. This, of course, is a very narrow interpretation of 'work' there are many forms of unpaid work. Within this study the majority of the young people and their parents similarly equated 'work' with paid employment on the open labour market.

7.2.1.1 Young People's Aspirations

The case studies demonstrated that the traditional school to work transition was prolonged for Ian, via training. However, the idea of becoming a chef and gaining a job on the labour market was both a clear and expected goal. It was central to his future plans and part of 'adulthood'. Amongst the remaining sample of young people (13), pre-school leaving the idea of 'getting a job' and 'working' within the labour market was a stated aspiration for six. On reinterviewing five of these six young people after they left school, all five continued to aspire to the idea of 'getting a job' and working after college. The notion of becoming a 'worker' was clearly recognised and valued as an important part of adult life, a desirable status to achieve, as reported in other studies (Anderson and Clarke, 1982; McConkey, 1989; Flynn and Hirst, 1992; Davies and Jenkins, 1993; Riddell et al, 1993; Gallivan-Fenlon, 1994; and Ward et al, 1994).

In contrast, for those young people (five) who communicated with the aid of symbols, 'work' and 'employment' appeared to be issues that were not really considered in any meaningful way. Indeed, only one of these young people, Susan, focused upon the

concept of 'work'. However, this was in the context of her own "book work" - she enjoyed doing puzzle books at home. Similarly, when the young people pointed to pictures of jobs that they would like to do, there was a sense that it was something within the jobs that they liked, such as, the animals or computer rather than the actual concept of 'work' or 'employment'. 'Work' was interpreted much more broadly the idea of 'having a job' in its conventional sense did not appear to be a central aspiration.

Two different types of 'work' (catering and caring) were highlighted within the case studies. Indeed, these also proved to be two of the three most popular types of 'work' aspired to by those hoping to get a job. The third was working in an office. At first sight one may consider these to be traditional work choices. All three of the young people who highlighted 'caring' were female, re-emphasising the gendered nature of work aspirations. On the other hand, one could argue that these are work choices grounded within a degree of realism. For example, Bob and Charisa, two physically disabled young people within the sample, both aspired to work in an office. Within his choice of job area Bob highlighted the issue of mobility as an important consideration:

> **Bob**: "I'm hoping to get a job with computers"
> **Researcher**: "What makes you want to work with computers?"
> **Bob**: "Um because it's easier for me to understand, there won't be a lot of moving around." (Cedar Drive, Pre-school leaving)

Where does this recognition evolve from? Does it emerge as a result of personal experience or advice received from others or is it an area that the young people have been channelled into via work experience? Within the study it was clear that the young people's ideas evolved from a variety of sources. Work placements were influential and office work, catering and caring did predominate here, furthermore, this type of work placement experience was associated with a number of the young people's future job aspirations.

In a similar vein to Ian, a small but significant number of young people (Luke, Bob and Charisa) held consistent ideas about the type of job that they would like to do, both pre and post-school leaving. They also clearly considered work to be a part of their adult lives, albeit a longer-term aspiration. Ian saw the idea of becoming a chef as an immediate and tangible goal, whereas Luke, Bob and Charisa saw their status of 'worker' as something for the future with their present status of 'student' as a stepping stone towards it. Ian was thus clearly one step ahead of his fellow peers.

For Ian the prospect of finding a job was viewed positively and obstacles, such as the prospect of periods of unemployment were largely ignored. In a similar manner,

unemployment was generally not raised in any detail within the wider sample. Indeed, only one young person, Ellen, pre-school leaving, raised this in passing:

> **Ellen**: "... I'd like to work in a cafe or something, serving or catering or something."
> **Researcher**: "You'd like to work in a cafe"
> **Ellen**: "Something like that or a restaurant but it's difficult to find something like that at the moment, so I'm hoping." (Beechview, Pre-school leaving)

Ellen's awareness of the difficulties of getting a job is interesting but when interviewed nine months later, she did not repeat her concern. It is also interesting to note that Ellen did not relate these difficulties to any disability. However, from the perspective of her foster parents, Ellen was viewed as somewhat unrealistic in her aspirations. Todd (1995), Todd and Shearn (1995) and Davies and Jenkins (1997) have explored further this complex idea of young people with learning disabilities being both unaware of their disabilities and the impact upon their lives.

7.2.1.2   *Parents' Perceptions*

From a parental perspective Ian's father clearly viewed a 'job' for his son as a highly significant factor within the transition to adulthood and independence. In a similar vein, amongst many parents, especially those from Cedar Drive, Beechview and Ash-hill, there was a general consensus that the idea of one's son or daughter gaining a job was both valued and wanted. A similar situation was found by Riddell et al (1993), Davies and Jenkins (1993), and Swain and Thirlaway (1994). However, in terms of the actual likelihood of this occurring, many of these parents were rather more reserved and apprehensive than their son or daughter, a finding which is in common with past studies (Conliffe, 1989; McConkey, 1989; Ward et al, 1991; and Gallivan-Fenlan, 1994). For many parents there were important differences between what they would like and what they saw as 'reality' for their son or daughter. Indeed, they were well aware of both the wider economic context and the danger of raised expectations. Economic considerations were highlighted by approximately half of the parents (eight sets). Indeed, some parents, in particular Bob's took great pains to explain that they were 'realistic' about the general job situation and the heightened competition for disabled young people:

> **Researcher**: "How do you see the sort of long term employment opportunities for Bob?"
> **Bob's Mother**: "How do I see them, I think they will be very poor, don't you?"
> **Bob's Father**: "To be quite honest I think that generally, I think there's very little for people leaving school, college, even university..." (Cedar Drive, Pre-school leaving)

The second issue of raised expectations highlighted an emotive issue and fear for a number of parents. For example, Louise's mother feared that aspirations could ultimately lead to unrealistic hopes and perhaps disappointment for her daughter:

> **Louise's Mother**: "No, she did fancy hairdressing but as I say, that's unrealistic I think to give her false hope that she will..." (Beechview, Pre-school leaving)

Furthermore, Ellen's foster parents suggested that 'unrealistic' aspirations could place undue pressure upon a young person to achieve. This raises the question as to what level parents should support the aspirations of their son or daughter? For many parents, erring on the side of caution was preferred, as high expectations were viewed as potentially dangerous and disheartening. However, one could argue, as Brisenden (1989, p.218) has done, that low expectations lead to low achievements for disabled young people.

However, parents did not always reach the same conclusions. Some did look forward to their son or daughter having a 'little' job, similar to parents within Ward et al's study (1994, p.135). This was most clearly and consistently expressed by Janet's mother:

> **Janet's Mother**: "All I'd like to see at the moment, I'd like to see her with just a group of people in a house together, you know with a life of their own ... having a little job that's all I want for her." (The Laurels, Post-school leaving)

Furthermore, Luke and Janet's parents, although aware of the problems that their son or daughter faced still wanted to think positively:

> **Researcher**: "Is employment definitely what you'd like Luke to go onto?"
> **Luke's Father**: "As opposed to unemployment?" ... "I can't see any alternative really."
> **Luke's Mother**: "As Jack says unemployment, what else is there? I mean you can't be a student for ever." (Cedar Drive, Pre-school leaving)

For Luke's parents being a student was regarded as a transitional status. Work and employment were clearly a step beyond this, part and parcel of adulthood.

In contrast, Ellen's foster mother took a somewhat more stark perspective. Work was acknowledged to be the social norm within society. As a result of this, Ellen's foster mother felt that Ellen's parents desired 'work' and a 'job' for their daughter. However, her foster mother felt that this was 'unrealistic'. She suggested that Ellen's ultimate destination would be the day centre in all probability, despite what her parents wanted. College was perceived "potentially as a bridging service between school and day centre..." (Todd et al, 1991, p.14). It was a stopgap, finally leading to nowhere in particular:

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> **Ellen's Foster Mother:** "But in all honesty Wendy, I honestly think, truthfully it's just somewhere for her to go to occupy her mind because I honestly and truthfully think that at the end of that term at college, whatever her parents want or whatever they think, it will be the training centre." (Beechview, Pre-school leaving)

Parents such as Ellen's foster parents may want 'realism' but it was unclear how far they 'would' or 'did' go towards challenging aspirations if they were viewed as 'unrealistic'. It is at this point that one should consider Todd (1995) and Todd and Shearn's (1995) idea of "fictional biographies" (Todd, 1995, p.22): ideas and aspirations held by young people with learning disabilities which are not seen as 'realistic' by either parents or professionals, but are similarly not challenged or questioned. For Todd this raises wider questions of young people's disability awareness. Todd's research introduces questions of social control, especially if the young person lacks an awareness of their learning disabilities and how others perceive them. Aspirations and 'realism' thus introduce a number of conflicting issues. On one hand, encouraging young people to aspire towards a career and employment can perhaps aid achievement. On the other hand, as parents here have demonstrated, many do not want to foster undue disappointment. Consequently, a desire to 'protect' one's son or daughter can be appreciated. Steering a path between these two extremes is thus a complicated procedure for all concerned: young people; parents; and professionals.

A small but significant minority of parents (largely within Oaksmere and The Laurels) though did not view the goal of 'work' or 'employment' as 'realistic' or 'feasible' for their son or daughter. As Eric's father noted:

> **Eric's Father:** "... what we need to look for, for Eric is an environment where he can live and have stimulation, so college is about training him for that, it not about training him for a job..." (The Laurels, Pre-school leaving)

However, one parent (Susan's mother) became more optimistic about her daughter's ability to hold a part-time job as a result of Susan's progress at college. Parental expectations were, therefore, not always fixed.

When parents did not think that their son or daughter could cope with or would get a job, the issue of alternative, 'adult' daytime activities arose. Two parents from The Laurels in Authority 3 (Julie and Eric's) had clear ideas of what they would like as an alternative to 'having a job'. Here, the importance of "purposeful" and worthwhile activities, independent of the family home but in a sheltered and structured environment, was central. This was similar to their current residential college experiences, as Eric's mother indicated:

Eric's Mother: " ... it's got to be purposeful, it's got to be not just spending time for time's sake, it's go to be some reason behind it as well."
[and] "... what I want is something like a scaled down Lakeside college, possibly a unit with eight young people, so there's enough young people around to keep him stimulated but there's also enough staff to do things with them ... um I don't want him to be just left sitting in front of a television all day." (Pre and Post-school leaving)

In contrast, parents at Oaksmere within Authority 1 (Fiona, Susan and Jason's) were much more vague in terms of their future daytime aspirations. However, there was generally a shared concern about 'centres'. Pre-school leaving, amongst four of the above parents (Fiona, Susan, Julie and Eric's), 'centres' were viewed negatively as inappropriate and unstimulating places. However, this was largely a social evaluation of what a 'centre' 'was' or stood for and not based on personal experience. As Susan's mother highlighted:

Susan's Mother: "I suppose I don't really know I've never been to one, no, I tell a lie, no, I've been to one once but I've only just like, I've looked through the doors and I've seen ... I suppose they do things as well at centres, don't they?" (Oaksmere, Pre-school leaving)

However, in gaining more knowledge of 'centres', via a friend's daughter's personal experiences, Susan's mother's fear of a lack of stimulation was reiterated, and the importance of meaningful daytime activities was again clear:

Susan's Mother: "I wouldn't like her to go to a centre and just sit in there, the centre all day just watching television. That is no good to her, that's exactly what Dawn does all day long ... if she's just going to go and sit in the chair all day at centre she can stay at home with me, she may as well." (Post-school leaving)

Susan's mother highlights the continuing social stigma attached to centres. However, parental perceptions were different. For example, Ellen's foster mother was both aware of this social stigma but also recognised some positive changes in recent years:

Ellen's Foster Mother: " ... there are only t' training centres um, which have a stigma, haven't they? But now they are doing more because it's more now, used as a base now, there's more outings into the community and different things" (Beechview, Pre-school leaving)

Other parents (Linda's and Steven's) shared this more positive outlook. They were satisfied with services so far received at the centres that their son and daughter attended as part of their leaving school package. Furthermore, opinions mellowed. After initial anxieties about centres 11 months later, Fiona's sister had come to acknowledge the potential social benefits that 'centres' could offer, providing social companionship and opportunities to meet others (Williams, 1995). This social companionship has an

important social and psychological function frequently associated with employment and 'having a job' (Jahoda, 1992).

This section has demonstrated that 'having a job' was aspired to as an important part of adult life by a significant number of the young people and their parents. However, none of the young people had progressed as far as Ian towards this goal. 'Work' and 'having a job' may have been socially accepted as an important signifier of adulthood however, as in past literature, parents were more apprehensive and guarded in their aspirations towards employment than their son or daughter. Parents' perceptions were influenced by a desire to be 'realistic'. Where parents acknowledged that getting a job was not a realistic goal, other 'future daytime occupations' were being considered, particularly activities, which had both 'purpose' and 'meaning'. This calls into question the relevance of the traditional school to work transition. However, it was clear that 'employment' was a valued aspiration and symbol of adult status for a significant number of the young people and their parents. This re-emphasises Ward et al's (1991, p.132; 1994, p.140) suggestion that a "paradox" surrounds the goal of employment for young people with a Record of needs (Statement in England and Wales). Young people and their families often desire employment but it is frequently delayed or even unattainable (see chapter two). For those parents who highlighted the importance of stimulating and socially participatory alternative daytime occupations, the challenge appears to be how to help families towards this. This concern has been explored by Ward et al's studies within Scotland (Ward et al, 1991, pp.131-132; Thomson and Ward, 1994, pp.88-89, 91-92; and Ward et al, 1994, pp.140-141). They advocate a much broader interpretation of 'employment', for example "productive daytime activity" (Thomson and Ward, 1994, p.89).

7.2.2 Living Away From The Parental Home

7.2.2.1 Young People's Aspirations

Perceptions of future living arrangements, and, in particular, the aspiration to live independently of the parental home varied. Some, young people suggested that they would like to live away from home, whereas others seemed settled there. Similarly, there were other young people who were more vague and undecided indicating that this was an area they had not yet considered. However, it is important to remember that aspirations and personal situations can change quickly, as Laura's transition demonstrated.

Within the sample six young people (Luke, Janet, Ellen, Charisa, Eric and Julie) talked of living independently or away from the parental home. All had attended, or were

preparing to attend residential college and had thus made or were about to make a significant break from home. Residential college may have afforded the young people an opportunity to leave home for varying periods of time, but they all returned home during the holidays. One must recognise that 'aspiring to' and 'actually' leaving home are two very different phenomena. However, it is significant that these six young people did value the idea of making a housing transition to a more independent status. However, for one respondent, Linda, having experienced residential college and living away from the parental home, she clearly indicated her desire not to pursue this option in the future.

Different young people held diverse interpretations and perceptions of living away from home. In common with Ian and Laura, four young people (Luke, Ellen, Janet and Charisa) wanted to live in their own home, either alone, with friends or with a personal assistant. As Charisa indicated:

> **Researcher**: "... and who would you live with?"
> **Charisa**: "A carer." (Beechview, Post-school leaving)

It was also clear, however, that timetables and expectations differed as to the time scale in which they expected things to happen. For example, Janet's pre and post-school enthusiasm to leave home was obvious:

> **Janet**: "I don't want to live at home no more." (Pre) *[and]* "I want to leave home if possible." (The Laurels, Post-school leaving)

Luke, Ellen and Charisa's aspirations were more vague and longer term:

> **Luke**: " 'Cos when I finish at Beechview and finish learning in a school environment and I go and live somewhere and those skills *[independence]* will be useful for what I do." (Cedar Drive, Post-school leaving)

Luke and Charisa were however, still only 16 or 17 years old. Similarly, uncertainty concerning 'when' and 'how' independent living may occur has also been noted by Hirst and Baldwin (1994, p.28). They found that disabled young people expressed greater uncertainty than their non-disabled peers.

Within the case studies it was clear that Ian felt ready and prepared for leaving home, something he partly put down to practical experiences gleaned from Beechview's residential independence course. In a similar manner, Charisa and Luke both valued the practical independence skills that going away to residential school or college had or would afford them. As Charisa illustrated:

Researcher: "Why do you like them *[independence skills]* best at college?"
Charisa: " 'Cos it's getting me up ready for moving into me own home."
(Beechview, Post-school leaving)

Julie and Eric communicated mainly with the aid of symbols and it was difficult to ascertain their specific ideas and aspirations. However, it was clear that they both enjoyed residential college, especially the residential aspect.

The common theme amongst many sample members was the idea of moving away from the parental home, either now or in the future. It was clear this was valued as an important part of being independent and 'grown-up'. In contrast, a small but significant number of young people (Linda, Jason and Susan) did not view leaving the parental home in a positive light. For Susan, leaving home was incomprehensible:

Researcher: "When you're adult and grown up like Mum, where would you like to live?"
Susan: "Home" (Pre) *[and]*
Researcher: "Who would you like to live at home with?"
Susan: "Mum" (Oaksmere, Post-school leaving)

Living away from home was for Susan only considered in terms of short respite 'holidays'. This was her current personal experience and was practically reinforced by the educational policy within Authority 1 of day college as the norm.

7.2.2.2 Future Living Arrangements – Parents' Aspirations

Ian and his father shared a recognition that greater independence was a good thing. Yet there were differences of perspective between families living in the different authorities. At Oaksmere (Authority 1), parents and their son or daughter seemed to assume that the young person would continue to live at home, whereas young people and their parents from The Laurels (Authority 3) looked more towards leaving home. There were, of course, some differences, and some changes over time. But those actively considering moving away from home were more likely to live in Authorities 2/3.

The importance of planning and early preparations when approaching a young person's transition from the parental home was clearly highlighted by Ian's father. Here, as we saw, he stressed a gradual and phased housing transition with support 'when' or 'if' needed. Parents from The Laurels and Charisa's parents from Beechview highlighted this too. Residential education was seen as an important catalyst and as playing a central role. For The Laurels parents, residential college was viewed as part and parcel of a wider, longer-term process. This was one within which family bonds were gradually reduced and seen as a progressive step towards greater independence, leading eventually to an opportunity for their son or daughter to start living their own life. Charisa's

parents illustrate how this connects to wider social norms of young people growing up and moving away:

> **Charisa's Mother**: "And she *[Charisa]* feels good about she's going onto college because her sister's hoping to go onto university or college or something." (Beechview, Pre-school leaving)

However, one must not forget the segregated nature of these residential colleges and the danger of only seeing and associating with disabled peers (CERI, 1985, p.10)

For Eric's parents there was a deeper moral dimension. Within their eyes, the idea of their son living at home with ageing parents was morally wrong:

> **Eric's Mother**: "But actually it's just not right for him to live with us in our circumstances when he's a young man, just that seems morally really. You know away from us ... got to live away from us with support." (The Laurels, Pre-school leaving)

In addition, there was also a practical dimension as three sets of parents (Julie, Charisa and Eric's) highlighted residential college and moving out of the parental home as an opportunity to begin to prepare for the inevitable, i.e. parental ageing and an inability to carry on caring. Julie's father highlighted this:

> **Julie's Father**: "... I think it would be best for Julie because I'm not getting any younger, she's hard work ... and it's a case of getting Julie settled for life and I'd prefer to do that while I'm able to do that rather than as a panic when I feel I can't do it, in say 10, 15 years time." (The Laurels, Pre-school leaving)

The idea that this was both a kinder and more humane approach was also emphasised. Hence, the onus was upon transition from the parental home as a gradual and planned process of adjustment for the young person. The aim was to avoid a sharp, unplanned and confusing experience in later life. As Eric's father indicated:

> **Eric's Father**: "He stays with us, watches us grow old and then when we pop off he's a middle aged man totally distraught, that would be totally wrong. So you have to take a long term view and that's what we did when he was probably five or six." (The Laurels, Pre-school leaving)

Moving out of the family home was thus seen as part and parcel of the life cycle, more specifically as part of 'adulthood' and 'adult' status. Consequently, it is unsurprising that when a young person has made the move to residential college and familial bonds have been weakened, parents frequently do not want their son or daughter to return home after college. All four sets of parents (Janet, Charisa, Julie and Eric's) stressed that they felt this would be a retrograde step. Charisa's mother clearly indicated her feelings:

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Charisa's Mother: "... 'cos you feel that that she's coming back home she'll loose all that sort of independence that she's gained while she's living away from home." (Beechview, Post-school leaving)

This parental fear of regressing rather than progressing if their son or daughter returned home was a well grounded one, as Sinson (1995, p.4 and 145) has demonstrated within her study of forty ex-residential college students. The young people who returned home lost more of their taught independence skills and were more dependent on their families than those who either lived independently or within small group homes. The importance of available, appropriate housing was a significant factor within both Laura and Ian's transitions. If young people are to remain independent after residential college then appropriate housing provisions must be available. This was an area of concern for all four sets of parents.

With this knowledge and fear, The Laurels parents, especially Julie's and Eric's, had adopted a proactive approach and were already considering and planning possible living arrangements, post-residential college. Eric's mother highlighted this:

Eric's Mother: "I've seen Eric's social worker... I asked her to come because I wanted to talk to her because we want to start looking round er for somewhere for Eric to live.... So I wanted to talk to her about exactly how to set about looking and what sort of places..." (The Laurels, Post-school leaving)

Within the case studies Ian's father ultimately aspired to his son progressing to his own house or flat. As one might expect, different parents had different aspirations and interpretations of living away from home and independence for their son or daughter. However, for parents at The Laurels, the key was independent living away from the parental home but within a sheltered and supported context (as Swain and Thirlaway (1994, p.168) have similarly noted). Janet's parents explained:

Janet's Father: "And live in a sheltered environment but independent."
Janet's Mother: " ... we want to see her with a life of her own just like the other two [siblings], live their own life, lead their own life. We don't want her to be dependent on us all the time." (The Laurels, Post-school leaving)

It was also clear that many parents at The Laurels felt in a similar manner to Ian's father, that as parents they had an important role to play within the transition process. Planning ahead was important although Charisa's father was fearful and reticent to address the post-college issue, acknowledging, "I try not to think about that."

Not all parents looked to their son or daughter leaving the family home or valued this as an important marker of 'adulthood' and the move towards 'adult' status. In fact, it was clear during pre-school interviews with Authority 1 parents at Oaksmere, that they had not actively considered the issue of future living arrangements in any depth. However,

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when the issue was raised it became apparent that they presumed their son or daughter 'would' and 'should' remain at home.

> **Researcher**: "Have you thought about the living aspect at all, in the future?"
> **Fiona's Sister**: "No, we haven't really thought about it yet."
> **Researcher**: "Do you foresee it with the family or in a sort of different environment somewhere else separately?"
> **Fiona's Sister**: "Well, I think she will stay with the family, yeah." (Oaksmere, Pre-school leaving)

Susan's mother also spoke of her daughter continuing to live at home:

> **Researcher**: "Do you think she will live here for quite a few years?"
> **Susan's Mother**: "She will do yeah, all being well yeah, yeah live as long as she wants. I suppose she'll be here as long as I'm here, as far as I'm aware, yeah..." (Oaksmere, Post-school leaving)

Conliffe (1989); McConkey (1989) and Gallivan-Fenlon (1994) have similarly noted the importance for many parents of their son or daughter continuing to live at home.

'Home' was seen as best for their son or daughter in terms of 'preference' and 'care'. Susan's mother stressed that her daughter preferred being at home:

> **Susan's Mother**: "... no she likes her home too much, does Susan, she's got everything, you know what I mean." (Pre-school leaving)

Jason's mother feared that 'others' would not provide such care for her son:

> **Jason's Mother**: "Well when Jason was younger I got asked 'bout these family placements for rest and that ... and I said 'no, I'd rather look after him myself' "
> **Researcher**: "So he doesn't have any respite. Have you ever had it?"
> **Jason's Mother**: "No, I've always looked after Jason myself, I've never felt safe with them places ... 'cos I'm always frightened that when they get there they don't come back, so I've always said 'nah, I'll look after him myself' " (Oaksmere, Pre-school leaving)

Leaving home, in whatever form, was felt to be potentially dangerous and thus to be avoided. This stood in contrast to Eric's mother from The Laurels, who similarly suggested that it was painful and frightening for parents but it was perceived as necessary. These differences between parents approaches towards future living arrangements and "letting go" have similarly been noted by Richardson and Ritchie (1989), Richardson (1989), and Swain and Thirlaway (1994). Susan's mother from Oaksmere was aware of potential difficulties in caring as she aged. However, in contrast to parents at The Laurels she had not yet practically addressed this. She was also concerned about how her sons and daughters may be involved in caring for Susan. This moral dilemma for parents over the role of siblings has been raised by Davies and

Jenkins (1993) and Swain and Thirlaway (1994, p.170). Furthermore, Ward et al found a similar difference of approach amongst a number of their parents:

> "Some were making sure that provision would be organised well in advance, while for others it was a matter of concern but an issue which they did not want to address immediately." (1991, p.109)

This section has highlighted that for a small but significant number of young people, living independently of their parents was an important aspiration, one associated with being 'grown-up' and independent. In contrast to two case studies, none of the young people had yet moved out of the parental home on a permanent basis. However, residential college or school was seen to provide an opportunity for some to embark upon a gradual transition away from home. But this was not the case for the entire sample. A small but significant minority did not value or aspire to the goal of living independently of their parents. Furthermore, parents differed in their approaches to, and assessments of, independent living. This was explored primarily with the aid of parents at The Laurels (Authority 3) and Oaksmere (Authority 1). Parents at The Laurels seemed much more prone to seek independent living arrangements and a 'sheltered' and 'supported' environment. In contrast, Oaksmere parents currently did not prioritise living independently of the family. Underpinning many of these parental differences was the important and much debated theme of "letting go" (Richardson and Ritchie, 1989). However, the systematic nature of these differences suggests that there were wider structural factors involved. For example, the importance attached to residential college differed amongst the authorities and thus the two schools. Within this there are also economic issues (as noted by the Oaksmere head in chapter four) and considerations of 'how' families are prepared.

7.2.3 Boyfriends, Girlfriends and Future Partnerships

7.2.3.1 Young People's Ideas and Aspirations

Laura's case study demonstrates how relationships with the opposite sex can, and do, change within a short period of time. Here, pre-school leaving an apparently casual relationship developed eight months later, into a mature relationship in which Laura was living with her partner. Within the sample of young people, seven had or had had a boyfriend or girlfriend. However, their attitudes, approaches and situations varied and changed over time, their relationships were not static. During the course of the research, some young people gained a boyfriend or girlfriend, whereas others noted the end of a relationship.

Amongst four young people it was clear that their relationships were time and context specific and based around school or college. This is in contrast to Laura's, which was in the more unsupervised and autonomous 'adult' setting of her own home. 'Context' and 'contact' were issues upon which one young person in particular (Janet) had strong feelings. Pre-school leaving Janet saw her boyfriend at school and the Gateway club. However, she lamented the fact that she never went out with him anywhere else:

> **Researcher**: "And where do you see Jack?"
> **Janet**: "At Gateway and school"
> **Researcher**: "... do you see him at any other times?"
> **Janet**: "I've never seen him"
> *[and]* **Researcher**: "When?"
> **Janet**: "We never go out together"
> **Researcher**: "You never go out together, would you like to?"
> **Janet**: "I would like to" (The Laurels, Pre-school leaving)

Janet's comments highlight the important question of supervision and the management of social relationships for young people with learning disabilities, an issue which Flynn and Hirst (1992, p.18) and Davies and Jenkins (forthcoming, p.23) similarly raised within their studies. Janet suggested that she would have liked more social freedom and opportunities to meet her boyfriend unsupervised. Nine months later and with a new boyfriend at residential college, Janet was more positive about opportunities to go out but still wanted to be able to go out with her boyfriend alone:

> **Researcher**: "At college do you go out by yourselves or do you go out with other people?"
> **Janet**: "Other people"
> **Researcher**: "Would you like to go out by yourself with him?"
> **Janet**: "Yeah" (Post-school leaving)

The literature (Davies and Jenkins, forthcoming, p.27) also suggests that young women are more closely sexually supervised than their male counterparts.

Within the sample it was clear that Laura was one step ahead of her peers. She had embraced the idea of living together with her partner and thus commitment. Amongst most young people this idea of living with a boyfriend or girlfriend had either not been considered or was seen as very distant. Janet was another exception, suggesting that she would like to get a flat with her boyfriend after residential college:

> **Janet**: "We might get a flat."
> **Researcher**: "Have you said anything to anyone about it?"
> **Janet**: "No"
> **Researcher**: "Have you talked to Paul *[boyfriend]* about it?"
> **Janet**: "Yeah, just me and Paul." (Post-school leaving)

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She was also more aware of social norms, i.e. that this is what other young people do. Her brother had a flat with his girlfriend:

> **Janet**: "Because my brother lives with his girlfriend, Rachel, they've got a flat, so I might go for a flat..." (Post-school leaving)

Janet appeared to take it for granted that in the near future she too 'would' or 'could' follow this route. This, once again raises issues surrounding young people's awareness of their learning disabilities and as Todd has noted the idea of "fictional biographies" (1995, p.22). Future ideas and aspirations held by young people with learning disabilities, which may not be seen as 'realistic' by others but are not questioned or challenged.

7.2.3.2 Parental Ideas and Approaches

As McConkey (1989), Heyman and Huckle (1995), and Shepperdson (1995) have demonstrated, sexuality is an issue capable of raising powerful emotions amongst parents. Consequently, the issue of relationships was discussed tentatively, often as and when parents raised issues. Within discussions it became clear that the 'social' idea of having a 'boyfriend', 'girlfriend' or 'someone special' was viewed positively by nine sets of parents. As Eric's mother exemplified:

> **Eric's Mother**: " I mean lots of students at The Laurels do, do and lots of them have boyfriend and girlfriend relationships, you know I think that's super, I think it's lovely, er but Eric hasn't" *[later]* " ...but we live in hope. I would dearly love him to have a special friend as a girl..." (The Laurels, Pre-school leaving)

However, her concept of a "special friend" has platonic rather than sexual connotations (see Shepperdson, 1995 for a discussion on the difference for parents of 'social' rather than 'sexual' relationships). How parents perceived their son's or daughter's relationship to the opposite sex did not always tally with their son's or daughter's interpretation. For example, Luke suggested that he had a girlfriend, whereas his parents did not imagine or perceive such a relationship:

> **Researcher**: "Do you have a girlfriend Luke, anyone special?"
> **Luke**: "Yeah"
>
> **Luke's Mother**: "...Luke had sex education at Cedar Drive, he knows what happens but I think he's more interested in trains and railway lines, I don't think he's, I'm not sure he treats girls as anything other than another person." (Cedar Drive, Post-school leaving)

Similarly, Janet's and Charisa's parents questioned their daughter's interpretation of 'having a boyfriend' compared to their own.

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Marriage was an important aspiration for Laura. Within the wider sample 'marriage' was also frequently discussed in a positive manner with the suggestion being that it would be 'nice'. However, beneath this there was also some scepticism. Three sets of parents (Susan's, Janet's and Eric's) felt that it was either not really feasible or was not seen as very likely. As Janet's father illustrated:

> **Janet's Father**: "... whether she could or appreciates what a settled environment is in that sense, a relationship, I don't know. Whether she understands marriage and the commitments of marriage, I'm sure she doesn't in that sense ... I don't think I could stop it but I don't thinks she would appreciate marriage..." (The Laurels, Post-school leaving)

For other parents such as Luke's and Charisa's, marriage was addressed as a somewhat distant phenomena:

> **Luke's Mother**: "(sighs) I sometimes think about if he will ever get married or if he will ever find anyone ... if he'll meet anyone who'd want to or if he'd want to pair up with anyone in the future." (Cedar Drive, Post-school leaving)

Amongst the eight young people reinterviewed, six viewed 'marriage' as a distant prospect. This idea of 'distance' may well have influenced some parents in their relaxed approach towards the idea of 'marriage'. It may also help to explain why other studies, such as McConkey's (1989, p.35) and Brotherson et al's (1988, p.171) found their sample parents were more emphatic that they did not want their son or daughter with learning disabilities to get married.

Laura's decision to move in with her boyfriend underlines very publicly an important social and legal marker of adulthood: namely, the expression of an individual's sexuality. Accepting that one's own son or daughter is sexually active can be difficult for any parent. Here, parents' attitudes towards and experiences of their son's or daughter's sexuality varied. Some parents (Steven's, Charisa's, Ian's and Janet's) acknowledged their son's or daughter's sexuality. As Janet's mother indicated:

> **Janet's Mother**: "... she's been found in the cupboard several times naked with a boy but that's just experimenting I think, horsing around..." (The Laurels, Post-school leaving)

On the other hand, an absence of sexuality was noted. Ellen's foster mother raised questions of parental 'non-acceptance', a denial of sexuality and thus adult status. She regarded Ellen's biological mother as still having to come to terms with the idea:

> **Ellen's Foster Mother**: " ... I mean her parents don't ever think that er, well they just do not think that she's ever any sexual feelings in any way or form." (Beechview, Pre-school leaving)

Others recognised it as an issue but saw it as a distant issue.

Another shared concern was the issue of young people's perceived 'vulnerability'. For example, pre-school leaving Laura's father had indicated his awareness to his daughter's vulnerability and, hence, his concern to protect her. The majority of parents similarly shared a concern about 'others' taking advantage, especially the parents of young women (Janet, Susan and Ellen's), as Janet's father highlighted:

> **Janet's Father**: "I mean she was in the club the other night. She was talking to a guy I didn't know and he was chatting away to her and sort of leaned over and put his arm round the back of the chair and immediately I was on guard..." (The Laurels, Pre-school leaving)

Fear of exploitation by others and a felt parental need to protect has been highlighted by Thomson and Ward (1994, p.83), Davies and Jenkins (forthcoming, p.25), Hendey and Pascall (1997, pp.6-7). Others have specifically mentioned this in a sexual context (Heyman and Huckle, 1995). This was also connected to the question of sexual knowledge. Three sets of parents noted a perceived lack of sexual understanding or awareness. In terms of sex education, eight sets of parents discussed the issue of sexuality. Six viewed sex education positively. It was viewed as an important part of a young person's education. This contrasts with Heyman and Huckle's finding that 17 of their 20 sets of parents did not want their son or daughter with learning disabilities to have sex education (1995, p.146).

The issue of 'care' was also important, especially in Laura's case. She may have accepted a caring role but her boyfriend also provided 'care' for her. Susan and Lisa's mothers further highlighted the importance of 'care' within a relationship, especially for young women. Would a boyfriend be able to care for their daughter in the future?

> **Lisa's Mother**: "... he thinks a lot about her ... you don't know what's going to be in t' future. You know is he goin' to get a good job when he leaves school, is he goin' to look after her and take care of her, you know..." (Beechview, Pre-school leaving)

7.3 Social Participation and Feeling 'Grown-up'

The previous section explored 'adulthood' and an 'adult' status from the perspective of three key transitions: school to work; housing; and domestic. Here, the focus was largely upon future aspirations towards these status transitions. However, for many of the young people these transitions were still to be accomplished. In this third and final section the analysis will be broadened. Firstly, additional dimensions will be explored, namely social independence and community participation. Secondly, we will explore a

range of factors, which seem to be associated with feeling 'more grown-up'. The role of parents will also be considered, especially the idea of 'letting go'.

7.3.1 Social Participation and Community Integration

The concept of social citizenship was briefly raised when discussing Laura's case study, especially in relation to social security and her receipt of invalid care allowance. Social citizenship will also be explored from the perspective of active, 'adult' social participation within society more specifically, leisure activities within the community. Here, the transition can generally be viewed as a move away from a state of social dependence upon one's family to greater social independence (Fish, 1986; McGinty and Fish, 1992; Ward et al, 1991; and Thomson and Ward, 1994). It is argued that this is related to achieving a socially valued presence within the community.

7.3.1.1 Young People's Experiences

Within the case studies Ian and Laura both indicated the importance of friends. Prior to school leaving these were largely from special school rather than locally based. Laura also indicated that she rarely saw her friends out of school because of the distance they lived from her. This was reiterated amongst wider sample members. When talking about 'friends', the young people were quite specific about a set of people based at special school or college. For many young people this also meant an absence of non-disabled peers as friends. This is similar to that reported in other studies (Conliffe, 1989, p.21; Chadsey-Rusch et al, 1991, p.26; Flynn and Hirst, 1992, pp.26-27; Hirst and Baldwin, 1994, p.78). Hence, special school or college was an important social meeting place for many of the young people. Within the wider sample only three young people (Eric, Janet and Louise) talked of seeing their friends outside of school with any degree of regularity. For the remaining sample members, although many said they saw friends, when probed, they were extremely vague. For example, Luke's 'sometimes' appeared to be a matter of chance meetings:

> Researcher: "Do you ever see your friends out of school?"
> Luke: "Sometimes"
> Researcher: "Where do you meet them?"
> Luke: "Sometimes I'm walking through town and I see, er see someone."
> (Cedar Drive, Pre-school leaving)

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This irregularity of meeting seemed largely to be accepted. Only Charisa tried to explain this recognising, as Barnes (1991) and Leicester and Lovell (1997) have noted, the role of geographical distance:

> **Charisa**: "Um, I haven't got many friends here ... because everybody lives quite a long way away from my house." (Beechview, Pre-school leaving)

Within the case studies the idea of 'going down the pub' or visiting a 'night-club' were valued as two 'adult' activities and forms of social participation. Within the wider sample, five young people similarly indicated that they too valued these activities and felt that they were 'grown-up' things to do. This remained only an aspiration for both Laura and Ellen however, their reasons were very different. Laura's were financially based, whereas Ellen suggested that her parents would not allow it, highlighting it as a matter of parental supervision and control of her social life:

> **Ellen**: "... and they *[her parents]* explain that ... clubbing and that, and drinking and stuff it's not a good idea."
> **Researcher**: "And would you like to go clubbing?"
> **Ellen**: "I would." (Beechview, Post-school leaving)

Ian, as we saw, valued 'going down the pub' without his family, i.e. unsupervised. However, within the wider sample, the four young people who valued going down their local pub indicated that it was largely a family affair. Hence, there was an element of parental supervision and also dependence.

Such family involvement was in fact common and has been reported in previous studies (Anderson and Clarke, 1982; Conliffe, 1989; Flynn and Hirst, 1992; Hirst and Baldwin, 1994; Richardson et al, 1994; and Davies and Jenkins, 1993, forthcoming). In addition, family input and organisation still appeared to be important when young people moved on to residential school of college. For example, of the five young people reinterviewed at residential school/college, when they returned home at weekends or for holidays their social lives once again appeared to be family dependent. Janet illustrated that in the holidays:

> **Researcher**: "And when you come home, do you go out with Mum and Dad a lot?"
> **Janet**: "Yeah, we still go to the club." (The Laurels, Post-school leaving)

Furthermore, as Hirst and Baldwin (1994, p.87) have noted, within this sample, family dependency was more pronounced the more severe a person's disability. For example, Susan's, Jason's and Julie's social activities tended to focus upon going out with their parents. As Julie suggested:

> **Researcher:** "And do you go out with Dad a lot?"
> **Julie:** "Yes"
> **Researcher:** "Where do you go out with Dad?"
> **Julie:** "Little Chef" (The Laurels, Pre-school leaving)

Within the sample two young people may have interpreted the idea of a 'club' as a 'night-club'. However, for the majority, 'clubs' were not perceived as such, they were interpreted as 'special' clubs, such as Gateway, or youth clubs. Gateway, for example, was an important social meeting place for Janet and Eric. It was a place to meet friends and have fun:

> **Researcher:** "How do you feel when you go to Gateway?"
> **Eric:** "Happy" (The Laurels, Pre-school leaving)

Time spent at Gateway was clearly valued. Davies and Jenkins (1993) and Hirst and Baldwin (1994) have similarly suggested the value attached to special clubs in extending social lives beyond the familial sphere. However, one must not forget that they are 'special' clubs and thus segregated from wider community participation.

During this period of research, many of the young people (12) were currently attending or had attended organised activities such as local youth clubs, especially those from Authorities 2/3. A noticeable factor behind this was the role of school or residential college, which frequently organised and directed entry into local clubs. This was prominent for young people at Cedar Drive, Beechview and post-school, residential colleges. For example, at Beechview and many of the residential colleges, opportunities to attend locally based clubs and organisations were built into the idea of a 24-hour curriculum. For Louise this provided an opportunity to meet and mix with local peers:

> **Researcher:** "What did you used to do there?"
> **Louise:** "Play, watch telly, play pool, table tennis, listen to music."
> **Researcher:** "Did you meet many new friends there?"
> **Louise:** "Yeah" (Beechview, Pre-school leaving)

Social activities at residential school or college were also highly valued. For example, the five young people reinterviewed who had moved on to residential school or college became extremely animated when talking about their social activities. It appeared that residential provision had either created social opportunities, where none had hitherto been available, or had created a more varied and active social life for the young people.

However, it is important to emphasise the continuing 'special' and 'segregated' nature of residential provision. 'Supervision' was ever present, as school and college not only organised the young people's education but also their leisure time. There are also questions of 'how far?' and 'for how long?' wider community participation is extended. Just because some of the young people attended local clubs, one cannot automatically

presume that they were integrated or to what degree. There is a subtle difference between integration and inclusion (Oliver, 1996b). Brisenden (1987, p.20) for example, has highlighted how he felt an 'outsider' when bussed in as part of a 'special' group to a local youth club. Secondly, local clubs may be attended with local peers but they are local to the residential school or college. What happens when young people leave residential school or college if they move back to their own home communities? This is an important issue and will be discussed within the following section.

7.3.1.2   Parental Assessments and Approaches

Assessment of a young person's social life sometimes differs between the young person and their parents. This was clearly demonstrated by Ian and his father. Ian was generally positive about his social life, whereas his father was frequently concerned. This was similarly demonstrated in the wider sample. Five sets of parents from Authorities 2/3 highlighted their son or daughter's social life as an area of concern, similar to McConkey's study of fifty two Dublin families (1989, p.21). Concern may have been concentrated amongst parents from Authorities 2/3, but there was also a significant number of parents (five) within both authorities who were either not unduly perturbed by their son or daughter's social life or viewed it in a more positive light. Parental interpretations differed just as parental expectations did.

Ian's father raised another parental dilemma: should he intervene within his son's social life or should he respect Ian's social choices? Within the wider sample this was not interpreted as such a dilemma. Providing opportunities for a son or daughter to improve their social life was generally viewed as a positive step to take. However, approaches differed, varying from seeing the importance of residential college to greater participation within the local home community. The first approach was the most popular and especially favoured by parents from The Laurels. Residential college was a chance to meet and mix with peers, discover new leisure activities and begin to develop an independent social life beyond the familial sphere. Janet's father was very aware of his daughter's narrow and family based social life:

> **Janet's Father**: "She's exhausted our facilities to be able to provide for her or to stretch her any further than we're doing now. She needs friends, peer group to mix with and to establish herself as a person in her own right, not as our daughter which she always will be when she's with us..." (The Laurels, Pre-school leaving)

However as McConkey has noted, parents often favoured this "...so that handicapped people could mix together..." (1989, p.21).

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Eight to 12 months later it was clear that the vast majority of parents whose son or daughter had moved onto a residential option felt that it had improved the young people's social lives. Eric's mother stressed the importance of extended social opportunities and peer contact:

> **Eric's Mother**: "... I mean he's doing a lot, it's opened up a whole lot of new experiences for him and he's enjoying them all, er, and also he's got young company around him the whole time..." (The Laurels, Post-school leaving)

Furthermore, five out of six parents felt that it had also improved their own social lives, providing more free time to do what they wanted. Janet's mother viewed it as an opportunity:

> **Janet's Mother**: "... it's been like looking after a child for 20 years and now to have that freedom it's nice, not that I want rid of Janet, don't get me wrong. That's not how I feel but it's nice to start thinking that we can now start living our lives, having a life together... (The Laurels, Post-school leaving)

Residential college was thus felt to help parents partly address a parental dilemma raised by Thorin et al:

> "Wanting to create a separate social life for the young adult and wanting to have less involvement in his or her life." (1996, p.119)

On one hand, residential college helped to create a separate social life for young people within which their parents were not involved. However, it was only a partial solution, due to its temporary nature.

Furthermore, the temporary nature of residential school or college also raised questions for parents regarding the future. This was particularly an area of concern for three sets of parents (Lisa, Louise and Janet's) due to the perceived dearth of social opportunities on returning home. For example, Janet's mother was very aware of the perceived dangers:

> **Janet's Mother**: " ... the social side, I do not want to bring her back here *[Authority 3]*, to go to *[Unitary city]* college, to come back here, coming back right where she's left, if you know what I mean. Not that I don't want her home but she's going to be back in the same situation she was before she went to Willow Lodge college, no social life, no friends as such." (The Laurels, Post-school leaving)

Janet's mother's fears would appear to be well grounded as Sinson's (1995, p.76) study has demonstrated. Sinson found that those who returned home after residential college were generally not as happy, had fewer friends and frequently returned to a family oriented social life. She also found that ex-students' social lives, wherever they lived,

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tended to focus upon 'special' clubs and disabled peers. It is very clear that post-residential school or college, a young person's local, social community is a crucial issue. Social activities and routes into the local community must be available for those returning home. Of the four young people who had left Beechview and returned home, two parents (Louise and Ellen's), when reinterviewed, expressed concern about the lack of social opportunities and clubs available.

In contrast, Geoffrey's mother in Authority 3 adopted the second approach - pursuing local community participation. Here, she was eager to help her son towards a more active and varied social life and felt that residential college was not the best way to do this, although promoted as a positive opportunity for her son by school professionals. She and her husband had rejected the option of residential college because they felt that this would create a social distance for Geoffrey from his home community and difficulties later on returning to the local community:

> **Geoffrey's Mother:** " ...because it's *[residential college]* so far away it would mean Geoffrey boarding. We wouldn't really like that, so we plumped for something which may not seem as wonderful on paper but will enable Geoffrey to live at home and get involved locally in things that he would be totally cut off from if he lived away and came back." (Cedar Drive, Pre-school leaving)

Geoffrey's mother had also worked hard with Geoffrey's social worker to try and create an active, community based social life for her son:

> **Geoffrey's Mother:** "Geoffrey plays the trumpet, his teacher is hoping eventually to get him into a band..." *[later]* "... and then he has joined the adventure club which is something really nice..." (Pre-school leaving)

This section has illustrated that many of the themes highlighted in previous research are still major issues. For the majority, family dependence remains a continuing factor. Residential school or college provides social opportunities for some young people but frequently these are still partial due to its temporary nature. Overall, the importance of, and need for *more,* social opportunities and routes into local activities has been clearly demonstrated.

7.3.2   Moving From Childhood Dependence?

7.3.2.1   Feeling 'More Grown-up' - Young People's Perceptions

In this final section the focus will turn to explore, 'what' made a number of the young people feel 'more grown-up' within their every-day lives. It will also examine personal symbols associated with being 'more grown-up'.

The idea of being 'grown-up' was generally recognised and viewed positively by the young people within the sample but there was a great deal of variation within its content. Some young people were able to articulate very clearly specific ideas and instances, which made them feel 'more grown-up', whereas others were unable to specify any such instances or ideas (see also Davies and Jenkins, forthcoming). In fact, the idea of being 'grown-up' appeared somewhat vague as exemplified by Julie:

> **Researcher:** "Yes, what did he *[teacher]* used to say about growing-up?"
> **Julie:** "I'm to be a good grown-up girl"
> **Researcher:** "A grown-up girl, uh hu and what do you do when you're a grown-up girl?"
> **Julie:** "I start to be a grown-up girl"
> **Researcher:** "Yes, and what do you do when you're a grown-up girl?"
> **Julie:** "I just start being a grown-up girl." (The Laurels, Pre-school leaving)

Here, two socially opposite concepts co-existed but were merged together as one: the idea of being 'grown-up' and an adult; and the idea of being a 'girl' and still a child. This perception of adulthood raises questions about 'eternal childhood' and young people with learning disabilities being perceived or treated as "eternal children", whatever their age (Doctor John quoted in CERI, 1988, p.19 and Barnes, 1991, p.55). Furthermore, for the young people who communicated with the aid of symbols it is recognised that a discussion of ideas surrounding the concept of being, or feeling, 'grown-up' is invariably thwarted by the more restrictive context of communication via symbols.

Amongst the young people who were able to highlight specific ideas and instances two key areas were explored: school and home. In terms of feeling 'grown-up at school' it became apparent that the young people valued tangible symbols and markers, something which they felt singled them out from younger pupils and thus gave them a special and more respected status. The two most frequently mentioned symbols were 'movement' and 'responsibilities'. Four young people highlighted the importance of permission to go outside of school, either independently or semi-independently. For example, Lisa felt 'more grown-up' when she was allowed to go to the shop with a couple of friends:

> **Lisa:** "Letting me go out on me own"
> **Researcher:** "... and where are you allowed to go on your own?"
> **Lisa:** "Go for a walk out on me own" *[later]* "Go to t'shop on me own"
> **Researcher:** "... and are you allowed to go by yourself?"
> **Lisa:** "I go with a couple of me mates" (Beechview, Pre-school leaving)

Three young people (Janet, Geoffrey and Ellen) valued 'responsibility', such as being asked to respond to requests or take messages to other teachers. This indicated to them that they were respected and trusted by teachers.

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Feeling 'grown-up' at home raised issues of greater independence and responsibility for a small but significant number of the young people. This was clearly demonstrated by Luke and Susan who had both taken steps, however small, to assert their independence and make choices. For Luke this entailed choosing when he wanted to go to bed at weekends. Susan too indicated that she valued having her own space at home - her bedroom, where she could spend time alone, doing her 'own' thing:

> **Researcher:** "Is there anything else that makes you feel grown-up ... at home?"
> **Susan:** "Here"
> **Researcher:** "Being in your room?"
> **Susan:** "Yeah" (Oaksmere, Pre-school leaving)

This has been noted in other studies (Davies and Jenkins, forthcoming, p.12). Davies and Jenkins associated this with a desire by young people to escape the constant supervision and management that tended to characterise their lives. Physically, Susan also seemed to be in control of who entered her bedroom as she had a low level lock on the door, which she could reach whilst sitting on the floor and which she emphasised she used.

> **Researcher:** "Do you think Mum lets you do anything else grown-up now that you're at college?"
> **Susan:** "Yeah"
> **Researcher:** "What?"
> **Susan:** "Lock door" (Post-school leaving)

A common theme within these steps or symbols was the value placed upon opportunities for greater personal autonomy. Within the three traditional transitions these small steps or symbols surrounding feeling 'more grown-up' could perhaps be ignored. For example, Susan still lived within the parental home and was dependent in many respects upon her mother. However, for Susan control over her own bedroom seemed to be a very important means to assert her independence and begin to take some control over her life. However, if these steps are placed in a wider context, for many of these young people, dependence and supervision are still very much part of their lives, as Davies and Jenkins (forthcoming, p.50) also confirm.

7.3.2.2 Parents' Role

Within the case studies it was clear that an important part of the young people's movement towards adult independence was family support, both in terms of providing a supportive context and, conversely, the withdrawal of support in order to aid independence. This was clearly demonstrated by Ian's father as he gradually withdrew into the background. "Letting go" was thus perceived as an important and positive act

but it was also related to external social indicators such as legal criteria and chronological age:

> **Ian's Father**: "... basically you don't have no option about it, because once he becomes 18 anyway, you're an adult, er legally whether they're, they're like a, still like a three year old or a five year old. They have that right and there's nothin' you can do to stop it." (Beechview, Initial interview)

The wider sample of parents, however, tended to focus upon personal rather than external factors as indicators of being an 'adult'. Consequently, although many parents wanted to view their son or daughter as an adult they felt that it was sometimes difficult to do so. For example, approximately half of the young people's parents highlighted at least one of three potential barriers: physical maturity factors, focusing upon parental perceptions of 'looking like' an adult; social maturity factors, such as parental evaluations of behaviour as socially immature' and, finally, disability levels, the gulf between a young persons' mental and chronological age. As in Davies and Jenkins' study (1993) parents recognised that their son or daughter was not a child but also felt that learning disabilities could and did affect their adulthood. These parental perceptions of a son or daughter as an 'adult', or not an 'adult', are important because they highlight associated factors such as physically looking like and socially acting as an 'adult'. These feelings may have influenced how parents approached the process of "letting go".

Amongst the wider sample of parents this idea of "letting go" was recognised as an important consideration. It was a step that they, as parents, should address but practically fears were held and barriers perceived. Two of the most frequently mentioned fears centred upon issues of 'pain' and 'risk'. The idea of "letting go" was perceived as a painful process by six sets of parents. It was viewed as a time of emotional turmoil and a great deal of anxiety. These feelings were not relished or welcomed and four sets of parents viewed it almost as an endurance test, something, which they must pass through so that their son or daughter could reap the benefits of greater independence. As Lisa's mother demonstrated:

> **Lisa's Mother**: "Well, first time I let her go into town was one Saturday. She said, 'can I go into town?'. 'I don't know Lisa, it's too busy' but I thought let her try it. I said, 'I'll drop you off here and I'll pick you up, ring me, I'll pick you up'. Well, it got to six o'clock and I was runnin' round town lookin' for her and she'd got the bus ... by the time I got home she was at home, you know ... it's a relief to see her but at t'end of t'day you feel so narked with her for not phonin' yer, you know. You can't shout at her, 'cos it's her independence, you know." (Beechview, Pre-school leaving)

The second issue of 'risk' has previously been raised within the context of young people's vulnerability, especially a daughter's sexual vulnerability. From a wider

perspective many parents (nine) generally perceived the world as a dangerous and threatening place, fearing that 'society out there' would exploit or take advantage of their son or daughter. Luke's mother succinctly summarised this, recognising that:

> **Luke's Mother:** "He's a very trusting kid, isn't he? He's not street wise and that's what worries me." (Cedar Drive, Pre-school leaving)

Furthermore, 'risk' was also viewed in terms of physical dangers within the home (Jason and Susan's mothers'): for example, the danger of scolding oneself when making a cup of tea. Parents faced and addressed these dilemmas in different ways. Some parents, like Ian's, sought to withdraw but the degree of withdrawal varied. Louise's mother felt that the process was one of gradually gaining confidence both in her daughter's ability to cope and her own judgement as a parent:

> **Louise's Mother:** "... it's only a case of you've got to let them do things, having the courage to let them do things once (pauses) and once you've done them once, then it's, it's better." (Beechview, Pre-school leaving)

Furthermore, the degree to which parents "let go" differed. Residential college was seen as an opportunity to initiate this process for The Laurels parents. Conversely, at Cedar Drive, Bob's mother did not initially welcome her son's post school residential choice and felt extremely hurt:

> **Bob's Mother:** "... why he wants to go to Beechview I don't know ... why he wants to leave home I don't know ... you know he's got a nice home here." (Cedar Drive, Pre-school leaving)

'Risk' was thus an important concept underpinning many parents' ideas and fears surrounding the issue of "letting go". The world was viewed as a 'risky' place hence, there was a desire to protect and minimise risks. Theorists such as Perske (1972) and Blatt (1987) have suggested that this is a moral right for young people. However, addressing and confronting 'risk' is a complicated area, as Schloss et al (1994) have noted. "Letting go" was clearly an emotionally painful process for Bob's mother. Consequently, it is important to recognise and respect that this is frequently a time when families need support (Brotherson et al, 1988; Richardson and Ritchie, 1989; Richardson, 1989; and Swain and Thirlaway, 1994).

Conclusion

Within this chapter 'adulthood' and an 'adult status' has been explored. In order to unpack these concepts two case studies were initially examined (Ian and Laura). These two young people were chosen because, although they were still involved within the transition to greater personal independence, they had both already made a number of

significant steps towards this goal. These transitions had been approached very differently and were much affected by gender. Within Laura's transition the domestic sphere and caring were central, whereas Ian looked towards and prioritised the labour market and his future status as a 'worker'. However, beneath this gendered dimension it was also apparent that there were many different variables interacting, such as material and economic factors, family support and the personal input of the young people themselves. Of course, one could argue that any analysis of two individual biographies is too personal and one should not generalise from these. Yet analysing the two cases does provide invaluable insights into a complex process. These insights have lead to a clearer and more informed understanding of the concept of 'adulthood' and have also highlighted some of the key factors that aided their transitions.

The two case studies were also a means through which the wider sample could be understood. It was clear that the wider sample of young people had not progressed as far as Ian or Laura. However, a significant number had clear aspirations towards similar transition goals. They clearly valued them as important symbols and indicators of being 'more grown-up', especially the idea of 'having a job' and living away from the family home. However, not all of the young people and their parents aspired to the same goals with the same degree of intensity or on the same time scale. Some did not yet aspire to these goals at all. For example, a small but significant number of parents did not view 'work' as a realistic option for their son or daughter.

It is also important at this early stage within the transition to consider issues or concerns raised by parents as they look towards the future. Two key issues were apparent: alternatives to work; and post-residential college opportunities for young people. Within the former the importance of stimulating and purposeful activities was clear for a small but significant number of parents (see also Ward et al, 1991; Thomson and Ward, 1994; Ward et al, 1994). A central fear for these parents was a future lack of stimulation, post education and a concern that 'centres' were unstimulating places. Within the literature however, it is clear that 'centres' have made some progress in recent years (Williams, 1995). This progress must of course be continued but it is also important for parents to have *more* information about them.

The second issue of post residential opportunities was raised as a concern by those parents (especially at The Laurels) who placed many hopes and aspirations upon residential college. It was viewed as a means to procure both a more independent life and adult social opportunities for their son or daughter. Longer term, post-college fears were already apparent and returning home was viewed as a retrograde step. Questions were raised concerning future housing options and, if a young person did return home, their social opportunities. The issue of housing opportunities for disabled people is a

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general area of concern (Morris, 1993b; Thomson and Ward, 1994, pp.81-82; Fiedler and Johns, 1997, p.3). Here, parental concern, once again, highlighted the importance of information and professional advice in order to avoid unnecessary anxiety. The continuation of a stimulating social life for a son or daughter was important for these parents. Hence, the question of returning home and a danger of social isolation within the local community was raised (see also Anderson and Clarke, 1982, p.347; Fish and Evans, 1995, p.81; and Sinson, 1995, p.150). A significant number of parents clearly felt that residential college enhanced their son's or daughter's social life. In fact, residential college was perceived as a sort of *surrogate* form of transition, an alternative symbol of a changing social status, especially when parents viewed traditional, institutional status transitions as currently unavailable. However, it is important to recognise that residential college is often a temporary solution to much deeper problems, such as, social opportunities and participation for disabled young people within the community. Residential college in many respects side steps these problems. Consequently, it is important to not only recognise the problem of social isolation and a dearth of local community based social opportunities but also to actively address them.

Chapter 8 – Summary And Concluding Comments

This study has been guided by two principle aims. Firstly, it has explored processes and procedures preparing young people for leaving 'special' schools and, secondly, it has examined the every-day experiences and future aspirations of a sample of young people and their parents. Chapter three divided these general aims into five areas, which chapters four to seven explored in-depth. These five areas focused upon: post-school opportunities and vocational routes; preparations for school leaving and service transitions; the development of transition plans via the Code of Practice (1994); young people's and their parents' experiences', and, finally, their future aspirations. Throughout chapters four to seven a number of shared themes and areas of concern emerged. These have been grouped together into a further five themes (future planning and information; participation and involvement; inter-agency working; post-school opportunities, and attaining 'adult' status). They will form the foci of this concluding chapter. These themes provide a holistic assessment of the study, drawing together its insights and conclusions. The sixth and final section of the chapter will consider current policies and potential implications and the need for further research.

8.1 Future Planning, Information and Advice During School Leaving

8.1.1 Future Planning

Within this study, the idea of 'planning' was generally welcomed and valued but ideas of 'how' planning was best approached varied enormously. Chapter five demonstrated that the 1994 Code of Practice's guidelines for the first 14-plus review and transition plans encouraged schools, professionals, young people and their families to consider longer-term, future objectives and provisions. This recognised the importance of moving beyond a next step to a more holistic approach, as noted by Wood and Trickey (1986, p.120). However, fieldwork within the focus schools demonstrated that transition-planning meetings were still frequently used as a time to plan for the 'next step' only, as was also found in Tisdall's (1996/97) previous work. Tisdall, in her study

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of FNAs within Scotland, highlighted that the meetings were focused upon a next-step approach at the expense of wider 'adult' goals and indicators (pp.6-7). However, within this study there was also awareness and recognition of the importance of longer and broader transition issues, even when 'next-step' considerations tended to predominate. Looking ahead to the future was frequently viewed as difficult and problematic. At three schools, in particular Ash-hill, The Laurels and Cedar Drive and amongst social service professionals it was often viewed as crystal ball gazing because future service provisions, especially funding and resources, were viewed as uncertain. At the time of interviewing (1995) this was accentuated in Authorities 2/3 by impending local authority changes. Furthermore, it was also felt that young people's impairments and thus 'needs' frequently changed over time. These uncertainties were perceived as practical barriers and thus tended to discourage a longer- term approach.

Chapters six and seven indicated that the question of 'planning' from a parental perspective raised complex and sometimes very forceful emotions. Some parents clearly would have welcomed longer-term professional discussions of the future, whereas other parents did not expect or want this. More specifically, half the sample of parents adopted and welcomed a step-by-step approach. Considering one step at a time was felt to be more manageable, practically and/or emotionally. In contrast, other parents were more willing to consider longer-term issues. The degree to which they embraced longer-term considerations varied. However, a small but significant number of parents (four) from Authorities 2/3 welcomed a longer-term approach and themselves took a pro-active role. Amongst these parents the perceived importance of residential college was a shared characteristic, not only as a next educational step but also as part and parcel of wider preparations for adulthood.

This study has thus demonstrated the complexity and diversity of approaches when planning for the future. Clearly, it is very important to plan for the future. Past studies (Anderson and Clarke, 1982, CERI, 1983; Hirst, 1985; Gallivan-Fenlon, 1994; Tisdall, 1996, 1996/97) have illustrated the many problems that can occur because of late or poor planning. Official policy guidelines, such as the Code of Practice (1994), are aware of this. They also advocate a more holistic approach to the transition years, as others have recommended (CERI, 1983; Fish, 1986; McGinty and Fish, 1992). However, it is also important to recognise the practical, institutional and economic problems that professionals can face, which can hamper this holistic approach. Furthermore, the diversity of parents' approaches and feelings about future planning must be respected. Professionals need both to be aware of and responsive to parents' ideas, experiences and personal circumstances (Richardson and Ritchie, 1989; Ritchie, 1989; Griffiths, 1994; Swain and Thirlaway, 1994; Orlowska, 1995 provide a wider discussion).

Consequently, although official policy recommendations may clearly advocate longer-term future planning, other issues need to be taken into account. For some parents longer-term planning needs to be approached and worked at gradually.

8.1.2 Information And Advice

Within the study, as one would expect, parents' assessments of information received during the transition period varied. This was particularly true of information parents received from school staff with regard to post-school opportunities and available career routes. However, a number of shared themes and experiences emerged amongst parents. For example, chapter six demonstrated that the vast majority of parents valued the 'specialist' knowledge of their focus school. They attached great importance to the school as a key provider of information, as Gallivan-Fenlon (1994) similarly found. Here, the informal, relaxed atmosphere of school was especially important. However, this is not to say that all parents were completely satisfied with the information provided. Indeed, over half of them, at one point or another, either raised questions or voiced concerns about the 'timing', the 'depth' or 'presentation' of the information that they had received. Concerns and/or suggestions focused upon three areas: 'when', 'how' and from 'whom' information was given. It was clear, for example, that 'early' information was valued, especially by parents in Authorities 2/3 looking towards residential college with long waiting lists and time consuming FEFC applications. 'How' information was presented to parents was also important. Presenting post-school opportunities in a more organised or collated format was highlighted. Finally, the issue of 'who' provides information was raised. The importance of looking beyond formal and professional to informal sources, such as parents who have experienced school leaving was noted. Here, help in allowing parents to 'network' may prove valuable in the future. Overall, there was a general feeling that *more* information would have been welcomed during this period.

Professional and family assessments of careers advice (chapters four and six), both school organised programmes and guidance from careers advisers was valued in *all* the focus schools. It was recognised as an important part of school leaving preparations. This is a positive development when one considers earlier studies (Anderson and Clarke, 1982; Hirst, 1985) and their assessment of careers provision. However, it was also clear that some school professionals and careers advisers *still* regarded this as a developing area, especially for young people with pronounced learning disabilities. Many young people and their parents recognised the role that the careers service had played within school leaving discussions. Indeed, six out of nine young people from Authorities 2/3 viewed their careers adviser as an important source of information

and/or as someone they could talk to. On the other hand, it was also apparent that a small minority of young people could not remember seeing their careers adviser. Hence, even if they had indeed seen them, little impact had been made. In a similar manner, although three quarters of parents interviewed indicated that they had talked to, or received, information from a careers adviser, assessments varied. Generally, most valued the information and support they received however, a small but significant number (five) raised questions about either the 'quality' or 'quantity' of information. Progress towards developing comprehensive careers programmes as an integral part of the school leaving process has clearly been made. However, the study highlights that there are *still* areas where improvements should be sought.

The question of 'special' and 'generic' careers advisers was also raised in chapter four. Within the focus schools, representatives clearly valued the idea of 'specialist' careers advisers with 'special' knowledge of SEN and post-school provisions. This is not all-together unsurprising when one considers the context and ethos of 'special' schools. However, the key point to note here is the importance placed upon detailed professional knowledge. This was also demonstrated in chapter five within the Code of Practice's transition plans (1994). Here, the official policy of LEA representatives writing young people's transition plans was questioned in Authorities 2/3 by two review co-ordinators. Issues were raised concerning LEA representatives' 'knowledge'. These concerns thus highlight two issues. Firstly, they re-emphasised the importance of professional knowledge and, perhaps more significantly, professionals *knowing* the young people with whom they are working. Secondly, they demonstrated that although the Code's policy of LEA officials writing transition plans may appear administratively rational there are important issues of 'distance' and 'knowledge' to be considered. This is an issue, which we will be discussed further, especially in section six of this chapter.

8.2 Participation And Involvement Within School Leaving Preparations

8.2.1 Appropriateness?

Chapter four illustrated that college link courses and work experience programmes were welcomed as a positive learning experience by both school professionals and the young people who had undertaken them. Regular attendance at a mainstream college was valued as an important means to ease the transition from special school. Furthermore, it was also clear that educational professionals within Authority 1 welcomed the policy of special schools joining together to share college courses. This provided an opportunity for students to extend their social network, to meet and mix with new peers. However,

although this was a positive experience for some of the young people there were still important issues surrounding social interaction and inclusion (see also Todd, 1995). Yes, the young people were moving out of special schools into a more 'adult' mainstream environment but their experiences of college were still separately organised and managed. College link courses were indeed undertaken with little non-disabled peer interaction. Thus, there many have been a degree of social 'integration' but this does not equate to Oliver's (1996b) notion of social 'inclusion'. The young people frequently remained a 'special' group, socialising within a very specific and segregated population of young people similarly labelled 'SEN'. This was also true of work experience programmes. Amongst the focus schools the world of work was not an experience open to everyone, especially those with pronounced disabilities. Wider socio-economic factors, such as placements available and the support that employers offered to schools were important. However, there were also attitudinal factors, professional assessments of student *appropriateness*.

Indeed, this theme of *appropriateness* pervaded professional, especially educational professionals', ideas and observations throughout the study. It was most clearly demonstrated within chapter five in relation to the Code of Practice's 14-plus transition review. Here, considerations of *appropriateness* emerged on two levels – general and individual. Within the former, ideas of *appropriateness* were raised in relation to the question – 'when to conduct transition reviews?' Officially, the Code of Practice highlights a chronological age rather than a specific school year:

> "the first annual review after the young person's 14th birthday ..." (1994, 6:45, p.117)

Consequently, as Wood and Trickey (1996, p.121) note there is a degree of ambiguity as a young person's birthday could fall in school years 9 or 10. This was mirrored within the study as an authority difference emerged within the focus schools. Within Authorities 2/3 (Beech-view, The Laurels and Cedar Drive) year 10 had been chosen, whereas in Authority 1 (Ash-hill and Oaksmere) year 9 was viewed as the appropriate time. Beyond the focus schools it was unclear if this also applied to all schools in each authority. However, it was apparent that this question of 'when', was one, which raised a degree of debate. Perceptions of the 'most appropriate time' focused upon maturity factors and/or school leaving age (16 or 19 years).

Interwoven within this lies the wider and more general question of 'when' to start planning for the future. A small minority of educational professionals could see the benefits of encouraging young people to become involved as early as possible, as Tisdall (1996, p.30) has emphasised. This, of course, highlights important policy implications that the Code could have upon schools, for example, in terms of

introducing pupils to 'choice-making skills' at an earlier stage within their school career. However, chapter five also demonstrated that a number of school professionals were clearly wary of planning too early, a fear Morningstar et al (1996, p.257) has also noted. Thus, the question of 'when' was felt to be complex although it was often a school-based issue. Hence, the focus schools valued opportunities to be flexible and autonomous in the making of decisions, basing these upon a personal knowledge of 'their' pupils. The significance of such "flexibility" and autonomy for schools when implementing the Code of Practice has recently been recognised and advocated as important in future policy developments within the 1997 Green Paper - *Excellence for all children: Meeting Special Educational Needs* (1997, 3:5, p.33). Decisions about the timing of transition reviews were also clearly guided by and dependent upon organisational considerations and the work commitments of external professionals. This presents a similar picture of tension between 'the needs' of students and institutional/professional 'requirements' within multi-disciplinary transition planning meetings, as Tisdall's (1996, p.29) study of FNAs within Scotland has also highlighted.

On an individual level, the question of *appropriateness* focused upon pupils' attendance at review meetings, particularly transition reviews. Chapter two documented a heightened general awareness to children's rights. Of particular importance was young people's right to participate and be consulted (see Article 12 of the UN Convention on the Rights of the Child, 1989; Franklin, 1995; Lansdown, 1995) and the importance of 'empowering' young people to take a more active role within transition planning (Tisdall, 1994, 1996, 1996/97). Official policy guidelines, such as the Code of Practice (1994, 6:59, p.122), have begun to recognise the significance of young people's involvement.

Within this study, chapter five demonstrated that 'participation' was valued and pursued by *all* the focus schools. However, interwoven within this, it was also clear that judgements of pupils' *appropriateness* pervaded professional assessments of review attendance within four focus schools. Judgements frequently used notions of 'competence' (see Franklin, 1995 and Lansdown, 1995 for a wider discussion) and drew upon assessments of 'age' and/or 'severity' of disability. For a small number of school professionals the question of young people attending review meetings also raised moral obligations and dilemmas. Parents' 'rights' and their ability openly to express feelings and fears within meetings were raised. Balanced against this, there were two concerns: firstly, the danger of speaking over a young person's head, especially if the young person had pronounced learning disabilities and, secondly, a felt need to shield some young people from hurtful information. Some supported the idea of young people attending only 'part' of their transition review. Thus, there were different approaches to

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parents and young people's attendance. For parents it was viewed as an automatic 'right' but for young people, qualifications were often attached. Of course, as Tisdall (1996, p.31) has noted, attendance is a rather superficial gauge of a young person's actual involvement. But, as this study has illustrated, it provides an insight into professionals' often-complex evaluations, such as those regarding ideas of 'competence'. Within any study involving a diverse range of special schools one would expect levels of participation to differ. Here, practical difficulties clearly existed and transition reviews were only a small part of young peoples' school-leaving preparations. Moreover, the focus schools valued and respected the idea of young people participating *but* professionals' protective feelings can and do prevent this. Thus, it is important to be aware of the dangers of protective feelings. As many social model theorists argue, this can easily lead into paternalism, even exclusion, however well meant (Brisenden, 1987, 1989; Barnes, 1991; Mason and Rieser, 1994). One must not loose sight of the basic fact that at each transition review and any subsequent reviews, a young person's future is being discussed – it is *his/her* review meeting.

8.2.2 Feeling Involved?

On the other hand, many young people and their parents felt that they *had* been consulted and involved within transition preparations (chapter six). Within school meetings over half of the young people and three quarters of parents interviewed felt that they had been asked questions and/or had their opinions sought by professionals. In fact, the majority of parents felt that school review meetings were conducted in an 'open', 'participatory' atmosphere. On one level, this is extremely positive as it suggests that professionals were consulting young people and their parents. However, it must be remembered that feeling involved and evaluating one's role as 'participatory' is relative. Current evaluations of what constitutes 'participation' and what is expected may depend upon past experiences. This also helps to explain why some young people and their parents could and did hold very different interpretations of the same situation.

Within chapter six, two issues emerged within school meetings which raised concerns about, or the potential for, family involvement. Firstly, there was the question of 'who' the young people regarded as doing the most talking within meetings – for the majority it was 'others'. Secondly, concerns were voiced about the context of school meetings, especially the potential for intimidation. This idea that review meetings could or can be an intimidating experience emerged from researcher observations and from the comments of participants and professionals. Tisdall (1996, 1996/97) has similarly highlighted this issue in her study of FNAs within Scotland. Concerns surrounding the context of school meetings raised important questions about 'who?' and 'how many?'

people should attend. Within any policy seeking to encourage the active participation of young people and their parents the importance of a supportive and relaxing context is paramount. However, the very nature of a formal multi-disciplinary meeting can endanger this goal, as Tisdall (1996, p.30) has noted. This is an issue becoming more significant within the 1990's, as official guidelines place more and more emphasis upon multi-disciplinary meetings as the key focus of transition preparations.

Within the Code of Practice, the initial 14-plus transition review is regarded as an important landmark and event for statemented young people and their parents. However, this study has demonstrated that amongst families their impact and perceived significance was not always clear. Within a sub-sample of families (four) from Authorities 2/3 both young people and their parents lacked specific knowledge about transition plans and a sense that it was 'theirs'. Parents may have valued the meeting as a "special leavers meeting" but only one young person recognised the significance of the review meeting and knew vaguely that he had written future plans in his Record Of Achievement. Of course, this was a sub-sample but it highlights that although the Code was adhered to and transition plans written, ambiguity still surrounds the Code and the 'role' of transition plans. Furthermore, the relative absence of any sense of 'ownership' re-emphasises two wider issues: firstly, the question of 'unknown' LEA representatives writing transition plans and, secondly, that professionals *still* need to continue working towards *greater* family participation, especially for young people.

8.3 Inter-Agency Working and Support

8.3.1 Inter-Agency Working

As the above section indicated, although school professionals were aware of potential problems surrounding multi-disciplinary meetings, this did not stop them from working towards inter-agency planning during school-leaving preparations. Within school meetings, especially 14-plus reviews, chapter five highlighted that *more* social service participation would have been welcomed. In the past, social services attendance at school meetings was felt to have been erratic, and was *still* regarded as patchy. This appears to be a common problem as Tisdall similarly noted the "lack of social work contribution" in FNAs within Scotland (1996/97, p.9). On one level, focus schools were aware of, and sympathetic to, the problems social services faced of large workloads and limited resources. However, it was also clear that greater social services attendance would have helped to foster more holistic and comprehensive assessments.

Chapters four and five indicated that professional evaluations of inter-agency working within the Authorities (1 and 2/3) were by no means uniform with both positive and

negative assessments. Progressive steps had been made towards a more collaborative ethos amongst different agencies. At a managerial level there were joint policies and within the field schools stressed that collaborative working was aided by the presence of 'on-site' health professionals. However, professionals were not complacent transition gaps and inconsistencies were noted.

This study has explored two areas of social service inter-agency working: Transition Officers within Authorities 2/3 and joint reviews within both Authorities (1 and 2/3). Social service and educational professionals viewed the introduction of Transition Officers as a positive development for families, providing both support and a point of contact during the transition years. However, two controversial issues emerged. Firstly, there was the question – when are the transition years? The variability of transition officer remits (beginning between 14 to 18 years) within Authority 2 and Authority 3, re-emphasised the lack of clarity that surrounds concepts such as, 'transition' and 'adulthood'. Furthermore, it also highlighted the lack of uniformity that can and does exist between different agencies. Within education legislation (Education Act, 1993) and associated guidelines (Code of Practice, 1994) 'transition' is officially considered from 14 years. In contrast, amongst social service transition officers the official starting point ranged from 14 to 18 years hence, the ever present potential for transition 'gaps' and a lack of co-ordination amongst different agencies. This is not new, as chapter two demonstrated (see Bradley et al, 1994, p.49) but it can hamper joint working. Interwoven within this variability lies the second issue – the question of 'need'. During the study it was apparent that financial and service boundaries played a role in directing service provision. Perceptions of, and being responsive to, young people's 'needs' was influenced by external factors, such as, social service inter-departmental age boundaries and the finances attached to them.

The importance of joint reviews, especially professionals undertaking parallel assessments, is highlighted within the 1994 Code of Practice's guidelines for the 14-plus review. Within this study, chapter five demonstrated that parallel assessments at 14 years, particularly social service assessments within the Disabled Persons Act (1986), were a somewhat *confused* and *confusing* area. Amongst school staff, especially review co-ordinators, there was a lack of clarity about the role of the 1986 Act and 'opinion' giving at 14 years. Thus, there is a need for *greater clarity* if professionals are to avoid missing an important opportunity at 14 years. However, parallel assessments were in the process of being addressed just before school leaving within Authority 1. There were future plans to combine final school reviews with social service leavers' assessments within the 1986 Act for statemented young people who were also viewed as 'disabled' (under the 1986 Act). A policy of joint reviews was not, however, seen as easy to

implement. Joint reviews were recognised as important but practical reservations were voiced. More specifically, some wondered how two different reviews could be joined together as one. This re-emphasises the very real organisational problems within inter-agency working.

Within the sphere of health there were also concerns about the continuity of services in a number of areas. This is not surprising as three of the schools (The Laurels, Oaksmere and Cedar Drive) had pupils on roll with severe disabilities and complex medical needs. Many of the issues discussed in chapter four re-emphasised general problems that previous studies have raised, such as inadequate provisions, inconsistencies and barriers towards collaborative working (Bax et al, 1988; Bax, 1990; Hirst et al, 1991; British Paediatric Association, 1994; Hirst and Baldwin, 1994; Begum and Fletcher, 1995; Johns and Fiedler, 1995). Hence, this study demonstrates that problem areas *still* persist for families during the transition years improvements *still* need to be made. On a more positive note, professionals raised four practical suggestions: *more* routine post-school following-up; *more* education and information for GPs; *more* help preparing families for the independent accessing of services and, of course, *more* resources and manpower.

Within the study, one issue seemed to be a relatively more recent area of concern - nursing provision within day colleges. This is important to consider due to the relatively recent expansion of the FE sector and courses for disabled students. The importance of health services and students' needs varies enormously amongst disabled young people they are not a homogenous group. However, amidst the many complex issues there are two broad areas of debate. Firstly, exclusion if a young person's health needs cannot be met (as noted in chapter four) and secondly, the danger of medicalising the lives of disabled students (see Barnes, 1991; Barnes and Mercer, 1996 for a more general discussion of 'medicalisation'). These are issues that more colleges will increasingly face. Furthermore, if schedule-2 course criteria within the 1992 Act do not become more inclusive, in line with the Tomlinson Committee Report (1996), severely disabled young people may also be excluded in other ways.

8.3.2 Young People and Parents Evaluations of Support

Chapter six highlighted that the level of support families in the past had received from social services varied enormously, and appeared to be ad-hoc rather than a coherent policy. However, it was also clear that parents' personal perceptions were important, especially past experiences of either being well supported or poorly served. In addition, not all parents wanted social worker support. For a small minority, social workers were associated with 'stigma' and being unable to cope. Furthermore, an assessment of

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Transition Officers by parents at The Laurels indicated that they recognised the post was filling a 'service gap' but how far it would or could actually do this was debated. Wider issues and policy constraints, such as resource factors were recognised by one parent.

Evaluations within the sphere of health services similarly differed. However, it is important to remember that not all the young people required specific health services. Furthermore, within chapter six it was clear that at this stage it was still too early to make a firm assessment of young people's and their parents' transition from school health services to adult services. However, therapy services were discussed, especially physiotherapy. Post-school leaving those who required this service still appeared to be receiving provision in one form or another and both young people and their parents were generally satisfied. However, within this assessment it must be recognised that many of these young people had moved onto a next-step with 'on-site' provision. This in turn had postponed service transitions for many families. The advantages of this, parents clearly recognised. However, a third of parents shared a fear that greater service changes would occur in the future when their son or daughter left education, especially 'on-site' provisions, and moved into 'adult' services. Post-education rather than post-school leaving was thus perceived as a potential watershed with an unknown future. Ward et al (1991), Hirst and Baldwin (1994) and Thomson and Ward (1994) have also noted this post-education fear.

Overall, this study had demonstrated that inter-agency working is valued as important, especially by professionals. Positive steps have clearly been made towards more collaborative patterns of working and, when it does work well, inter-agency collaboration can and does bring many benefits for both professionals and families. However, in practice it is not easy to achieve. The areas of concern and incoherence that *still* persist within the study illustrate this. Some professionals suggested improvements but it must be recognised, as previous literature has documented (especially Bradley et al, 1994), that such suggestions are frequently pitched against wider and deeper professional and/or economic barriers.

8.4   Post-School Opportunities

8.4.1   Further Education and Training

Chapter two highlighted the expansion of FE for disabled young people, especially young people with learning disabilities within the last twenty years. This is partly a result of legislative recognition, especially the Education Reform Act (1988) and the Further and Higher Education Act (1992) (Stowell, 1987; Bradley et al, 1994). Chapter

four demonstrated that professionals generally welcomed this expansion. In fact, the idea of education as a 'right' for young people was raised at two schools (Oaksmere and The Laurels). Amongst parents (chapter six) there was an initial sense of relief that there was something after school for their son or daughter to move onto. Some parents translated this into a longer-term wish for their son or daughter to stay in education for as long as possible, thus postponing the transition from education. Hence, it is not surprising that post-school leaving, 94% of young people within the sample remained in some form of education (school, college or continuing education) either full or part-time.

On the other hand, although an expansion of college places was acknowledged, chapter four highlighted that there were still a number of professional concerns and reservations. Most importantly, it was felt that access for disabled young people was still 'conditional' within some local colleges upon two factors: firstly, environmental considerations and questions of disability severity and secondly, perceptions of *acceptable* students. This was interwoven by one Head (Oaksmere) with a consideration of colleges as independent institutions and, as Fish and Evans (1995, p.72) note, the creation of a "post-16 market". Thus, it is clear that, although the young people and their parents often felt that they were making a choice, it was a choice from a very narrow and specific set of 'special' options. Furthermore, the question of *acceptable* students relates to the wider issue of 'accreditation', especially the separation of schedule-2 and non-schedule-2 courses within the 1992 Act. Here, concerns, as noted above (National Institute of Continuing Education, 1996; Tomlinson Report, 1996) have recently been raised in relation to disabled people, especially those with pronounced learning disabilities and exclusion. Within this study, a small number of professionals were concerned about the possibility of this occurring. However, Authority 1 did seem to be aware of this potential danger during the research period it was exploring local provisions.

Within the sample, only one young person (Ian) went into youth training. Amongst the focus schools more generally, there was a low take-up of training at both 16 and 19 years. However, the issue of 'training' raised a number of important questions surrounding 'provision' for young people with learning disabilities (chapter four). A small number of professionals (three) within Authority 1 noted the focus upon vocational qualifications within training schemes. There were fears that the newly introduced 'OPEX' scheme was not 'appropriate' to meet the needs of young people with learning disabilities. Hence, there is a concern that young people leaving special schools, such as Ash-hill, will be disadvantaged and perhaps excluded in the future, if vocational criteria and the provision of 'appropriate' schemes is not recognised and

addressed as an issue. 'Accreditation' was thus raised as an area of concern in a similar manner to Tomlinson and Colquhoun's (1995) discussion of vocational qualifications and the danger of exclusion for young people with SEN.

8.4.2 'Work' and 'Employment'

Within the sample no one had yet moved into paid employment (although two young people had part-time jobs). However, this follows the wider social trend for an extended period of education and training (Coles, 1995). Pre-school leaving, chapter seven demonstrated that almost half of the young people interviewed aspired to the idea of 'getting a job' in the future, a similar picture to that presented in previous studies (Anderson and Clarke, 1982; McConkey, 1989; Flynn and Hirst, 1992; Davies and Jenkins, 1993; Riddell et al, 1993; Gallivan-Fenlon, 1994, Ward et al, 1994). Thus, the idea of becoming a 'worker' was recognised and valued as part and parcel of 'adult' life. Whether these young people will achieve this is, of course, open to question. If past studies are anything to go by (Hirst and Baldwin, 1994; Thomson and Ward, 1994) many will be disappointed. Certainly, focus school professionals were often sceptical of employment prospects for their students. Furthermore, parents (especially Ash-hill, Beechview, Cedar Drive) may have valued the idea of young people gaining a job but they were often more apprehensive and guarded about the possibility of this than their son or daughter (see also Conliffe, 1989; McConkey, 1989; Ward et al, 1991; Gallivan-Fenlon, 1994). Parents wanted to be 'realistic'; hence their concern over the wider economic context and the danger of raised expectations. Parents could thus experience conflicting emotions – wanting to encourage aspirations but also fearing undue disappointment for their son or daughter.

For young people with pronounced learning disabilities (Oaksmere and The Laurels), school professionals and parents felt that post-education, opportunities were limited. Day centres were seen as the 'usual' destination following a college course. Chapter four highlighted that staff at Oaksmere ultimately saw their students' long-term future as focused around day centres. This serves to re-emphasise Todd et al's (1991, p.14) and Swain and Thirlaway's (1994, p.166) earlier comments that college is often no more than a stopgap for young people with learning disabilities. Similarly, chapter seven demonstrated that a significant number of parents at Oaksmere and The Laurels (five out of six) did not view 'work' or 'employment' as realistic for their son or daughter. Parents' attitudes to day-centres varied. Pre-school leaving, amongst those who discussed day centres, over half expressed a sense of fear at the future prospect of this. Concern focused upon a belief that day centres would be unstimulating. This fear appeared to be based upon social evaluations and presumptions rather than personal

experiences. Pre-school leaving there was thus a lack of accurate knowledge and information about day centres. This situation demonstrates two themes within the study: firstly, the importance of accurate information and thinking beyond the next step and secondly, the strength of social presumptions and shared fears. Providing *more* information about day centres may have allayed some parents' fears.

Overall, the study highlighted the importance of not only 'work' and 'employment' but also alternative daytime occupations. Within the latter, stimulation and social recognition are important factors parents wanted their son's or daughter's activities to be both 'purposeful' and 'meaningful'. Consequently, the challenge appears to be how to foster and aid a transition towards socially valued, 'adult' and stimulating activities for disabled young people, especially for young people with pronounced learning disabilities. This challenge is by no means new. Indeed, it has previously been recognised as an important but complex area by the series of studies within Scotland. They suggested that a "paradox" surrounds employment (Ward et al, 1991, pp.131-132; Thomson and Ward, 1994, pp.88-89, 91-92; Ward et al, 1994, pp.140-141). This study has also highlighted the need to look beyond narrow interpretations of 'employment' to broader ideas about 'meaningful' daytime occupations or as Thomson and Ward suggest "productive daytime activity" (1994, p89). Parents at Oaksmere and The Laurels recognised this and focused upon 'alternatives' to employment, especially, *stimulating, socially recognised and valued* daytime occupations.

8.5 Moving Towards 'Adult' Status

Within the literature surrounding the concept 'youth' (chapter two), three interlocking institutional status transitions were reviewed: the school to work transition; the housing transition and the domestic transition (Wallace, 1988; Jones and Wallace, 1992; Coles, 1995; Jones, 1995). Past studies exploring the concept of 'adulthood' for disabled young people have also suggested a number of 'adult' status markers (Fish, 1986; Ward et al, 1991; McGinty and Fish, 1992; Thomson and Ward, 1994). The models presented are diverse, however a number of the markers highlighted share some similarities with the above institutional status transitions.

Assessing the traditional idea of sharp institutional status transitions it is important to recognise that they present a very static and over-simplistic picture of transition, which can be inappropriate for many disabled young people. This study has demonstrated that the opportunity structure has expanded for disabled young people preparing to leave school, in terms of opportunities such as college links, work experience and FE courses. However, chapters four and five have also demonstrated that this expanded opportunity structure does not always apply for all disabled young people, inequalities and

differences can and do exist. Indeed, the opportunity structure that disabled young people face is frequently mediated and interpreted by professionals. Consequently, professional perceptions and their many taken for granted ideas about the *appropriateness* of certain transition preparations or opportunities for some disabled young people are important. This is because they may well influence how parents and young people come to view the transition years and themselves. However, it is also important to recognise that the transition years are a very personal and individual experience for many families. Chapter seven clearly demonstrates that different young people can and do take different transition steps. This potential for difference needs to be recognised and appreciated within any analysis of the transition years.

8.5.1 Two Case Studies

This study has focused upon transition preparations. The young people within the sample were beginning to embark upon the transition to 'adulthood'. Within Fish's (1986, p.9) three stages of 'transition', the young people had only just entered the second stage encompassing further education and vocational preparations. This was mirrored within the study as the vast majority of young people and their parents were beginning to engage with, and explore, the transition from childhood. In terms of 'adult' markers many of the young people clearly valued and aspired to one or more of the traditional institutional status transitions, especially, as noted above, the idea of 'having a job'. However, these remained aspirations yet to be achieved.

In contrast, chapter seven demonstrated that two young people (Ian and Laura) had progressed further than their peers within the sample. They had made significant steps towards greater personal independence. In terms of institutional status transitions both Ian and Laura had embarked upon a 'housing' transition and thus a "housing career" moving out of the family home (Jones, 1987; Wallace, 1988; Coles, 1995). However, they had very different personal circumstances, Ian having attended a weekly residential school had thus experienced living away from home. In contrast, Laura had attended a day school. Despite this, the decision to leave home had brought significant life changes and future hopes for both. Ian viewed moving in with a landlady as a prelude to having his own flat, and, for Laura, forming a partnership with her boyfriend signified the beginning of a 'domestic' as well as a 'housing' transition. However, it is important to note the *gendered* nature of their transitions towards 'adulthood'. For Laura, greater 'adult' independence and an 'adult' status had been sought and gained from traditional female roles of domesticity and caring rather than a school to work transition. Conversely, Ian looked towards and prioritised a labour market career, especially the acquisition of 'worker' status.

Whilst, it is recognised that these significant steps evolve from two individual case studies, their contribution to, and importance within, the study of transition towards 'adulthood' can be summarised by two factors. Firstly, they provide a positive picture of significant steps towards 'adulthood' for young people who have attended 'special' schools. This is a social status, frequently presented in a very negative light. The focus in chapter seven upon these two 'positive' case studies helps to present a more balanced study, one, which is not wholly negative or pessimistic about the transition to 'adulthood' for young people with learning disabilities. The use of case studies within past literature, especially the series of studies within Scotland (Ward et al, 1991, 1994; Thomson and Ward, 1994) has similarly provided some positive examples. Secondly, important insights can be gleaned from the young people's biographies. Of course, one must be wary of making wider generalisations but it is important to appreciate the contribution that personal, in-depth insights can and do make into an extremely complex period within the life-course, especially for young people with learning disabilities. Ian and Laura clearly highlighted a number of important factors and signifiers of 'adulthood' which were important to *them*.

These insights have unravelled a more informed understanding of the complexities surrounding the concept of 'adulthood' and also 'some', but by no means all of the factors underlying transition. Within Ian and Laura's biographies, the multi-layered nature of transition to 'adulthood' was apparent. Their steps were not dependent upon one factor but as Chadsey-Rusch (1991, p.31) has similarly noted, many inter-related and interacting variables. Furthermore, it was clear that some things were shared, especially their aspirations and a desire for independence. The material context, both economic and educational, particularly, local opportunities and structures were also important, as was family support and parental approaches to and experiences of "letting go" (see Richardson and Ritchie, 1989; Ritchie, 1989; Swain and Thirlaway, 1994 for a discussion of letting go). Of course, there were also individual and different factors, especially the importance and level of professional support received. Ian's transition steps once again emphasise the benefits of *early* planning and good inter-agency collaboration and working (see also Fiedler and Johns, 1997, p.3 and 29). Furthermore, they also highlight many policy objectives which current legislation seeks to promote and achieve (Disabled Persons Act, 1986; Children Act, 1989; NHS and Community Care Act, 1990; Education Act, 1993). In contrast, Laura's transition steps remind us that one cannot always plan a future. Events can and do 'just occur'. This highlights an element of 'chance' but within traditional *gendered* social roles and expectations.

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8.5.2 The Role of Residential College

Within this study, residential college was highly valued by a significant number of professionals, parents and young people. In fact, for the majority of parents and young people who had experienced or were experiencing residential options (school or college) they were viewed positively. This was especially true for four young people with pronounced learning disabilities and their parents within Authorities 2/3. Moving away to residential college was viewed as an important step on the road to 'adulthood'. It was a tangible symbol of change, a son or daughter was progressing beyond 'childhood' dependence to a more independent status. Amongst the four young people who moved onto residential college there were three areas within which status changes were recognised and valued. Firstly, moving away from the parental home and the acquisition of a more independent status. Parents welcomed residential college as an opportunity gradually to loosen familial bonds. Residential college was thus regarded as an important but controlled catalyst within the process of "letting go" and limited risk taking. Amongst the young people, living away from home and a chance to do more things independently were similarly valued. Secondly, there was a marked development of social independence. Parents welcomed an opportunity for their son or daughter to foster a more independent and 'adult' social life without family input. Furthermore, the four young people clearly valued their residential college activities and a chance to do things with peers. Third and finally, parents welcomed the chance for their son or daughter to develop educational and/or vocational skills. Here, parents particularly valued the acquisition of life-skills, practically preparations for a more independent future.

Residential college obviously does not signify 'the' acquisition of 'adult' status. It is a transitional or intermediary stage within the move from 'childhood' dependence to 'adult' independence. However, for these parents and young people it was a very important stage. Furthermore, for young people with pronounced disabilities, especially learning disabilities, an idealised model of sharp institutional status transitions, such as establishing one's own home or the school to work transition is often inappropriate. Within this study, these transitions were not yet possible and in the longer-term were regarded as 'inappropriate' by parents. Hence, residential college, especially for those with pronounced disabilities was viewed as a sort of *surrogate mode of transition*, providing a gradual break with past 'childhood' dependence. Viewing residential college as a *surrogate mode of transition* once again highlights the limitations and inflexibility of traditional transition models for young people with learning disabilities who do not fit into society's stereo-typical norms and patterns. The idea of residential

college as a *surrogate* helps us to begin to formulate an approach which is both more flexible and sensitive to the transition years.

However, the very transitional nature of residential college raises important questions about students' longer-term future. On one hand, residential college marks a significant break with the past but, post-college, there is the question of returning home. Within this study, returning home was regarded as a retrograde step (by the four parents) but it was also recognised as a real option for the future. Parents feared that, on returning back to the family home, their son or daughter would resume family dependency and/or a limited social life. This fear appears well grounded as Sinson's (1995) study of ex-residential college students has demonstrated. Chapter seven focused upon two areas of concern: appropriate future housing/accommodation and community participation. Frequently, the former is regarded as problematic (see Morris, 1993b and Thomson and Ward's, 1994). Within this study, parental concern evolved from a fear of the unknown and a lack of information about future housing opportunities. Once again, the importance of *more* and *earlier* information was highlighted. Within the latter area, Anderson and Clarke (1982), Fish and Evans (1995) and Sinson (1995) have discussed the issue of community reintegration and a danger of social isolation from local peers. Here, some of the young people attending residential options seemed socially to be isolated from local peers, and during holidays/weekends reverted back to a family oriented social life.

Residential college remains a controversial issue (Anderson and Clarke, 1982; CERI, 1985; Fish and Evans, 1995). Practically, it is often a more expensive option than a local day college. This is an important consideration for local authorities, especially health and social services if they are jointly funding a young person with the FEFC. At the time of writing (February 1998) Authority 3 was beginning to re-examine its policy towards residential college. Consequently, changes may occur in the near future. This, of course, will have implications for local provisions. Furthermore, there are also important philosophical concerns about residential college. Social model theorists critique residential college as a continuation of 'separate' and 'specialist' provision. Thus, it is important to recognise that in its role as a *surrogate mode of transition*, residential college re-emphasises 'able-bodied' society and that young people with learning disabilities and their parents, once again have to turn to 'separate' and 'special' provision. However, as chapter seven has indicated, problems and fears surrounding young people's personal independence and their social life do not disappear, post-college. Going away to residential college may change the young person but society usually remains the same. Thus, there is a danger, as Sinson (1995, p.150) has pessimistically noted, that residential college can be a positive but brief period of

independence and social participation within the lives of some young people. Recognising the hopes that a significant number of parents and young people attached to residential college within this study, it is important to try and ensure that residential college is more than a brief interregnum of independence and stimulation. Ian's case study presented a positive example of a young person building upon residentially acquired independence skills. Working towards independence is, of course, a complex and an individual process. However, as the two case studies illustrated, wider factors impinge, not only material provisions but also social attitudes. On one hand, provisions, such as local housing and leisure schemes are recognised as important by professionals, and improvements are being, or have been, made. However, *more* are clearly required. On the other hand, social attitudes and presumptions about young people with learning disabilities are much more difficult to address. In this way, although recognising the potential importance of residential college as a *surrogate mode of transition*, its limitations and philosophical presumptions cannot and should not be ignored.

8.6 Policy Implications And Future Research

8.6.1 Current Policy Implications

State benefits are currently high profile as politicians from 'New Labour' associate rising numbers of people claiming benefits with the traditionally right wing idea that costs are "spiralling" out of control (Hutton, *The Observer*, 21/12/97, p.22). Recently, the focus has moved to disability benefits, such as Disabled Living Allowance (*The Independent*, 15/12/97, p1; *The Guardian*, 16/12/97,p.15; *The Observer*, 21/12/97, p.1). Many simplistic conclusions can be drawn from this. For example, it is often presumed that it must be easy to get information about benefits because 'so many' people are now claiming them. However, this study has demonstrated that this is not the case and accessing benefit information *still* remains an important area of concern for many people. Indeed, chapter six highlighted that almost half the parents within the sample were concerned about benefit information and access to it. Parents generally felt uninformed, especially with regard to entitlements. The two most frequently voiced concerns were that information was either inaccessible, or ad-hoc and too informal. When professional (i.e. social workers) or accessible sources of information (such as schools) were available, they were valued and welcomed. Thus, *more* direct and professional benefit information was required during school leaving preparations. Accessing information about benefits during the transition years is not, however, a new concern. Thomson and Ward (1994, pp.90-91) highlighted this area within their studies in Scotland (see chapter six). Indeed, they focused upon the important role of social

workers and advocated writing appropriate benefit information into young people's 'Record of Need' (statement within England and Wales).

Within England and Wales, the Code of Practice's 14-plus transition review and the writing of an individual transition plan perhaps offers a way to develop further Thomson and Ward's ideas for young people and their parents to access accurate information on benefits. Theoretically, the 14-plus review appears to be an ideal opportunity for all statemented young people to receive personal benefit information from the social worker invited to their review meeting, well before school leaving. However, as this study has indicated this is not as simple as it seems. Chapter five demonstrated that social workers attendance at 14-plus reviews could be patchy and erratic. Furthermore, not all-statemented young people are eligible for benefits and there are many non-statemented young people (especially physically disabled) who are eligible, require information, but do not fall within the Code of Practice. Consequently, there is *still* a need for *more* benefit information generally to be accessible to the public.

Within the Code's guidelines, this study has also highlighted that LEA representatives writing transition plans needs carefully to be considered. Is it always appropriate or beneficial for 'all' schools? On one level, the Code's prioritisation of 14-plus reviews and the official importance attached to transition plans is to be welcomed. However, chapters five and six have demonstrated that, although, clearly valuing and welcoming the idea of written transition plans, the focus schools raised a number of areas of concern and some important questions. In particular, two educational professionals within Authorities 2/3 raised concerns surrounding the danger of 'unknown' and 'unknowing' LEA representatives writing transition plans and the question of 'ownership', especially the 'felt ownership' of transition plans for young people. Wood and Trickey (1996, p.120) have also noted the significance of 'ownership' for young people. It is important here to consider the Government's Green Paper - *Excellence for all children: Meeting Special Educational Needs* and its suggestions for future policy developments. The Green Paper recognises both the importance of increasing schools "flexibility ... to interpret the Code's guidance in light of their own circumstances." (1997, 3:5, p.33) and the administrative and bureaucratic burdens that they can face. This is to be viewed as a positive step forward. Indeed, this study has demonstrated that the focus schools would welcome increased flexibility of interpretation and reduced bureaucracy.

The Green Paper's policy suggestions towards "increasing inclusion" are also important to consider (1997, chapter four). Particularly the idea that mainstream and special schools should work more closely together and that special school provision should be flexible rather than static, i.e. a pupil may attend full or part-time, long or short-term:

"We want to develop an educational system in which specialist provision is seen as an integral part of overall provision, aiming wherever possible to return children to mainstream..." (1997, 4:2, p.44)

Increasing opportunities for more statemented young people to be included within or experience a mainstream setting are to be welcomed. Indeed, chapter four demonstrated that the focus schools within this study valued any links to local mainstream schools that they had established. However, most young people within the focus schools did not experience mainstream education until the end of their school career, via a college link course. Perhaps, if the Government's proposals are adopted, more young people will experience a mainstream educational setting before this. This would be a positive development, but it is not easy to achieve. Chapter four and section two of this chapter have demonstrated that college link courses within this study were still segregated and 'special'. Past legislation, such as the Education Acts (1981, 1993) may have advocated increased 'integration' but in practice they have been largely ineffective (Coles, 1995). Hence, the challenge beyond the Green Paper is to try and move past the rhetoric of 'inclusion' to actual and effective implementation.

For many disabled young people, the future in terms of employment opportunities does not look good. On one hand, disabled people's rights have recently gained greater political credence and prominence. More specifically, the question of disabled people and employment has been raised within the Disability Discrimination Act (1995). However, within the latter, concerns have been voiced that the Act does not address or challenge disabling working environments and social prejudices. Thornton and Lunt (1995a, 1995b) have argued that the Act's onus is still upon the individual, it is the individual disabled worker who has to instigate a complaint against a specific company rather than addressing structural issues:

"The government's Disability Discrimination Bill with its new individualised right against discrimination in employment is a watershed in British policy. But it has missed an opportunity to address the structural disadvantage disabled people face in employment." (1995b, p.21)

Tomlinson and Colquhoun (1995) and Corbett and Barton (1992) have also discussed this onus upon individuals rather than wider structural factors, in relation to the move towards accreditation and the focus upon vocational qualifications. Similar concerns were illustrated within this study in relation to recent training schemes. Of course, there are positive schemes for young people with learning disabilities. This study highlighted the praise that a local Barnardos catering scheme has received. However, as with supported employment schemes within the UK (Bass and Drewett, 1996; Beyer and Kilsby, 1996, 1997), these remain relatively few and far between, and available only to a minority. Thus, in many ways opportunities for disabled young people, especially

those with pronounced learning disabilities to gain a 'real', long-term job, have not significantly improved in recent years.

In contrast, amongst young people in general, the Government is currently focusing upon employment opportunities for 18 to 24 years olds with their 'welfare to work' programme (*The Guardian*, 1/1/98, p.6; *The Observer*, 4/1/98, p.17). 'Gateway' schemes are being piloted in 12 areas and offer unemployed young people up to four months intensive employment preparation and then a choice of pursuing one of five, employment, training or education options. Those who refuse to participate face loosing up to 40% of their benefit (*The Guardian*, 1/1/98, p.6). The Government unsurprisingly is extremely positive about the potential of this "Gateway" programme and the creation of 'real' opportunities and jobs for unemployed young people. Obviously, it is currently too early to assess these but it is important to note that there has, as yet, been no real discussion of how the programme could help disabled young people (or young people with SEN – legally not regarded as 'disabled'). General assessments of past training schemes have noted that employers are often reluctant "to take on" unemployed young people (Keegan, *The Guardian*, 1/1/98, p.6). If it is generally difficult to motivate employers then the future does not look very positive for disabled young people (or young people with SEN). Social prejudice towards disabled people, especially the idea of disabled people as 'productive' workers, remains an ever-present factor as Thornton and Lunt (1995a, 1995b) and Barnes (1996b) have noted. Thus, the idea that employers will suddenly be 'inspired' to employ disabled young people (or young people with SEN) does not seem very likely. Even so, as this study has highlighted many disabled young people do *still* aspire to work and value the idea of a 'having a job'. Hence, at this time many disabled young people look set to face a bleak future, both in terms of limited employment prospects and financially, with the threat of some disability benefits being cut or means tested (*The Observer*, 14/12/97, p.27; *The Guardian*, 16/12/97, p.15).

8.6.2 Future Research

This study has provided in-depth insights into school leaving preparations and the concept of 'adulthood' at two key points: pre and post-school leaving. A panel study approach was chosen providing an opportunity for both continuity and the development of rapport. A diverse sample of young people with learning disabilities and their parents were followed over a two year period. Time constraints inevitably determined the length of the fieldwork. Of course, it is recognised that as the transition to 'adulthood' extends over a number of years the insights and conclusions drawn within the study must be placed in context. This study reports on experiences gleaned from a relatively early

stage within the transition years. Hence, there is scope for further study, especially during and beyond the college years. This would develop and expand the study's longitudinal perspective and more specifically, provide an opportunity to explore both post-education transitions, which many parents feared, and further progress towards 'adult' aspirations.

It is tempting to conclude by calling for an extension of this research with the sample of young people and their parents to reach a more holistic assessment of the transition years. Indeed, this study has demonstrated that transition steps are multi-layered and the transition years an extremely complex and complicated period within the life-course. The young people within this study were clearly engaged within the transition towards 'adulthood', following this sample of young people would ensure continuity and an extended analysis of important variables within the transition steps of disabled young people. But, while this is an exciting possibility and would strengthen our understanding of the full process, the sample is not by any means perfect and this must be recognised. Within further research, two factors could be considered. Firstly, the sample was relatively small. If a further study was undertaken some young people and their parents would, over time either 'opt-out' or become "lost" to the system as Thomson and Ward's study (1994, p.26 and p.79) demonstrated. Secondly, within the current sample 'ethnicity' was a peripheral issue. This was due to the small number of ethnic minority families within the focus schools' sample population. Consequently, within any further research a more in-depth consideration of 'ethnicity' and the impact that this can have upon transition experiences is an important area to develop and explore. In addition, with regard to policy developments, this study has explored the initial implementation of transition reviews within the Code of Practice (1994). Further study, assessing not only 'if' the Code develops and changes over time, but also 'how' would be advantageous. In particular, exploring the outcome of the Government's positive proposals for review meetings within their current Green Paper (1997) should be a crucial item on the future research agenda.

Appendix 1 – Family Pen Portraits

Oaksmere School (Authority 1)

Susan – Susan has learning disabilities and limited speech. At home she likes to move around on her bottom and outside the house she uses a wheelchair. Susan lives with her mother and younger sister, who also has learning disabilities. Susan is a very independent young person and values her 'own space'. She spends a great deal of time in her bedroom listening to 'pop' music and watching television. When I first met Susan, she was 19 years old and preparing for day college. Six months later it was clear that she had adapted well to college life. Susan's mother was particularly pleased with her increasing independence and maturity. However, the future was becoming a source of concern. Susan's mother hoped that there would be something 'stimulating' for her daughter after college but feared that the day centre was her only option.

Fiona – Fiona lives at home with her family. She has learning and physical disabilities and uses a wheelchair. Fiona's family felt it was inappropriate for me to speak to Fiona due to her learning disabilities and limited speech. Furthermore, as English was the second language of her Asian parents I spoke to Fiona's younger sister (18 years old) who was about to take her A' levels. At that point in time, the family were preparing for Fiona to leave Oaksmere, a school she had attended from an early age. It had been decided that Fiona would progress to a two-year continuing education course run by the LEA. Eleven months later, Fiona's sister felt that the course was stimulating but hoped that Fiona's part-time place would soon become full-time, as her sister was often bored at home. Longer-term, the family were looking for a place at a local day centre.

Jason – Jason has learning disabilities and limited speech. He uses a wheelchair and has severe epilepsy, which requires constant supervision. Jason lives with his mother and younger brother on a large but rundown council estate. His extended family lives nearby. Jason loves music and spends many hours listening to his hi-fi. When I first met Jason he was 19 years old and preparing, with Fiona, for the continuing education course. Ten months later, his mother felt that he had adapted well to leaving Oaksmere and was enjoying his course. However, she was uncertain what the future would bring.

Ash-hill School (Authority 1)

Laura – When I first met Laura she was 18 years old and living with her parents, younger brother and sister. At the time, she was undecided about the next-step after school but was considering college. Laura's father expressed concern at his

daughter's lack of direction and more generally, opportunities for her as a young person with learning disabilities. However, when I met Laura eight months later her life had changed enormously. She had moved in with her boyfriend and adopted both a domestic and caring role. Her boyfriend was physically disabled due to an industrial accident. Financially, money was tight but Laura was positive about the future and hoped to get married in couple of years.

Steven – Steven lives with his mother, his father has recently died. When I visited Steven, he appeared a rather shy 18-year-old who was very conscious of his speech impairment. He quickly decided that he would prefer me just to speak to his mother. At the time, Steven's mother was unclear of her son's next-step and felt that everything was still up in the air. She explained that Steven's hobby was drama and ideally, he would like to do a drama course at college. However, Steven's mother was unsure if this was possible as she lacked appropriate information. Eleven months later, although the next-step had proven problematic to organise, Steven was attending a drama course three days a week and a day centre the remaining two. She felt her son had become more independent but was concerned about the future, especially support for young people with learning disabilities.

Beech-view School (Authority 2)

Linda – Linda lives with her father, stepmother and younger sister in a small, rural town. Linda has both learning and physical disabilities. She is a wheelchair user and has recently had a lift installed at home in order to aid access upstairs. When I met Linda she was 17 years old and preparing to leave Beech-view residential school. At that point in time, she had already spent an extra year at Beech-view because; previously her school leaving plans had fallen through at the last moment. This time, Linda was preparing to spend three days a week at college and two days at a local day centre. However, it was clear that college and returning home each night were the things that Linda was looking forward to. Her father was also looking forward to Linda returning home each evening as he had recently left the army to care for his daughter.

Lisa – Lisa lives with her parents, her older brother has learning disabilities and attends Willow Lodge Residential College. However, he regularly returns home as the family are all avid football supporters. When Lisa was seven years old she was involved in a car accident and suffered severe physical and brain injuries. When I met Lisa she was 18 years old and completing the independence course at Beech-view. Both Lisa and her parents wanted her to continue in education. Lisa favoured the local day college with her friends from Beech-view. Her parents preferred a residential option, such as Willow Lodge but recognised that funding would be problematic. Nine months later, residential college had not materialised, Lisa however, was pleased to attend the local college.

Louise – Louise lives with her parents and older brother in a small village. Louise has learning disabilities. Similarly to Lisa, Louise was also 18 years old and preparing to complete the independence course and move onto day college. Ten months later, Louise was enjoying her college course and had become more independent. She now travels home from college on the bus with a friend rather than being collected by her mother. However, Louise was rather lonely, she

missed the weekday evening social activities of Beech-view. Louise's social life was also a constant source of concern to her mother as she felt her daughter was isolated from village peers.

Charisa – Charisa has learning and physical disabilities, movement in both her arms and legs is limited. However, Charisa is fully mobile as she has an electric wheelchair. When I first met Charisa, she was 16 years old and preparing to leave home for residential college. This was a decision that Charisa had very clearly made herself, although her parents fully supported her. In fact, her parents faced many changes in their lives as their other daughter was planning to go to university. When I returned eight months later, Charisa was not disappointed with college life. Her parents also felt that she had matured and become more independent. However, they were fearful about the future, especially Charisa returning home and loosing her independence skills.

Ellen – Ellen lives with foster parents as her natural parents are working abroad. She has an older brother and sister living in London. Ellen clearly enjoys living with her foster parents and had quickly been drawn into their wider family network. Ellen has Downs Syndrome. At our first meeting Ellen was 19 years old and preparing to leave Beech-view and move onto the local day college. However, nine months later things have not gone well for Ellen. The college course had been a constant struggle and it had been decided that she should finish after one rather than two years. However, Ellen remained optimistic about the future and hoped that a job would 'come up', but her foster mother was less optimistic.

Ian – When I first met Ian he was 18 years old and living at home. At this time he had just decided to finish the independence course at Beech-view two months early as a training opportunity had arisen on a highly recommended Barnardos catering scheme. Preparations were also underway for Ian to live independently of his parents. Both Ian and his father thus felt that his life was in the process of changing in a number of ways. Seven months later, many changes had indeed occurred. Ian was now living with a landlady and thoroughly enjoying his independence. Both Ian and his father were optimistic about the future and hoped that he would soon have his own flat. However, Ian's social life remained a source of concern for his father as he felt his son, a young man with learning disabilities was isolated from his wider peers.

Cedar Drive School (Authority 3)

Bob- Bob lives with his parents and older sister in a modern bungalow. He has a close relationship with his grandparents who live nearby. Bob has a genetic condition, which inhibits growth and restricts his ability to walk and hear. At our first meeting Bob was 16 years old and preparing to leave Cedar Drive, a school he has attended from an early age. Bob was looking forward to pursuing a two year residential, independence course at Beech-view with his friend Luke, from Cedar Drive. Twelve months later, Bob was thoroughly enjoying the course at Beech-view, especially, social activities during weekday evenings. Bob's parents initially had reservations about the residential aspect of the independence course, but later, they felt Bob had become a more confident young man. However, Bob's long-term future remains rather uncertain.

Luke – Luke has learning disabilities and physically one arm is much weaker than the other, this makes certain tasks difficult. As noted above, Luke also chose the residential, independence course at Beech-view as his next-step at 16 years. At our first meeting, Luke was excited at the prospect of 'staying over' at Beech-view. Nine months later, he was enjoying the independence opportunities that the course had brought. However, he also enjoys returning home to his parents and younger brother at weekends due to his hobby of train spotting. On a Saturday he visits the local station while his mother goes shopping. Ultimately, Luke hopes to work at a station, however, his parents are rather more sceptical of this occurring.

Geoffrey – Geoffrey lives with his parents and three younger brothers and sisters in a town 20 miles from Cedar Drive. Geoffrey has learning disabilities. He is a very sociable young man and thoroughly enjoys the clubs and activities (youth club, Adventure Scouts, The Gateway club and music lessons) that his mother has encouraged him to join. Geoffrey also has a part-time job delivering newspapers after school and every week looks forward to receiving his 'wages'. On leaving school at 16 years, Geoffrey and his parents had chosen a local special school with a post-16 unit. His parents felt that this was an important stepping stone before mainstream college at 18 years.

The Laurels School (Authority 3)

Julie – Julie has learning disabilities, limited speech and severe epilepsy, which requires careful and continuous monitoring. Julie is an only child and lives with her father. Her mother died a few years ago and her father has taken early retirement in order to care for her. Julie has a very close relationship with her father and two grandmothers, both of whom regularly stay at the weekend. At our initial Easter meeting, Julie was 19 years old and preparing to leave home for Lakeside Residential College. Julie was aware that she was going to residential college and seemed quite relaxed about this. Her father was optimistic, viewing Lakeside College as a positive opportunity for his daughter. Twelve months later, he felt that Julie had matured and was enjoying a varied and active social life with her peers, but was concerned about the future, post-college.

Janet – Janet lives with her parents and younger sister, her older brother has left home and shares a flat with his girlfriend. Janet has Downs Syndrome. She is both a very independent and sociable young person, welcoming every opportunity to do things for herself. However, her parents felt that living at home there were few social and independence opportunities for her. Thus, they were pleased that Janet had an opportunity to progress to Willow Lodge Residential College. Janet too was looking forward to this. Nine months later, it was clear that she loved college life and was keen to talk about her new friends and social activities, especially dancing in the musical 'Grease'. However, it was also clear that Janet was rather lonely during the college holidays, a situation of which her parents were aware.

Eric – Eric has learning disabilities and limited speech. He lives with his parents and has an older sister in London, whom he enjoys visiting. At our first meeting it was clear that Eric is a very sociable young man. He attended a number of special clubs and clearly valued his friends at The Gateway club. He also enjoys

listening to rock music. When I first met Eric he was 19 years old and preparing to leave The Laurels and progress to Lakeside Residential College. His parents were apprehensive about the move but felt that it was a positive step for Eric to take as they wanted him to be as independent as possible. Eight months later, Eric was enjoying college but his mother was concerned about the future. She wanted to find options which would continue to stimulate her son.

Appendix 2 – Young People's Topic Guides

Pre-School Leaving 1

General Introduction
1. Tell me about some of the holidays or visits that you've been on with ... school.

B. What Next
1. What do you want to do when you leave school?

2. Next placement/option:

Have visited ...? (Probe with whom, when)
Did you like it?
What did you like best/didn't you like?

   a) Did you talk to someone like the head/ a teacher/ a worker/ the boss when you visited ...?
      What was it like?
      Did anyone help you prepare for your meeting with ... ? (Probe who, how)

   b) Did your Mum/Dad come with you?
      Did they like ...?

   c) What are you looking forward to at ...? (Probe good/bad points)

3. Choosing:

   a) What made you choose ...?

   b) Did you think of going anywhere else?

   c) Who helped you choose ...? (Probe how much)

   d) What sorts of things are your friends in class going to do when they leave school?
      Could you have chosen ...?

   e) Have you been to see any other colleges/centres?
      Did you like them? (Probe why/why not)

4. What would like to do after ...? (Probe any long-term plans - esp. work)

C. Preparations For Leaving School

<u>Careers Lessons</u>

1. Do you have lessons when you talk about things you can do when you leave school?

2. Who takes you for these lessons?

3. Tell me about what you like best/don't like about these lessons (probe what, why)

4. Do you find these lessons helpful? (Probe why)

   Do you like thinking about: - Leaving school? (Probe why)

                                                - Yourself and what you can do? (Probe why)

5. How does Mr/s ... help you to think about your 'special needs'?
   Is this helpful? (Probe why/why not)

Careers Advisor

1. Have you talked with Mr/s ...? (Probe when)

2. Tell me about your talk with Mr/s ... (Probe choices/options)
   (a). Did Mr/s ... ask you what you wanted to do after school?
   (b). Did you talk about going onto ...?

3. Was meeting Mr/s ... helpful? (Probe why)
   Does Mr/s ... listen to what you say?

4. Did you meet Mr/s ... by yourself or with Mum/Dad? (Probe if what wanted)

College Link Courses

1. Tell me about the things you have done at college.
   Tell me about the courses that you liked best/didn't like (Probe why)

2. Is it easy to get around the college?

3. What are the teachers like at college? (Probe if different to teachers at school)

4. Social aspects:
   a) Do you like going to the canteen at lunchtime? (Probe best/worst thing)
   b) Have you made any new friends at college? (Probe who)
   c) How do you feel when you go to the college each week?

5. Has going to college every week helped you to think about leaving school and going to college? (Probe why/why not)

6. Do you know anyone who is already at college?
   Tell me about some of the things that they've told you about college? (Probe good/bad points)

Work Experience

1. Tell me about your work experience? (Probe enjoyment, what did)
   What were the best/worst things about work experience? (Probe why)

2. Was this your first choice?

3. Did you talk about work experience at school? (Probe how)

4. Was doing work experience helpful? (Probe why/why not)

Life Skills

1. Do you have lessons on learning to do things for yourself and being more independent?

2. What sort of things do you do in these lessons?
   Tell me about the best/worst thing within these lessons? (Probe why)

3. Is it helpful to have lessons like this?

4. Are there other things you would like to do in life skills? (Probe what, why)

5. Now that you'll soon be leaving ... school, do you think the teachers treat you more grown up, like an adult? (Probe how they do/don't and who)
   What sort of things do you do at ... school - that make you feel grown-up?

D. Annual Reviews

1. Do you go to meetings at ... school, when your parents, teachers and other people who help you all meet together to talk about leaving school?

2. Can you remember who was there?

3. Tell me, what's it like going to these meetings (Probe feelings, usefulness)

4. When do you get a chance to say something? (Probe if does - when, how?)
   (a). Who do you think talks the most?
   (b). Do you think everyone gets on OK?

5. How do the teachers talk about these meetings? (Probe when, who)

6. Do you go to any other meetings with people who help you (Probe which, whom with, what like)

7. Have your teachers talked about a special meeting when you all talk about leaving school and plan for the future? (Probe transition planning - knowledge of, attendance at, experiences of, feelings about)

E. Speaking Out For Yourself

1. Who helps you to think about leaving school and moving on?
   a) Do you talk about what you want to do?
   b) Do you talk about how you feel?

2. When you have meetings where you talk about leaving school/the future:
   a) Do you think what you say is seen as important?
   b) Do other people listen to you? (Probe: if do - how, if don't - why)
   c) Are there people who help you to say what you want to say? (Probe who)

3. Is it hard to tell people what you think?
   What would help you?

4. Who do you feel always tries to listen to you? (Probe who, why)

F. Talking With Parents

1. Have you talked to Mum/Dad about leaving school?
   (a). Is it easy talking to them about leaving school? (Probe reasons)
   (b). Have you talked about going somewhere else/doing a different course?

2. How do Mum/Dad feel about you leaving ... school?

3. Are they pleased you're going onto ...? (Probe why/why not)

4. How have Mum/Dad helped you think about leaving school?

5. Has anyone else in your family helped you think about leaving school? (Probe who/how)

G Talking With Social Worker (if appropriate)

1. Do you have a person who comes to see you and Mum/Dad - who you can talk to and helps you (a social worker)?

2. Do you talk about leaving school with Mr/s ...?
   (a). Does Mr/s ... ask you what you want to do?
   (b). Does Mr/s ... listen to you?
   (c). Is it helpful talking to Mr/s ...?

3. Do you talk about being more grown up and becoming an adult with Mr/s ...? (Probe when)
   Do you talk about anything else? (Probe what)

4. Have you talked to any other people about leaving school and becoming more grown up? (Probe who, what talked about)

<u>Respite</u>

1. Do you sometimes say overnight with other young people at .... ?
   (a). Do you like staying there?
   (b). Tell me about the best/worst things at ....

2. Will you still go to ... when you leave school? (Probe - if not, where will go)

H. Health Needs (If appropriate)

1. Do you work with Mr/s ..., the nurse/physiotherapist/speech therapist or their helpers at school?

2. How do you feel about leaving Mr/s ...?

3. Do you think it will be different at ...?
   Have you met the physiotherapist/speech therapist at ...?

4. Do you go to the hospital to see a Doctor? (Probe when)

5. What's it like working with Dr...?
   (a). Have you always worked with Dr...? (Probe any changes)
   (b). Does Dr... work with children or adults?

I. Feelings About Leaving School

1. Tell me, what's the best/worst thing about leaving school? (Probe, why)

2. Is there anything that is worrying you about leaving school?

3. How do you think ... will be different from school? (Probe what, why)

4. Do you think that you've had lots of help in thinking about leaving school? (Probe reasons, ideas)
   Who has been most helpful?

J. Personal Independence and Leisure

<u>Leisure</u>

1. What do you like doing in your spare time, when you're not at school? (Probe who with?)
   Where do you like to go?

2. Where do you meet your friends?
   Tell me about your friends

3. Who's your best friend?**
   (a). Tell me about ...
   (b). What do you like doing with ...?

4. Do you have a boy/girlfriend?**
   Tell me about ...

<u>Personal Independence</u>

1. Do you go into town much?
   (a). Who do you go with?
   (b). How do you get into town?

2. Do you like going shopping?
   (a). What do you like to buy?

(b). Does anyone help you choose?**
(c). Do you choose your own clothes? (Probe what likes, who helps)**

3. Do you have your own money to spend?** (Probe - how much)
   (a). How does this make you feel?**
   (b). Who gives you your money?**
   (c). Tell me, what do you like to spend your money on?**
   (d). What don't you like spending your money on?
   (e). Can you buy what you want with your own money?

4. Now that you'll soon be leaving school, do Mum/Dad let you do more things by yourself, without their help? (Probe what, how much?)
   Do Mum/Dad let you help them at home? (Probe what, how makes feel)

5. What do you think will be the best thing about leaving school and being grown up?
   (a). What things will you want to do?
   (b). Where would you like to work?
   (c). Where would you like to live?**
   (d). Who would you like to live with?**

Ask young people if they would like to ask me anything about myself.

Pre-School Leaving 2 (Symbols)

Ice Breaking Game
Magazine Pictures - choosing likes and dislikes*

B. School

1. When you're at ... school how do you feel? *[Faces]*
   What makes you happy/sad at ... school? *[Symbols]*

2. Who are your friends at school? *[Photo]*

C. Preparations For Leaving

<u>College Links</u>

1. How did you feel when you went to college? *[Faces]*
   What makes you happy/sad at college? *[Symbols]*

2. How did the college teachers make you feel? *[Faces]*

3. When you go to the canteen for dinner, how did you feel? *[Faces]*
   What makes you happy/sad when you go into the canteen?

4. Do you have any friends at college?
   Who are your friends?

5. Have you made any new friends at college?
   (a). Who are your new friends?
   (b). How do your new friends make you feel? *[Faces]*

Work Experience

1. Have you helped people to do their jobs – at work?

2. What did you do? *[Pictures]*

3. How did you feel? *[Faces]*
   What made you feel/sad happy at work?

<u>Talking About</u>

1. Does Mr/s ... talk about leaving school?

2. How do you feel when you talk about leaving ... school? *[Faces]*
   What makes you feel happy/sad about leaving ... school? *[Symbols]*

3. Do you talk to anyone else at school about leaving ...?
   Who? *[Symbols of Staff]*

4. Do you talk about being grown up like Mum/Dad?

5. Now you're in Mr/s... class, do the teachers treat you more grown up, like an adult?
   What makes you feel grown up like an adult at ... school?

6. What makes you feel grown up like an adult at home?
   (a). Do Mum/Dad let you help them at home?
   (b). What do you help Mum/Dad with?
   (c). How does helping Mum/Dad make you feel? *[Faces]*

7. Do you talk about being independent - doing things without other people's help?
   Who talks to you about doing things without other people's help? *[Symbols]*

8. How do you feel when you do things without other people's help *[Faces]*
   (a). What do you like doing without help - by yourself?
   (b). Do the teachers at ... school let you do things without help?

9. Do Mum/Dad let you do things by yourself?
    (a). What do Mum/Dad let you do?
    (b). How does this make you feel?   *[Faces]*

D. Speaking Out.

1. When you are worried/sad at ... school, who did you talk to?**   *[Photos, symbols]*

2. Who do you like talking to?

3. Who listens to you?   *[Symbols]*
    Do other people listen to you?

4. Who helps you think about leaving ... school?   *[Pictures, symbols]*

E. Reviews/Meetings.

When Mum/Dad come to school to talk to Mr/s ... and any other people who help you -

1. Do you hear Mum/Dad and the other people talking?

2. How do you feel when you go into the room?   *[Faces]*

3. Who talks to you?   *[Pictures of People]*
    (a). Do you say anything?
    (b). Who talks the most?

4. How do you think the people feel there?   *[Faces]*

5. Has Mr/s... talked about a special meeting when you think about and talk about leaving school?

F. Next Move

1. When you leave ... school, where do you want to go?   *[Symbols]*

2. Have you been there to visit?

3. How did you feel?
    What made you happy/sad?

4. Who helped you to think about going to ...?   *[Pictures/Symbols]*

5. When you're as old as Mum/Dad what would you like to be doing? **

G. Talking to Mum and Dad

1. Who do you talk to about leaving school   *[Symbols of family members]*

2. How do you think Mum/Dad feel about you leaving school?   *[Faces]*

H. Services

School Professionals and Health [If appropriate]

1. Who do you work with – Mr/s... the nurse or the physiotherapist?   *[Symbols]*

2. How do you feel when you work with Mr/s ...?   *[Faces]*

3. How will you feel when you leave Mr/s ...?   *[Faces]*

4. Do you work with a Doctor at the hospital?

5. How do you feel when you work with them?   *[Faces]*
    What makes you happy/sad when you work with the Doctor?

Social Worker (If appropriate)

1. Do you have a person who comes to see you and Mum/Dad - who you can talk to and helps you (social worker)?

2. How do you feel when you talk to Mr/s ...? *[Faces]*
   What makes you feel happy/sad?

3. What do you talk about?
   (a). Do you talk about leaving ... school and being grown up?
   (b). How do you feel? *[Faces]*

4. Do you talk to Mr/s ... with Mum/Dad?
   Do you talk to Mr/s ... without Mum/Dad?

Respite (If appropriate)

1. Do you sometimes stay at the ...?

2. How do you feel when you stay at ...? *[Faces]*

I. Leisure and Personal Independence

Leisure

1. What do you do in your spare time, when you're not at school? *[Symbols of Activities]*
   Who do you do this with? *[Symbols]*
   How do you feel when you do this? *[Faces]*

2. Do you go to any clubs?**
   (a). What do you do there?
   (b). How do you feel when you go to ...? *[Faces]*

3. Do you have any friends at ...?**
   (a). Who are your friends?**
   (b). How do you feel when you see your friends? *[Faces]*
   (c). Who's your best friend?**
   (d). What do you like doing with ...?
   (e). Do you have a boy/girlfriend?**
   (f). Where do you see him/her?

4. Do you go out with Mum/Dad?
   (a). What do you do?
   (b). How do you feel? *[Faces]*

Personal Independence

1. Do you go into town?
   (a). Who do you go with? *[Symbol])*
   (b). How do you get into town? *[Symbols]*

2. How do you feel when you go shopping? *[Faces]*
   (a). When you go shopping what do you like to buy? *[Symbols]*
   (b). Does anyone help you choose?**
   (c). Who helps you choose?** *[Symbols]*
   (d).Do you buy your own clothes?**
   (e).What do you like to buy? *[Symbols of clothes]*
   (f). Does anyone help you choose?**
   (g). Who helps you choose?** *[Symbols]*

3. Do you have your own (pocket) money to spend?**
   (a). How does this make you feel?** *[Faces]*
   (b). Who gives you your (pocket) money? *[Symbols of People]*
   (c). What do/don't you like spending your (pocket) money on?** *[Symbols]*
   (d). Does anyone help you choose?**
   (e). Who helps you choose?** *[Symbols]*

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4. When you leave ... school and are grown up:-
   (a). What grown up, adult things will you like doing?
   (b). Where would you like to live?**
   (c). Who would you like to live with?**

Ask the young people if there is anything that they would like to ask me?

General knowledge for Young People's Pre-School Leaving Topic Guides developed from:-

Roberts, D. et al (1988), Appendix One, pp.1-38 (especially idea of faces and feelings).

Thomson, D. and Ward, K. (1994), "Transition to adulthood interview schedule", Appendix Two.

Ward, K. et al (1991), "Interview with young person", Appendix Two, pp.155-156.

* Idea gleaned from 'People First' - handout on ground rules and ice breaking exercises for group sessions.

** Denotes specific ideas and questions similarly used by Roberts et al (1988), Appendix One, pp.5-17, p.35.

Post-School Leaving 1

Introduction

Last year we talked about going to ... college, to do ... course, did you go to ... college?

Tell me a little bit about the course/what you're doing at ... college?

B. College Feelings

Do you like going to college?

1. Tell me about what you like best at college?
   Is there anything you don't like about college?

2. Do you like the course?
   Tell me about what you like best/don't like about the course?

3. Do you think going to college is different from being at ... school?
   What sorts of things are different/the same?

4. Do you miss ... school?
   What sort of things do you miss/don't miss? (Probe people, activities?)

5. Would you like to go back to ... school?

6. Do you talk to Mum/Dad about going to college?
   (a). How do you think Mum/Dad feel about you going to college?
   (b). What do you think they like/don't like about college?

C. Future Preparations at College

<u>Careers Lessons</u>

1. Do you have careers lessons at college, you know, lessons when you talk about what you might like to do after you leave college?

2. Do you like them at college?
   Tell me about what you like best/don't like about college careers lessons

3. Do you think that careers lessons at college are different from careers lessons at ... school with Mr/s ...? (Probe how)

4. Which do you like best so far? (Probe why)

<u>Careers Advice</u>

1. Have you seen a careers adviser at college?

2. Tell me about your talk with Mr/s ...?

3. Did you talk to Mr/s ... by yourself or with Mum/Dad?

4. Was it helpful talking to Mr/s ...? (Probe how, Why)

<u>Work Experience</u>

Last time we talked about your work experience at ... school:

1. Are you going to do some work experience at college? (Probe when)

2. What job would you like to do on work experience at college?

If have done some:	(a). Tell me about your work experience (Probe what did, enjoyment)
	(b). Did you talk about work experience at college?
	(c). Can you think of any ways that work experience was different at college to work experience at school? (Probe how)

Independence Skills

At ... school we talked about doing life skills, such as ... :

1. Do you do life skills at college?

   If do: (a). Tell me about the life skills that you've done at college

   (b). What's the best/worst thing about life skills at college (Probe why)

   (c). Do you think life skills at college are helpful? (Probe why)

   (d). Are life skills at college different to life skills at ... school? (Probe how)

   (e). Which do you like best? (Probe why)

Meetings at College

Last year we talked about having meetings at ... school when your Mum/Dad came to school to see the teachers - Annual Reviews:-

1. Have you had any meetings like this at college?

   If No: (a). Do you think you will have them (Probe when)

   (b). Do you think they will be useful? (Probe how)

   If Yes: (a). Did you go?

   (b). What did you talk about in the meeting?

   (c). Did you get a chance to say anything? (Probe when, how)

   (d). Do you think it was seen as important/listened to?

   (e). Who do you think talked the most?

   (f). Was the meeting at college different to meetings at school? (Probe how)

2. When you were at ... school, did you have a special meeting with Mum/Dad, your teachers and other people about going to college, you know, when someone wrote down everyone's ideas?

Can you remember seeing these ideas? I think it's called a transition plan.

D. College Life and Independence

<u>College Life</u>

1. Have you made any new friends at college? (Probe who)

2. What course are they doing?

3. What are the teachers/lecturers like at college?

4. Do the college teachers/lecturers treat you the same or more grown-up than teachers at ... school?

   If same: - How?   If more grown-up: - How?

                                                               - When?

5. How else do they make you feel grown-up?

6. Now you're at college, do Mum/Dad let you do more things by yourself? (Probe what, when)

7. Do they treat you grown-up, like an adult?

   If Yes: - How?   If No: - Why?

             - When?   - What would like?

<u>Travelling to College</u>

1. How do you get to college every day/week/term?

2. Who do you go with?

3. Do you like going by ...?

4. Is it easy or difficult to get to college?

5. How else could you get to college?

E. Talking with Social Workers
Last time we talked, you told me that you did/did not have a social worker, you know someone who comes to talk to you and help you.

Do you have a social worker now?

If No: (a). Do you think you should have   If Yes: (a). Do they come to see you?
         one?   (If not – who do they see?)

         (b). Would you find it useful?   (b). What do you talk about?

         (c). What sorts of things do you   (c). Do you like them coming?
         think they may be able to help
         you with?

                                                         (d). Can you think of any ways
                                                         that they have helped you
                                                         (Probe how, when)

F. Health Needs (If appropriate)

<u>Speech Therapy/Physiotherapy</u>

Last year we talked about your speech therapy/physiotherapy at ... school:

1. Do you have speech therapy/physiotherapy now? (Probe where)

2. Is it different to speech therapy/physiotherapy at ... school?

3. Do you think you have more or less speech therapy/physiotherapy now, than when you were at ... school?

4. How often do you have speech therapy/physiotherapy?

5. Do you like it more or less than speech therapy/physiotherapy at ... school? (Probe why)

<u>Doctor</u>

Last time we talked about going to see the Doctor and you told me that you went to see Dr...:

1. Do you still go and see Dr... or do you see a new Doctor?

2. Do you know why you've got a new Doctor?

3. Tell me about some of the ways that Dr...is different to your old doctor, Doctor?

G. Leisure

1. Now that you've gone to college, tell me a little bit about some of the things that you like doing in your free time when you're not doing lessons (Evenings and Weekends)

2. Where do you like to go? (Who with)

3. Have you joined any new clubs? (What)

4. Do you go out with Mum and Dad?

5. Where do you go with them?

6. When do you see your friends? **
   (a). Where do you see them?
   (b). Do you go out with your friends? (Who with, Where)

7. Do you ever see your old ... school friends? (When, Where and Who)

8. Do you have a boy/girlfriend? (Name, Age) **

   If Yes: - When do you see ...?   If No: - Would you like to have a boy/girlfriend (Why)

            - Where do you like going?

9. Would you like to get married?**

   If Yes: - When?   If No: Why not?

            - Why?

H. Aspirations

When we talked before, you told me that you might like to work ...:
Would you still like to work ...?

   If No: - Why not?

- What would you like to do? (Why)

When we talked before, you told me that you might like to live in ...:
Would you still like to live in ...?

    If No: - Why not?

             - Where would you like to live?** (Why)

Post-School Leaving 2 (Symbols)

Ice Breaker Game

Magazine pictures - choosing likes and dislikes *

B. College Feelings

1. Last time I came to see you we talked about leaving ... school and going to ... college:

2. Do you now go to ... college?   *[Symbols, photo]*

3. When you go to ... college, how do you feel?   *[Faces]*
    What makes you happy/sad at ... college?   *[Symbols]*

4. What do you do at college?   *[Symbols]*

5. Is ... college different from ... school?
    (a). How is ... college different to/the same as ... school?   *[Symbols]*
    (b). How does this make you feel?   *[Faces]*

6. Do you miss ... school?
    How do you feel when you think about ... school?   [Faces]

7. Would you like to go back to ... school?
    What would make you happy/sad about going back to ... school?   *[Symbols]*

8. Do you talk to Mum/Dad about going to college?
    (a). How do you think they feel about you going to ... college?   *[Faces]*
    (b). What makes Mum/Dad happy/sad about ... college?   *[Symbols]*

C. College Life and Independence

1. Have you made any new friends at ... college?
    Who are your new friends at college?
    How do you feel about your new friends?   *[Faces]*

2. How do you feel when you think about your ... school friends?   *[Faces, photo]*
    (a). Do you miss them?
    (b). Who do you miss?

3. How do you feel when you think about the teachers at ... college?   *[Faces]*
    What makes you happy/sad?

4. At ... college, do you talk about being grown-up and adult?
    (a). At college who talks about being grown-up/adult?   *[Symbols]*
    (b). How do you feel when you talk about being grown-up and adult at college?
    [Faces]
    (c). What grown-up and adult things do you like doing?

5. At ... college do you do things by yourself, without other people's help?

    If Yes: - What do you do?

                  - How do you feel when you do things by yourself?   *[Faces]*

6. Now you're at ... college, what do Mum/Dad let you do that's grown-up and adult?
    How do you feel when you do this?   *[Faces]*

D. Future Preparations at College

<u>Meetings</u>
At ... college have you had any meetings when Mum/Dad come to college and talk to your teachers?   *[Symbol]*

1. Did you hear Mum/Dad and the other people talk?
   How did you feel?   *[Faces]*

2. Did you talk to anyone?
   (a). Who talked to you?   *[Symbols]*
   (b). Who talked a lot?
   (c). How do you think the people felt there?   *[Faces]*

3. Do you like meetings at ... college when Mum/Dad come to talk to your teachers?
   Which meetings do you like best - meetings at ... school or meetings at ... college?

<u>Talking About</u>

1. At ... college do the teachers talk about leaving college?
   Who talks about leaving college?

2. How do you feel when they talk about leaving college?   *[Faces]*

E. Services

<u>Therapies</u>

1. At ... college, do you have somebody who helps you: move your legs, you know, a physiotherapist/to speak, you know, a speech therapist?   *[Symbols]*

   Yes: - What's their name?

           - How do you feel when you work with them?   *[Faces]*

   No: Does anyone help you? (Who)

           How do you feel when you work with them?   *[Faces]*

<u>Doctor</u>

1. Have you been to see a new doctor?   *[Symbol]*
   (a). How did you feel when you saw a new doctor?   *[Faces]*
   (b). What made you feel happy/sad?

<u>Respite</u>

1. Do you still go to (name) and sleep overnight?
   Do you go to a new place to sleep overnight?

2. How do you feel when you go to (name)?   *[Faces]*

F. Leisure

1. What do you like doing when you're not working in lessons at college/in your free time?
   (a). Who do you do this with?   *[Symbols]*
   (b). How do you feel when you do this?   *[Faces]*

2. Do you go out with Mum/Dad?
   (a). Where do you go?   *[Symbols]*
   (b). How do you feel when you do this?   *[Faces]*

3. Do you go to any clubs? **

    Yes: (a). What do you do at ...?

               (b). How do you feel when you go to ...?   *[Faces]*

    No: (a). Would you like to go to a club?

               (b). What would you like to do?

               (c). How would this make you feel?   *[Faces]*

4. Do you see your old ... school friends?   *[Photo]*

Yes: (a). Where do you see them?	No:	(a). Would you like to see them?
(b). How do you feel? *[Faces]*		(b). How would you feel? *[Faces]*

5. Do you see any other friends? **

Yes: (a). Who do you see?	No:	(a). Would you like to see them?
(b). Where do you see ...? *[Symbols]*		(b). How would this make you feel? *[Faces]*
(c). How do you feel? *[Faces]*		

6. Do you have a boy/girlfriend? **   *[symbol?]*

Yes: (a). What is their name?	No:	(a). Would you like a boy/girlfriend?
(b). Where do you see ...?		(b). How would this make you feel? *[Faces]*
(c). How do you feel when you see ...? *[Faces]*		

G. Aspirations
When you're grown-up like Mum/Dad:- **

1. What grown-up, adult things do you want to do? **

2. Where would you like to live? **

3. Who would you like to live with? **

4. Would you like to get married? **

5. How would this make you feel?   *[Faces]*

General knowledge for Young People's Post-School Topic Guides developed from:-

Roberts, D. et al (1988), Appendix One, pp.1-38 (especially idea of faces and feelings).

Thomson, D. and Ward, K. (1994), "Transition to adulthood interview schedule", Appendix Two (especially leisure and aspirations sections).

Ward, K. et al (1991), "Interview with young person", Appendix Two, pp.155-156, (especially college, leisure and aspirations sections).

* Idea gleaned from 'People First' - handout on ground rules and ice breaking exercises for group sessions.

** Denotes specific ideas and questions similarly used by Roberts et al (1988), Appendix One, pp.5-17, p.35.

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Appendix 3 – Parents' Topic Guides

Pre-School Leaving

A. General Information

To begin with, could you tell me a little bit about ... school, in particular how long (son/daughter's name) has been there and how it meets (name's) needs.

Probe:

(i)   Views about the school.

(ii)   Needs of (name).

(iii)   How far meets these needs.

B. Leaving School

Leaving school is a big step in anyone's life, could you tell me a little bit about when you first stated to think seriously about (name) leaving ...?

Probe:

(i) When?

(ii) Why?

Feelings

Now (name) is approaching school leaving, could you tell me a little bit about your own feelings and those of (name) towards leaving ... school?

For Instances: - Leaving teachers

                   - Leaving school routine

                   - Leaving friends

Preparations

Schools usually help pupils to start thinking about leaving and moving onto new places. School preparations often include such things as:

- College Links
- Independence Skills Training
- Careers Lessons
- Careers Advisers coming into School
- School Visits
- Work Experience

Could you tell me about some of the things that ... school has done to help (name) think about and get ready for leaving and moving on?

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Probe:

(i) What (name) has done at school.

(ii) People involved.

(iii) Usefulness

(iv) What parents most remember (name) talking about (person, visit, lesson) and why.

(v) Has school encouraged (name) to be more independent? - In what ways

(Name's) leaving school is obviously also an important time of change for you as parents. Do you feel that ... school has helped you to think about and prepare for (name) leaving and moving on?

For Instance: - Information

- Careers advice

- Talks

- Visits arranged

Could you tell me a little bit about the things that you have attended at ... school and if they have been helpful to you.

Probe:
What things they have gone to at school?

(i) Usefulness.

(ii) Support provided by school.

(iii) Accessibility of staff and careers adviser

(iv) What parents most remember or value and why.

(v) Involvement of parents
School/Home contact - how promoted, evaluation.
Did you feel that the school involved you?
Were you given opportunities to participate?

(vi) Suggestions (more or less of).

Annual Reviews and Joint Working

I am told that Annual Review meetings are regular occurrences at ... school. Do you know the one's I mean? - When people all meet up at school to talk about (name's) progress and leaving school. From you own experiences, could you tell me a little bit about these meetings.

For Instances: - Who attends

- What they're like to attend

- What happens

Probe Annual Reviews:

Attendance

(i) What they're like to attend?

(ii) Usefulness.

(iii) Do you have an opportunity to say what you think? (When, level of encouragement)

(iv) How far is (name) involved? (Evaluation of)
Does (name) have an opportunity to say what s/he thinks?

(v) Do you think people listen to you or (name)?

(vi) Who seems to be the most forceful or take the lead?

(vii) Do the other people seem to get on?

(viii) Any disagreements?

(ix) Can you think of any times when an annual review has gone really well or really badly?

Probe General Joint Working:

(i) Can you think of any other times when professionals have worked together for (name's) future plans?

(ii) Can you think of any times when you perhaps seem to have been given contradictory advice or been pulled in different directions by professionals?

Transition Planning

Schools are now generally introducing a new idea at 14 years, 'transition planning'. This is basically when the school has a special meeting within the annual review, in which parents, young people and any professionals who help (name) get together to think about (name's) future and begin to write a plan for the future. Could you tell me a little bit about any personal contact you've had with these 'transition plans' at ...?

Probe:

(i) Does (name) have a transition plan?

(ii) Experiences of.

(iii) Usefulness of plan or idea of planning.

C. Future Opportunities

We've talked about preparations for leaving school at ..., could you now tell me a little bit about how you see the actual choices (name) has of what to do when she leaves school.

How did you find out about these choices and what do you think or hope (name) will do when s/he leaves school?

Probe:

(i) What are the choices?

(ii) Feelings towards them?

(iii) How found out about them.

(iv) What one hopes (name) will choose and Why?

(v) Who helped with choosing?

(vi) Gaining funding.

(vii) Can you tell me what (name's) school friends are planning to do after leaving ...?

(viii) How do they see the long-term opportunities for (name)? (especially work – type, when)

D. General Support and Help

We've talked about ... school staff and also the careers adviser's help and support. In a more general manner are there any other people, for instance social workers, doctors,

family or friends or any other forms of support such as support groups who you feel have been important to you during this time?

If so, how have they helped and supported you?

Probe:

(i). Who has helped?

(ii). If professional support - who initiated support and parental views on relationship.

(iii). How helped?

(iv). Value of support

Alternatively, can you think of any times during this period when (name) is preparing to leave school that you have wanted help or supported from others but felt there has been none?

Probe:

(i). When?

(ii). Why feels a lack of support.

(iii). Issues parents feel important to have support on.

(iv). Suggestions (more/less of).

E. Adulthood and Future Changes.

Leaving school is also an important step towards growing up and being seen as an adult member of society by others. Could you tell me a little bit about how and when you talk about growing up with (name) at home?

Do you feel that other people, perhaps teachers, careers advisors or social workers also talk to you and (name) about growing up and becoming more independent?

Probe:

(i). What sorts of things have you discussed? (probe – doing things oneself, making choices, living independently, relationships).

(ii). Has this been easy/difficult?

(iii). Usefulness.

Do you think that your relationship with (name) may change when s/he leaves school and moves to ...?

How? (In what ways - positive/negative)

Are there any other things you think might change for you, as parents and (name) when s/he leaves school?

For Instances: - Leaving school/child health services and moving to adult health services

- Leaving child respite services and moving to adult respite services

- Claiming benefits

- Family changes within the home

- Social life changes

<u>Probe</u>:

(i) Do you think there are any problems in moving (name) from support which is available at school to adult provision?

(ii) Do you think respite provision will change at all?

(iii) Do you think support levels will remain the same?

(iv) Which services have been helpful or informative?

(v) Do you feel prepared for any changes?

(vi) Receiving financial advice on claiming benefits.

(vii) (Name's) role within benefit management? (How organises)

(viii) Perceived changes within parents' own life. (Social, employment, financial)

(ix) How (name) spends leisure time now and any perceived changes when leaves school?

(x) Hopes and fears of future - short and long term. (Work, care, independent living, relationships)

F. Summary

We've talked about a lot of issues surrounding (name) leaving school and moving on:

1. What do you feel are the most important things that people should consider for (name) when leaving school?

2. Is there anything that you feel could or should be improved?

G. Recap

1. Review what have covered.

2. Are there any other things, which you think are important and I haven't covered?

Post-School Leaving

A. Getting to College

When we spoke last time (name) was hoping to go to ... college, could you bring me up to date on what (name) is currently doing and if you've had any problems getting a place at ... college:

Probe:

(i). Current position

(ii). College course undertaking

(iii). Any problems encountered: - Place unavailable

                                                   - Financial

                                                   - Travel

(iv) How approached problems?

B. Life at College

Settling In

(Name) has been at ... college for a term, I know its only early days as yet but I was wondering how you felt s/he has settled into college life:

Probe:

(i). Enjoyment of course

(ii). Meeting and making new friends at college, esp. courses of friends?

(iii). Integration into college community or wider community if residential.

(iv). Any pros or cons parents feel so far about college.

Coping with Changes - Young Person

Leaving school and moving to ... college has obviously brought many changes for (name), how do you think (name's) coped with these changes during his/her first term:

For Instance: - Travelling to and from college

                         - Leaving ... school – missing friends and staff

                         - Moving from a day school to a residential college

                         - Returning home from residential college

Probe:
(i). How coping with travelling.
(ii). Whether misses friends and staff

(iii). Is (name) treated differently by staff at ... college? (adult?)

(iv). If residential - not coming home at night

(v). Enjoyment of residential so far

(vi). If returning home – how has adapted

(vii). Enjoyment of living at home

Coping with Changes - Parents

Similarly, there have also been many changes for you as parents during this first term, how do you feel that you have coped with these changes so far?

For Instance:-   - Travel arrangements

                    - Leaving ... school- support of teachers and staff

                    - (Name) not coming home each night

                    - (Name) now coming home each night

                    - Benefit changes – moving to college or reaching 16

Probe:

(i). If travel arrangements are working from parents point of view

(ii). Loosing school support

(iii). Contact with school: - Any contact since Summer

                            - Have parents wanted any contact?

                            - Do parents miss support of school?

(iv). How parents are coping with residential aspect?

(v). Any changes that has brought to parents lives: - Financial

                                                        - Employment

(vi). How independence aspect of residential panning out?
(vii). Any regrets about residential college?
(viii). How parents adapting to (name) returning home each night?
(ix). Any changes that has brought to parents lives so far?

(x). Any benefit changes: - Organisational help?

                         - How feel have coped?

                         - Any suggestions

C. Contact and Support

Moving to college has meant leaving ... school and its staff, during this first term at ... college could you tell me about any contact or support that you've had with the college and how you've found this?

Probe:

(i). If has had any contact - what for?

(ii). Feelings towards contact - good or bad, amount.

(iii). Ease of contact: - How approachable?

                        - Knowing who to contact?

(iv). Support received: - How?

                        - Usefulness?

(v). Parental involvement so far: - Being kept informed?

- Feeling included?

College Meetings
When we met last time we talked about Annual Reviews at ... school, you know, when people all meet up at school to talk about (name's) progress, during this first term at college have you had any meetings?

If you have, could you tell me a little bit about these meetings:

For Instance: - What it was about

- Who attended

- What it was like to attend

Probe:
(i). Attendance
(ii). What like to attend?
(iii). Usefulness
(iv). Did (name) attend? ·
(v). Did you or (name) have an opportunity to say anything? (Probe when?)
(vi). And differences to meetings at ... school?

(vii). Further contact with or experiences of Transition plans? (Do they have a copy of the transition plan?)

If haven't had any: - Are there any arranged for the future?

- Do you think there will be?

- Would you like any?

- What sort of meeting would you like? (Probe what about, who to attend)

Joint Working
Can you think of any times when different professionals, such as social workers, teachers, careers advisers or health professionals have worked together for (name) during this period of leaving school and moving to college or thinking about the future?

Can you think of any times when you perhaps seem to have been given contradictory advice or been pulled in different directions by professionals?

D. Service Changes

Last time we met, we talked about some of the changes you thought might occur after (name) leaves school and goes to college, such as changes in social worker involvement, respite care or medical care. Have you found that there have been any changes in the services you receive so far?

For Instance: - Contact with a social worker

- Respite care within adult services

- Getting physiotherapy/speech therapy for (name)

- Seeing a Doctor or specialist outside of school services within adult services

Probe:

(i). Level of contact with services? (Probe desired and actual)

(ii). Support over period: - Level of (Probe desired and actual)

- Quality of

(iii). Which services have been most helpful?

(iv). Changes in services, pre and post school   - Level of
leaving:

- Quality of

(v). Any more changes foreseen in the future?

(vi). Accessing services: - How?

- Evaluation of – easy or difficult?

- Help received

- Amount of service received – comparison to ... school

(vii). Any concerns or problem areas?
(viii). Any suggestions?

E. Social Life and Relationships

Last year, we talked about what (name) likes to do in his/her free time, do you think that leaving ... school and going to ... college has changed what (name) does in his/her free time at all:

For Instance: - Clubs that goes to (type of?)

- Activities that enjoys

- Friends that sees

Probe:

(i). What likes doing in free time and who with?

(ii). Any changes?   - For (name) going residential

- For (name) returning home

- Evaluation of changes

(iii). Contact with old ... school friends
(iv). Seeing new friends

Do you think your own social life has changed as a result of (name) going to college?

If Yes: How   If No: Would have liked it to?

            Evaluation of

Leaving school and going to college is seen as a time when young people grow-up, they become students rather than pupils. Do you think that leaving school and going to ... college for a term has changed (name) at all?

If Yes: - In what ways?   If No: - Changes in the future?

          - Evaluation of

Do you think it has changed your relationship with or how you treat (name)?

If Yes: - In what ways?   If No: - Changes in the future?

          - Evaluation of

This might not be the easiest issue to talk about but I know a lot of parents I have talked to are concerned about issues to do with sexuality, sexual awareness, sex education etc. Does (name) have a boy/girl friend?

Probe:

(i). Boy/girlfriend: - Parents feelings towards

                         - Seriousness of

Do you think you are more concerned than other parents with a young person of the same age might be?

(ii). Sexuality: - Awareness of facts of life

                     - Parents feelings to (name) being sexually active

                     - Contraception - attitudes towards

F. The Future

Last year we talked about your hopes and fears for (name) in the future, in terms of, what (name) would do after college and where she might live. Since we last met, have you had any professionals, such as social workers or people at college talk about (name's) future?

Probe:

(i). If had Chats with professionals: - Who with?

                                            - What about?

                                            - Usefulness?

(ii). If haven't had chats: - Would parents like to?

                                - What about?

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Similarly, as (name) has moved to college, do you now have any plans, concerns or anxieties for the future?

(i). Any plans:　　- After college

　　　　　　　　- Future living arrangements

(ii). Any concerns/anxieties?

G. Summary and Suggestions

We've talked about a lot of issues surrounding (name) leaving ... school and his/her first term at ... college, in summary:

Probe:
(i). What has been the most helpful thing/person during this period of leaving school, going to college and moving towards adulthood?

(ii) Did leaving ... school and moving to college go better or worse than expected?

(iii). If you could go back and do the whole thing again, is there anything that would do differently?

(iv). Could ... school or any of the other professionals have made (name's) move to college any easier?

(v). Any suggestions how leaving school could be made easier or improved?

H. Recap

1. Review what have covered.

2. Are there any other things, which you think are important and I haven't covered?

General knowledge developed from:-

Ward, K. et al (1991), "Interview with parent/carer", Appendix Two, pp.156-157.

Appendix 4 – Professional Topic Guides (Code of Practice)

Introductory Topic Guide

A. The School

Do you think you could tell me a little bit about ... School, especially the pupils that you support and any general school policies.

<u>Probe:</u>

1. Age range

2. Catchment area

3. Ability range

4. Age at transition

5. School policies

<u>Career Destinations</u>

Could you describe the career destinations of the young people when they leave ... School.

<u>Probe:</u>

1. What are they?

2. Who does what?

B. Job and Role

We've talked a bit about the school do you think you could tell me a little bit about your role during the transition period, especially your aims and objectives.

<u>Probe:</u>

1. General aims and objectives?

2. Evaluation of achievement.

C. Preparing Young People For Leaving School

We've talked about your role, can you now tell me a little bit about how the school generally prepares and supports young people for leaving?

<u>Probe</u>:

1. Who prepares?   - Teachers

                     - Careers teacher

                     - Careers adviser

                     - Social workers

2. When

3. How

4. Support provided (Probe evaluation of)

5. Choice making: (a). What choices made?

                      (b). How made?

                      (c). Who helps?

                      (d). Any problems

D. Acts

We've talked a little bit about your job and the school's preparation of young people. Could you now tell me a little bit about the new 1994 Code of Practice in ... School - especially for young people 14 to 19 years approaching the transition from school.

<u>Code of Practice</u>

<u>Probe</u>:

1. Attitude to

2. How implementing?   (a). First transition reviews

                         (b). Transition plans

                         (c). Any problems

                         (d). Evaluation of

3. Effects?   (a). Upon workload

                (b). Response from other professionals (Social Services, Careers advisers, Health)

                (c). For young people

4. Concurrent assessments
Working with the 1986 Disabled Persons Act
(a). Importance of Act
(b). Definition of 'disabled'

Over the past few years there have been other pieces of legislation relating to children and young people with disabilities - could you tell me a little bit about how this legislation has changed your job, if you think it has, during the transition period.

<u>Children Act</u>

<u>Probe</u>:

1 Has it affected your work during this period?

How?   (a). Liaison with other professionals

(b). Listening to young people

(c). Partnership with parents

(d). Independence and a 'normal' life

2. Changes - evaluation

NHS and Community Care Act

Probe:

1. Has it affected your work during this period?
How?
Liaison with adult services

2. Movement to adult services: (a). Co-ordination

(b). Any changes?

(c). Evaluation of

FE Funding Council

Probe:

1. Has it affected your work or the transition period?
How?

E. Working with Other Professionals

Can you tell me a little bit about any other professionals who are involved in this preparation - who they are and any problems that can occur?

Probe:

1. Who?   - Careers

- FE

- Health

- Social services

2. When?
Frequency

3. Professionals role

4. Willingness to collaborate
Evaluation of

5. Past relationship

F. Working with Young People

The young people themselves and their individual needs and choices are obviously central, can you tell me a little bit about how you work with the young people during this period?

1. Developing a relationship.

2. Listening to young people: (a). Any problems

                               (b). Communication

                               (c). How overcome?

3. Role of young person.

G. Working with parents

Parents are obviously concerned about their child's future, can you tell me a little bit about how you involve parents within this period, especially how the school maintains contact and provides support?

Probe:

1. Frequency of meetings

2. Providing support
Evaluation of

3. Main concerns of parents

4. Potential for conflict with yp's ambitions: (a). What areas?

                                             (b). Effects?

                                           (c). How resolved?

5. Parents role

H. Future

We've talked about recent legislation, in summary can you tell me about the things that you feel are the most important to consider during this period and anything that you feel could be improved.

Probe:

1. Most important things to consider?

2. Areas which could be improved?
How?

3. What makes a 'good'/'poor' transition?

I. Recapping

1. Review what have covered.

2. Are there other thing that you think are important and which I haven't mentioned?

Review Co-ordinators - 2nd Topic Guide

A. Implementation

Last year we talked about your initial thoughts surrounding the Code of Practice, in particular the 14+ transition planning meeting. Now that a year has elapsed, how do you feel that the implementation of the Code has progressed and developed within ... School?

Could you take me through the process of creating a transition plan for a young person at ... School?

Probe:

1. How organises 14+ transition meetings

2. Timing of the reviews: (a). When? (Year and day/evening)

        (b). How long an average transition plan meeting takes?

3. Attendance: (a). Who?

        (b). Issue of numbers

4. Information: - Collating from different sources

5. Typical transition plan: (a). Key issues

        (b). Other issues?

        (c). Who writes?

6. When written: (a). Do young people and parents see?

        (b). Who holds onto?

7. Reviewing by the school?
   How is it passed onto next stage institution?

8. Degree of variation between schools?

B. Support

During this period of initial implementation, support and guidance are obviously important considerations, how do you view the support that you've received from the LEA and also staff at ... School?

Probe:

1. Support and guidance from LEA: (a). How and When?

        (b). Evaluation of

2. Role LEA has played within transition planning?
   How does LEA view transition planning?
   Views upon transition plans that LEA has drawn up?

3. Support and guidance from Staff: (a). How and When?

        (b). Evaluation of

C. Effects

Implementing the Code of Practice, in particular transition planning may have led to changes within the process of preparing young people for leaving school. Are there specific areas within which you feel the Code has led to any such changes or had an effect upon?

For example, the process for young people and their parents, your own role and the work of external agencies during the process.

<u>Probe:</u>

1. School's leaving preparations, has it changed: (a). What you do?

        (b). When you do it? (timing of)

2. YP and their Parents - Experiences of the process

3. Own role as co-ordinator - Changes or effects upon?

4. External agencies   (a). How reacted to transition planning meeting?

    (b). Difficulty of arranging participation of different groups (Who arranges?)

    (c). Who have found most valuable?

    (d). Is the participation of all groups always necessary?

5. Multi-disciplinary working   (a). Collaboration

    (b). Clarity of roles

6. Concurrent assessments: (a). Working with the 1986 Disabled Persons

    (b). Working with Social Service or Health assessments?

    (c). Is the Social Services still the lead body?

    (d). Are there enough assessments?

D. Issues Surrounding and Evaluation of Transition Planning

During this last year or two as you have implemented The Code of Practice, do you feel that it has raised any important issues or considerations for you at ... School?
If so, could you tell me about some of them?

<u>Probe:</u>

1. Young people's involvement in the process: (a). Listening to young people's ideas? (How?)

    (b). Preparations (gaining young people's ideas?)

    (c). Within the meeting

    (d). Level of awareness of the process taking place?

2. Young people's role - Has it changed from the past?

3. Young people's involvement in the end product?

4. Feedback from young people: - good or bad?

5. Parental response to transition planning:

(a). The general process

(b). Degree of awareness of the process taking place?

(c). Parental participation within process

(d). Involvement of young people

(e). Number of meetings school has

6. Information:

(a). Accessibility of for parents and young people?

(b). How provided before meeting?

(c). Does the school start early enough?

7. Atmosphere of meeting:

(a). Degree of formality, pre and post-Code?

(b). Ease of speaking for parents, young people

8. Timing:

(a). Parental responses to? (year, when in day)

(b). Parental attendance? (who attends, who doesn't?)

(c). Is this the ideal time?

9. Looking ahead:

(a). How far looks ahead when transition planning?

(b). How Young people and parents respond to this?

(c). Any problems?

10. Conflict between young people, parents or professionals:

(a). Does it occur?

(b). How approaches?

11. When drawn up do you think the transition plan is viewed or used as an active document or an admin document?

12. Issue of Ownership - Who owns the transition plan?

It has been suggested that transition planning could lead to rather one directional and focused planning for young people, propelling them in a specific direction at a time when young people can and do change their minds about the future.
Do you think this is a valid concern?

E. Summary

We've talked about many different issues regarding transition planning, in summary:

Probe:

1. Can you think of any really good or bad transition planning meetings?
   Do you think there were any specific factors that made them good or bad?

2. Degree of difference that transition planning has brought to leaving school process?

3. The main pros and cons that transition planning has brought?

4. Any suggestions how it could or should be improved?

General Knowledge of past transition meetings developed from the articles of:-

Tisdall, K. (1996, 1996/97) and Thomson. G. et al (1995b)

Appendix 5 – Interview Guidelines

Ideas from the literature and my own personal experiences, especially pilot interviews.

Interview Preparation

Always establish the importance of interviewing the young person alone (Flynn, 1986; Roberts et al, 1988; Davies and Jenkins, forthcoming)

1. I found it was sometimes useful to conduct parent's interviews first, especially when a young person had limited speech. Parents could provide invaluable background information about important people/events (importance of significant others, Flynn, 1986).

2. Establish my role as a researcher and the purpose of the study (as Lowe et al, 1987, p.75 suggests).
    However, make it clear that I cannot change anything in the young person's life.

3. Establish the young person's role making it clear that they are in charge.
    i.e., that they can stop the interview whenever they want and only answer the questions that they want (as Lowe et al, 1987; Beresford, 1996, Ward, 1997 and Davies and Jenkins, forthcoming highlight).

4. Explain about using the tape recorder and choosing a name.
    If the young person cannot think of one, then suggest that we choose one together.

5. Try to quickly assess the value of using the ice breaker game or generally, visual stimuli for each young person.
    Try to avoid a patronizing situation developing (remember Roberts et al's concerns 1988, p.18).

During The Interview

1. Try to always be flexible, consider different formats and approaches as and when appropriate (Wyngaarden, 1981; Flynn, 1986).
   Aim to find an approach that each young person seems to be comfortable with.

2. Always give the young person time to answer and try to avoid leading questions (Wyngaarden, 1981, p.111). However, prior information was often invaluable as it helped me to personalise questions and thus make them more meaningful (avoid abstract questions – Flynn, 1986, Hirst et al, 1990).

3. Try to always be sensitive to non-verbal cues, i.e. if a young person appears to be uncomfortable or upset (Booth and Booth's researcher "sensitization", 1996, p.61 and Ward's 1997 guidelines)

4. Always have visual material well organised before and at hand during an interview. When using visual stimuli try to be methodical and not to rush as this can be confusing for the young person.

5. When drawing upon visual material, if a young person appears to be confused or contradictions emerge, try to rephrase the question or adopt a different approach at a later point within the interview (Wyngaarden, 1981).
   However, it is important to try and avoid making the young person feel that they are being tested or that they have previously, given the wrong answer (remember Simons et al's, 1989, p.13 idea of respecting responses and contradictions).

6. When a young person had limited speech, I found it was useful if I could keep talking, repeating what they said. Then if the tape did not pick up the young person's voice, it hopefully picked up mine.
   I also found that this reconfirmed for the young person what they had just said.

Ending The Interview

1. Try to always end on a positive note. Give the young person an opportunity to ask me questions.

   If a young person asked me a question during the interview I always answered and tried to make it conversational (remember the importance of rapport - Wyngaarden, 1981; Atkinson, 1988; Biklen and Moseley, 1988; Cattermole et al, 1988; Prosser, 1989 and Beresford, 1996).

2. If appropriate, tell the young people what I like to do in my spare time. Try to avoid the meeting being one directional (importance of reciprocity, Walmsley, 1993).
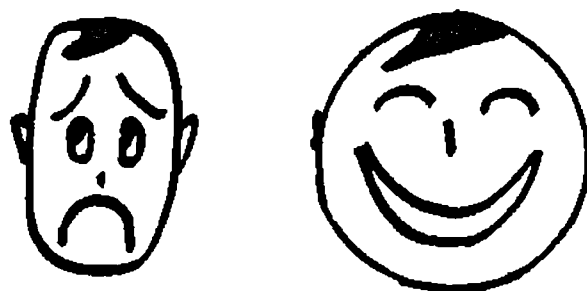
3. Always ask the young person if they would like to listen to the tape.

   I found that some enjoyed listening to themselves.

Appendix 6 - Faces

Face Set 1: Male and female 'happy', 'ok' and 'sad' faces taken from Roberts et al's (1988, post Appendix 2) five faces.
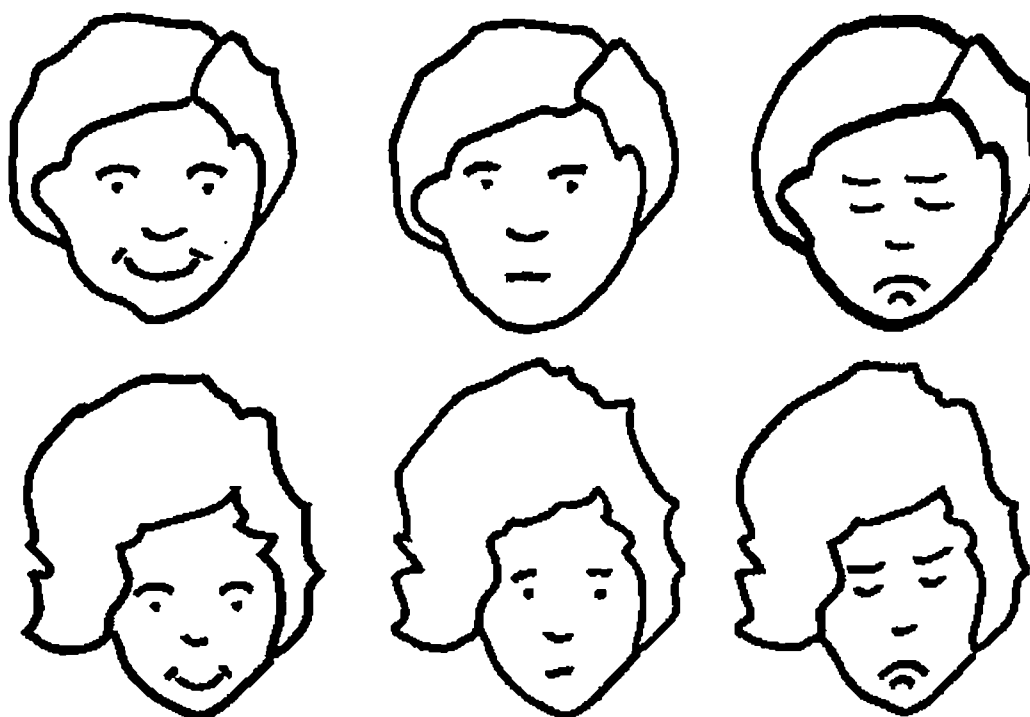
Face set 2: 'Sad' and 'happy' Rebus faces taken from Meldreth Manor School's Handbook (1989/90, p. 18 and 19)

SAD   HAPPY

List of Abbreviations

CERI	Centre for Educational Research and Innovation
CLDT	Community Learning Disability Team
DES	Department of Education and Science
DFE	Department For Education
DfEE	Department for Education and Employment
DHSS	Department of Health and Social Security
DLA	Disability Living Allowance
DoH	Department of Health
DSS	Department of Social Security
FE	Further Education
FEFC	Further Education Funding Council
FNA	Future Needs Assement (meeting)
GCSE	General Certificate of Secondary Education
GP	General Practioner
HMI	Her Majesty's Inspectorate
LEA	Local Education Authority
NHS	National Health Service
NVQ	National Vocational Qualification
OPCS	Office of Population, Censuses and Surveys
OPEX	Opportunities and Experience
SEN	Special Educational Needs
SENCO	Special Educational Needs Co-ordinator
SSD	Social Service Department
UN	United Nations
UPIAS	Union of the Physically Impaired Against Segregation

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