

Thesis

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SCHOOL LEAVERS WITH MULTIPLE DISABILITIES : AN
EXPLORATORY STUDY OF THE ISSUES AND PROBLEMS
RELATING TO THE PLANNING AND PROVISION OF
FORMAL POST-SCHOOL SERVICES



Declaration

I declare that this thesis was composed by myself and that the work in which it is a record was performed by myself.

This thesis has not been accepted in any previous application for a degree.

All other sources of information have been specifically acknowledged.

Signed: M. M. Hubbard.

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SCHOOL LEAVERS WITH MULTIPLE DISABILITIES : AN EXPLORATORY STUDY OF THE ISSUES AND PROBLEMS RELATING TO PLANNING AND PROVISION OF FORMAL POST-SCHOOL SERVICES

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ABBREVIATIONS

SLWMD	- School Leavers with Multiple Disabilities	2
YPWMD	- Young People with Multiple Disabilities	2
FNA	- Future Needs Assessment	3
IPSD	- Indicators of Personal and Social Development	13

CONFIDENTIALITY

In order to ensure complete confidentiality throughout the thesis, Young People are referred to by their initial, the schools are referred to by letters A, B and C and post-school placements are referred to by letter and number.

SCHOOL LEAVERS WITH MULTIPLE DISABILITIES : AN EXPLORATORY STUDY OF THE ISSUES AND PROBLEMS RELATING TO PLANNING AND PROVISION OF FORMAL POST-SCHOOL SERVICES

Abstract

This research is an exploratory study of the issues and problems encountered by Young People with multiple disabilities when they leave school and for whom formal post-school service provision is relevant within the Scottish setting. The research problem is tackled by a qualitative and an empirically grounded study with a central focus was on the way in which decisions about the nature and range of services are made and their potential for making a major impact on quality of life. From conception, the study was innovatory and it was necessary to combine methods of data collection and to analyse in ways that had previously not been used in the field. The design and methods are eclectic with an emphasis on in-depth case-studies.

The research process began with the development of a functional classification used to define the sub-population. This was followed by an investigation of the structure and organisation of the Future Needs Assessment process which is central to the planning of formal post-school provision, together with Carer perspectives and opinions of the process. The next phase was to examine the nature and range of formal post-school service provision in relation to the issue of quality of life and in the meeting of developmental needs. Discussion then took place with the Young People and the Carers about their judgements of post-school provision and 'ideal' provision. The final phase developed recommendations on the practical application of the research findings.

The major research findings, derived from the fieldwork evidence, indicate that there is a radical change in emphasis in the transition from school to adult-based formal service provision which result in the limitation of services and of personal choice. There is a major disjunction in the

quality of life experienced by the Young People. The Future Needs Assessment process fails to adequately plan for the transition to formal post-school provision which fails to meet individual personal and social development.

The major recommendations, derived from the research, state that the Future Needs Assessment process must play a more effective role in identifying the post-school needs of the School-leavers to ensure that formal post-school provision and delivery planning is individually-centred and 'needs-led'. In addition, there should be greater choice of provision which follows the 'independent /enabling /empowering model and which will offer the School leaver the potential to experience a high quality of life.

CHAPTER ONE
INTRODUCTION : THE RESEARCH PROBLEM AND THE RESEARCH STRATEGY

1.1 Overview

This research is an exploratory study of the issues and problems relating to the planning and provision of formal post-school services for Young People with multiple disabilities. The project commenced in October 1986 and the fieldwork in Scottish Council for Spastic establishments was finally completed in July 1989. The central focus is on the way in which decisions about the nature and range of formal services are made, and their potential for making a major impact on the quality of life of school leavers with multiple disabilities.

The presentation strategy is as follows. The research problem is set out in this chapter. Chapter 2 is devoted to a critical analysis of relevant literature that provides a background to the research problem and Chapter 3 outlines the research design and pattern of data collection. Chapter 4 is used for the presentation of the results of each stage of the work and the fifth chapter focuses on the analysis and interpretation of the data. The final chapter draws together the analytical conclusions, and presents a series of policy and practice recommendations based on the research findings.

This introduction to the research outlines the research problem and the initial aims and objectives. It is followed by a description of the research sample and an examination of the rationale for the research, focusing on the wider and more general issues surrounding the research statement. Finally the research strategy is outlined. This involves exploring ways of identifying needs which take into account personal and social development at the level of the individual, in addition to concepts of 'needs' which are built into categorisations of services.

1.2 The Research Problem

The overall aim of the research study was to identify and analyse the issues and problems encountered by individual school leavers with multiple disabilities (SLWMD) when they leave school and for whom formal post-school service provision is relevant.

When a young person reaches school leaving age, (16 or 18 years) the individual is about to embark upon a major new stage of life. The general cultural expectation is that the young person will be emerging from childhood into adulthood. SLWMD, because of their level of functioning and dependency, require certain services to support and enable them to pursue a full and ordinary life-style. A wide range of services are made available to the individual within the school/home environment but when the young person leaves school, the pattern of services, and because of this, new contexts of and responsibilities for service provision and processes of delivery necessarily arise. During childhood, paediatric, educational and welfare provisions are normally available to meet the various needs of young people until they become 16 years. At this age they are eligible to leave school and their status according to law changes for they are now referred to legally as a 'young person'. As some members of the sub-population on which this study is based are either aged 16+ or became 16 during the course of the research, it was decided to refer to all members of the sub-population as 'young person with multiple disabilities' (YPWMD). In addition all parents and other adults who serve as principal carers are referred to as 'Carers'.

The new, formal post-school provision is expected to meet the changing needs of YPWMD. This includes continuing to provide certain services and possibly adding new services required because of continuing developmental needs, maturation and the changing contexts in which the young person is living. Furthermore, this adult provision is expected to

contribute to the high quality of life opportunities and ensure that ordinary expectations and aspirations can be realised. However, information from various sources (research studies; practitioners and professionals specialising in the field; carers; researcher's own experiences) has suggested that the transition does not go smoothly and the outcome is unsatisfactory for a significant number of young people. Heron and Myers (1983) describe one pattern of transition when at 16 years the co-ordination of physical, educational and welfare support ceases as, 'a drop over a metaphorical cliff of services'. Problems occur with the planning of formal post-school provision and its delivery to the individual with the result that the individual lacks the opportunity to experience quality of life. Discussions with YPWMD, their carers, teachers and involved professionals support these claims and urge for the present situation to be altered and become a positive experience for all involved.

Post-school service provision is expected to take on board the need to provide opportunities for continued development. The progress the young person has made during the time at school can only be achieved if skills are further developed and maintained and the young person is able to function as independently as possible and experience self-determination, self-motivation and self-esteem.

This project focuses upon 1 major aspect of the school leaving process, the 'Future Needs Assessment' (FNA) and review procedure which seek to identify post-school needs and ensure that appropriate provision are made for the post-school situation. The changes being studied are likely to have a major impact on the quality of life of YPWMD. The study took place at a time when recent legislation was being implemented and major changes were being made in the organisation of social work and related agencies.

1.3 The Research Process

The initial aims of the research were: -

- 1 To adopt or adapt an existing classification of disabilities/people with disabilities so as to define a population of YPWMD in order to investigate how the changes in formal service provision associated with school leaving affect opportunities for quality of life;
- 2 To investigate the structure and organisation of FNA meetings;
- 3 To find out Carer's perspectives on 'post-school' needs and their impressions on FNA processes;
- 4 To examine the nature and range of formal post-school service provision in relation to the issue of quality of life of YPWMD;
- 5 To discuss both YPWMD and Carer judgements on the 'package' of formal post-school services achieved; and to collect information on the elements of such a 'package' considered 'ideal' by YPWMD/Carers;
- 6 To develop recommendations on the practical application of the research findings.

The review of classification systems undertaken during the opening weeks of the research rapidly led to the conclusion that none of the existing classifications of disability/people with disability were appropriate for associating levels of personal and social functioning with levels of formal post-school service provision and distinguishing YPWMD for whom formal services are judged essential from others. This led to an immediate addition to the aims, namely to develop a functional classification in terms of which to define a sub-population for the research investigation and to indicate clearly the characteristics of the wider population to which the results of the current exploratory study should, in principle, be applicable.

1.4 The Research Sample

The research was an exploratory study of YPMD receiving or who had received education under the auspices of the Scottish Council for Spastics. They attended schools labelled, School A, School B and School C. Schools A and C are residential schools and School B is a day school.

The criteria for inclusion was that the Young People had to be aged 13 + and they experienced multiple disabilities. For the purposes of the study, the term 'multiple disabilities' was defined as being appropriate when an individual experiences specific difficulties in functioning in more than 1 of the following areas; mobility, motor skills, communication, comprehension and basic life skills. In the selection of the sub-population, the decision to focus on those SLWMD was deliberate and so this study's research sample differed from recent research carried out at Dundee University with 'mildly, mentally handicapped' school leavers (May and Hughes, 1984). Chapter 2 commences with a discussion of different classification strategies and argues that none of the contemporary approaches were applicable to the research problem. A new classification procedure was developed that hinged around the concept of 'need' and is based on levels of functioning.

All the members of the sub-population would be described as having 'special educational needs'. Consequently, mainstream education could not meet their educational needs and so they attend a 'special' school. Most of the members have undergone a multi-disciplinary assessment (referred to as 'recording') and possess a 'Record of Needs'.

The age factor was carefully chosen. Children younger than 13 could not be included as they would not embark upon the school leaving process until the fieldwork period was near completion. By including pupils aged from 13 upwards, all different parts of the FNA procedure could be observed and monitored. As the project's fieldwork was intended to take place over

approximately a 3 year period it was planned that profiles of the Young People would be built up, incorporating a longitudinal aspect into the research design and allowing an insight into the interaction of all the factors responsible for leading to the final outcome.

77 pupils, aged between 13 and 19 years were members of the sub-population, taken from the 3 schools. This number was pre-determined as this was the total number of pupils in the 3 schools that met the criteria for inclusion. The pupils aged between 15 and 18 years were described as 'school leavers' as they had embarked upon the FNA process. Pupils in the sample younger than 15 years were referred to as 'pre-school leavers' and those aged 18 + as 'post-school leavers'. Out of the 77 Young People, 48 were residential pupils and 29 were day attenders. 8 regions are represented with the exclusion of Borders Region. This provided the study with a geographical dimension for it allowed for the observation of different regional practices while at the same time having the advantages of a small sample.

The research fieldwork strategy involved 5 separate strands. Only 1 of these strands involved the total 77 Young People, the sub-population. The remaining 4 strands involved a sample number from the sub-population. These samples differed in number and criteria for inclusion. They are discussed fully in Chapter 3, the research methodology.

The size of the sub-population and samples taken from that group were small because the project set out to be qualitative and therefore the samples were too small to make detailed statistical comparisons. The advantages are that the experiences of each SLWMD and their Carers can be closely monitored and analysed which can lead to a detailed insight into the problems and issues.

1.5 Background and Rationale for the Research

Several factors led to the setting up of the research project and these formed the background to the study. They will be examined in turn.

Legislation plays a significant role in this area of educational/social policy and in the last 20 years there have been considerable changes. This research project was undertaken at a time of such change and uncertainty. Prior to the 1974 Education (Mentally Handicapped Children) (Scotland) Act, there was little provision available to children with multiple disabilities. Children were described as 'ineducable' but with the Act this trend was reversed and the consequences were for services to be revised. Great developments were achieved with educational services. Quality of life increased dramatically as did the expectations of SLWMD who wanted to continue to receive the type of services they were accustomed to and continue the progress they had achieved while at school. Formal post-school service provision appears not to have developed at a comparable rate making for potential difficulties, the precise nature of which could be established by investigation.

Recent legislation, passed a relatively short time before the commencement of the project, has brought about further changes and an attempt to marry together educational provision and post-school provision. 2 Acts, the Education (Scotland) Act, 1981, following the Warnock Report (1978) and the Disabled Person's (Services, Consultation and Representation) Act (1986) were of particular relevance. These 2 Acts had profound repercussions for the SLWMD in terms of the services they received at school and formal post-school service provision and required both the Education and Social Work Authorities to review their policies and practice.

The assessment of post-school needs is a fundamental part of the school leaving process to ensure that appropriate provision can be secured

when the YPWMD leaves school. This is carried out through the FNA procedure which is a legal requirement and detailed in the Education (Scotland) Act 1981. Chapter 2 includes a description and commentary of the sections of the Act that are relevant.

The Disabled Person's Act (1986) became statute 6 months before the beginning of this project. It came about from a Private Member's Bill instigated by the increasing awareness of the deplorable position people with disabilities were experiencing because of the unfulfilment of needs and the critical shortage of essential services. If fully implemented this Act could drastically improve the present situation for the SLWMD, as it sets down a procedure whereby post-school needs are to be assessed by the Social Work Department and necessary services provided accordingly. No other legislation prior to this Act has stated who has responsibility for this type of service provision.

When the research project was being developed, there was significant debate taking place on the topic of community care and the wider choices of service provision to take into account the Principles of Normalisation. This was to culminate in further legislation, (Community Care Act 1990). The project set about examining the planning and provision of formal post-school services within this context of policy development, but it must be noted that the community care legislation had not been passed at the time of the fieldwork.

The project was also carried out at a time of mounting economic difficulties. It needs to be recognised that formal (and informal) service providers were faced with limited budgets and restricted resources so that Local Authorities, Voluntary and Private Organisations were having to make finance-led decisions concerning cut-backs and curtailment of the range and quality of provision. Social Work Departments in many regions of Scotland were experiencing re-organisational changes and direction of policy

changes. These upheavals necessarily had an impact on service provision and so had to be closely considered when post-school provision planning was to be studied. By comparison, both policies and organisation structure of Education Departments remained much more stable during the period of fieldwork.

As with many Local Authority Departments, Private and Voluntary Organisations were also experiencing new developments. The Scottish Council for Spastics was 1 of these organisations. This organisation was undergoing significant changes in structure and policy and contributing to the pioneering role of the Voluntary sector as identified by Central Government. The Scottish Council for Spastics had also commented in detail on the Wolfenden Report (1978) and were developing policies accordingly. The Scottish Council for Spastics aimed to ensure that future developments were thoroughly planned and targeted at areas of priority need. This was seen as requiring an accurate information base on potential school leavers including a detailed assessment of the provisions individuals required. The Scottish Council for Spastics clearly recognised a shortage of appropriate provision.

A further reason for conducting the research project was to contribute to the development of knowledge in a neglected field of study. At the time the project was initiated, ^{there was} _A no published research that directly focused on SLWMD with particular reference to the planning of their formal post-school service provision and quality of life in Scotland.

Therefore the rationale for the focus of this research was clearly related to the changing contexts in which formal services for SLWMD were being developed. The years 1986-1989 may be characterised as a period of rapid social change. New policies based upon the Education (Scotland) Act, 1981 and Disabled Persons (Consultation, Services and Representation) Act, 1986, were in the processes of being implemented against a background of

national, economic 'crisis', the re-organisation in Social Work Departments, associated changes in the voluntary sector (including the Scottish Council for Spastics). In addition, ideas were emerging about appropriate patterns of community care and there was considerable uncertainty in advance of the 1990 legislation about the new directions in policy and practice that these would entail. The lack of relevant research on YPWMD was also a major factor in the choice of the research focus for this study.

1.6 The Research Strategy

The research problem was tackled by a qualitative and an empirically grounded study within the setting of the Scottish Council for Spastics. A qualitative approach was adopted as it allowed for an in-depth study of a small sample of SLWMD. To achieve the depth of meaningful conclusions sought, the topic of the research demanded that the individual be at the centre with a holistic focus on their needs and quality of life. If a large number of SLWMD had been involved in a survey using a mainly quantitative approach, a lot of significant detail would be lost and hidden and it would have been conceptually difficult to design and pilot an appropriate questionnaire. A quantitative-experimental approach would not have provided the descriptive data required that illuminates interactive relationships and process as well as the outcomes and the research design did not demand a representativeness of the research population nor a generality of the findings. Inferences and implications drawn from the research conclusions will not come from direct statistical findings. Regarding logistical considerations, the small size made the fieldwork manageable and allowed the 5 strands of the strategy to be implemented successfully with the limited time and finances available.

In order to collect detailed data on individual circumstances the project was empirically grounded so that the concepts and arguments were continuously tested and, if necessary, revised in the light of the information and evidence collected. It was the researcher's intention throughout to use the findings to produce recommendations that could be applied in practice. From its conception, the research study was innovatory and so it was necessary to combine methods of collecting data and analysing data in ways that had previously not been used in this field. In order to tackle the aims identified in the research statement, a strategy divided into 5 separate strands was evolved. These strands are described in detail in Chapter 3 with the results set out in Chapter 4 and analysed in Chapter 5. The design and methods are eclectic, with an emphasis on qualitative data and in-depth case studies used to develop a functional classification of disability and provide information on the FNA procedure and the support and accommodation resources available after the Young Person has left school. The 5 separate strands of the research were: -

- 1 The compilation and execution of a profile questionnaire to define a sub-population of YPWMD and to develop a functional classification.
- 2 The systematic and objective analysis of the FNA procedure.
- 3 The discussion with Carers of the YPWMD in the study about their experiences of the FNA procedure.
- 4 The evaluation of formal post-school¹ service provision in different settings.
- 5 The investigation of the experiences of the YPWMD and their Carers with respect to formal post-school provision.

CHAPTER TWO
CONTEXT AND BACKGROUND TO THE STUDY

2.1 Introduction

There is a vast literature on disability/ handicap/ impairment. This review is highly selective and concentrates on:-

- works which were consulted in order to assist with the design of this research study
- works which are relevant to the analysis of the findings of this study
- literature providing information essential for placing a study of YPWMD and their school leaving experiences in the late 1980s in Scotland in context.

There is confusion with the more fundamental terminology of 'disability', 'handicap' and 'impairment'. These terms have a long history of imprecise usage and are sometimes used interchangeably (Carver and Rodda, 1978). Several attempts have been made to clarify this terminology (Harris, 1971; Wood, 1975; Wood and Braidley, 1978; World Health Organisation, 1980; Weale and Bradshaw, 1980). A general consensus is emerging that 'handicap' refers to disadvantage experienced by the individual as a result of a disability which precludes the individual from experiencing a 'normal' life, disablement is socially produced. 'Impairment' refers to an abnormality in the body's structure with disablement exteriorised. The term 'disability' refers to a person's ability to function with disablement being objectified. Different levels of functioning and relative disability lead to different degrees of disability (Weale and Bradshaw, 1980). This is the sense in which disability is used in this study and the terms 'disability' and 'people with disabilities' are used rather than 'handicap' or 'impairment'.

This review first examines issues in the classification of disability/ people with disabilities and explores relations between the nature of

classifications, the purposes for which they were constructed and the range of ways in which they are used. As previously noted, no classification examined proved to be appropriate for use in the present study.

The focus then shifts to concepts of 'need'. This section is used to highlight a number of potential pitfalls and to indicate how and why the concepts of 'indicators of personal and social development' (IPSD), 'developmental needs' and 'service-led needs' came to be adopted for the study.

The next section reviews relevant contributions from the literature on quality of life and reasons for the development of IPSD.

The following section aims to review relevant literature on the planning and provision of formal post-school services for SLWMD and draw upon the literature on relevant legislation and policies to establish the immediate background and context of the present study.

The final section summarises research findings on SLWMD.

2.2 Towards a Functional Classification of Multiple Disability

Most classifications relating to people with disabilities/ handicaps/ impairments, attempt to provide definitions which distinguish those with, from those without disabilities/ handicaps/ impairments for specified purposes. There is also a tendency to draw a firm distinction between mental and physical aspects of disability, although a preliminary review of the literature on classifications of disability reveals that various combinations are usually recognised at a secondary level under designations such as 'multiple disability', 'multiple handicap' or 'multiple impairment'. The degree of disability (eg. ranging from 'mild' to 'profound') is also typically incorporated as one of the dimensions of a classification system. Whichever system is adopted, there is a confusing

array of terminology which do not coincide conveniently (Kirman, 1965; Carver and Rodda, 1978; Malin, Race and Jones, 1980; Anderson, 1983). The relevance of the majority of classifications for this research, which focuses on YPWMD of a relatively severe nature, proved to be negligible because of the difficulty of drawing useful distinctions along the 'mild - severe' continuum. This is compounded by a lack of sufficient scale points to measure differences in capacities and functioning among the target population, namely SLWMD.

A major, though obvious point that emerges from an examination of systems for the classification of disability, handicap and impairment, is that the purposes for which a classification is designed need to be taken into account when assessing its research impact and social utility.

Twentieth century medical classifications are strongly geared to the identification of categories of disability or impairment which are either indicative of an appropriate form of treatment, or proposing a specific aetiology which identifies an 'untreatable' condition.

Educators gear their classifications to what in modern jargon has come to be called, 'special educational needs' (Warnock Report, 1978). They are interested in identifying the degree of 'mental handicap', 'intellectual impairment' or 'retardation' and relating this to the design and content of the curriculum. Educational classifications are heavily biased towards pedagogy and cognitive and intellectual development, and until the mid 1970s, discriminations between 'educable', 'suitable for training' and 'ineducable' were built into the most widely used classifications.

Educators also address issues of physical impairment and disability with special emphasis on their implications for pedagogy. There is a long tradition of special schools for 'the Blind', 'the Deaf' and 'the Crippled' for example, and of social schooling arrangements for those with speech

defects, Epilepsy and 'other Physical Defects'. The growing emphasis since the beginning of the century on encompassing definitions in the field of mental disability is related to the priority of cognitive and intellectual functioning in the thinking of educators, whereas, in most instances, a physical disability tends to be associated with difficulties which inhibit participation in normal learning processes. The apparently small numbers of children with relatively severe multiple disabilities has led to them being treated as exceptional in relation to the dominant categories.

Hogg and Sebba (1986) produced a 2 volume work on 'Profound Retardation and Multiple Impairment' which proved to be useful in crystallising issues at the research design stage. Precisely because Hogg and Sebba focused on 'profoundly and multiply disabled' children, and found it necessary to devise their own measures of developmental functioning, there are clear parallels with the present study. Their assessment of the overall situation in the mid 1980s is very similar to that reached in the early phases of this study : " To both research workers and those providing services, people with profound retardation and multiple impairments have constituted a major challenge with respect to understanding their functioning and delivering appropriate programmes." (Preface p. X)

Over the past 100 years, classifications and sub-classifications have been used as a basis for social differentiation, social segregation and resource allocation (Mittler, 1979; Malin, Race and Jones, 1980). Certain classifications and their associated terminology have been embodied in legislation related to disability as a means of defining disability for purposes of the provision of services. People with disabilities, especially those with more severe disabilities, were defined as different and as eligible for services for people labelled in terms of their category of disability. Services could be offered or withheld according to the category of disability to which people were assigned (Robinson and

Robinson, 1965; Hogg and Sebba, 1986).

This approach to incorporating specific labels for the identification of categories or sub-categories of people with disabilities into legislation for purposes of determining eligibility for formal services continues today. It tends to have the effect of concentrating considerable discretionary decision making power in the hands of bureaucrats and professionals. By contrast, the issue of entitlement (ie. the definition of categories or sub-categories of people with disabilities with rights to specialised services) has only recently become a major focus of political debate. The Chronically Sick and Disabled Persons (Scotland) Act (1972), though ostensibly setting out rights and concomitant obligations, appears to have been largely honoured in the breach. This serves to emphasise the major dilemma of how to legislate for the enforcement of rights.

From 1968 to 1986, there were several major pieces of legislation which taken together constitute a radical legislating approach to incorporating definitions which focused on how a person with disabilities functioned as a individual and what services were required to support and develop different areas of functioning, (Social Work (Scotland) Act, 1968; Chronically Sick and Disabled Persons (Scotland) Act, 1972; Education (Mentally Handicapped Children) (Scotland) Act, 1974; Education (Scotland) Act, 1981; Disabled Person's (Services, Consultation and Representation) Act, 1986).

The earliest of these, the Social Work (Scotland) Act, 1968, embodies an approach which puts general duties of Local Authorities to make appropriate service provision for those in need including people with disabilities.

The culminating piece of legislation, the Disabled Person's (Services, Consultation and Representation) Act, 1986, contains a major elaboration of the services provision approach, firstly by incorporating the principle that services or treatment should be tailored to the needs of the

individual, and secondly, by providing for the representation of people with disabilities by persons who are not necessarily employees of the service provision agencies. (N.B. Sections 1 and 2 have not yet been implemented). (Addendum : The Community Care Act (1990) substituted this legislation).

1 outcome of the classification systems that have developed over time and the definitions of disability used by different bureaucrats and professionals is a process of labelling which can be either stigmatising or empowering or both. This process has been widely analysed and criticised (Hunt, 1966; Carver and Rodda, 1978; Ryan and Thomas, 1980; Valletutti and Sims-Tucker, 1984). Classification can be used for a variety of purposes. One common usage has been to label people as 'different' with the implication that segregation is necessary or at least highly desirable and part of a process of social control (Centre for Educational Research and Innovation, 1981). Classifications and the labels derived from them can contain hidden values that have little to do with the purposes for which they were originally developed. Definitions can be taken to imply inferiority relative to 'normal individuals'. Such negative attributes can be emphasised to the extent that people with disabilities are lumped together and treated as a class apart.

Labelling can significantly lower expectations about a personal and social functioning (Mittler, 1979). It becomes a 'self-fulfilling' prophecy where a person is judged, for example through an I.Q. score to function at a certain level and no opportunity is offered for that person to develop. Progress through training and development may be stunted because it is supposed the individual would be unable to benefit from them. Consequently no progress is achieved and the original assumptions about the person's performance is reinforced. Labelling can also lead to a person to be treated in stereotyped, categorical terms rather than as an individual with

very specific variations in abilities and potential. The effect is to homogenise cultural and behavioural responses.

Efforts to reduce the effects of labelling will not eliminate the characteristics or behaviour which it designated but can, in principle, have an impact by reducing the negative social responses to such characteristics or behaviours. Changing a label however, may not achieve the desired effect of destigmatising or promoting positive evaluations. For example, little changed regarding the stigma attached to the term 'mental defective' when it was replaced by 'mental handicap' (Government White Paper, 1971). Tyne (1981) argues that devaluation is part of a vicious circle, with it occurring when a person is seen as socially different and negatively valued, leading to social expectations that cause individuals to devalue themselves, so the devaluation process is perpetuated. This pattern is then encompassed in service provision and delivery.

The usefulness of a classification of disability or of people with disabilities must be determined in relation to the purpose for which it is being used, but it must be noted that this does not prevent other people from using the classification in unconventional ways. Given the inadequacy of existing classifications for the purposes of the present research, it proved necessary to develop a functional classification in order both to delineate the relevant population of YPWMD and to differentiate functional capacities at the level of individual profiles.

2.3 Concepts and Indicators of 'Need'

The research aimed to find out the effect formal post-school services has on the personal and social development of the YPWMD. Without continued development, the individual is unable to acquire the skills

and capacities that can lead them towards independent and autonomous functioning. Formal post-school services can provide the opportunity for development for YP^{WMD} as they require access to human and material resources beyond the general range of resources used by other young people. Specific resources can help them transcend specific disabilities so they are not disadvantaged. Indicators of personal and social development can be used to identify stages of development and determine what service are required for development to continue. This concept of 'need' and the subsequent classification are development-led. A study of literature on 'needs' showed that the concept of 'need' and the classifications of 'need' were service-led and not development-led which resulted in a new classification of 'need' to be evolved. Existing concepts and classifications of 'need' are briefly described together with the research's 'indicators of need'.

2.31 The Definition and Classification of 'Need' in the Literature

1 Concept of 'need' determined by perception

The concept of 'need' determined by perception is put forward by Forder (1974) who considered different perceptions of need and grouped them under the following 5 headings: -

- 1 Basic minimum standards
- 2 Comparative need
- 3 Felt need
- 4 Perceptions in terms of specific techniques
- 5 National need.

Bradshaw (1980) presents a classification of 'need' incorporating 4 different definitions with some overlap with Forder's presentation. Bradshaw's 4 categories are: -

- 1 Normative need - where need is defined by reference to a 'desirable

standard'.

- 2 Felt need - where need is equated with 'want' so such a need can be limited by knowledge and information.
- 3 Expressed need - where the need wanted as in Felt need is then demanded.
- 4 Comparative need - where need is defined by comparing individuals who receive services and are therefore not in need to an individual receiving no services and is therefore in need.

Both Forder and Bradshaw define some needs as being 'felt' needs.

However the question must be asked if it is feasible to think of needs in terms of what someone wants? Does this interpretation imply 'real' need or merely greedy desire and therefore can it be legitimately used in an academic study? Both classifications also include the concepts of 'comparative need' and 'basic needs'. Forder compares basic needs with the average standards in society. Bradshaw extends this comparison by focusing on the meeting of need through service provision with those members of society who are not in receipt of any services. However the definition of 'comparative needs' treats the situation in stark black and white and omits to take into account those persons who have needs which are only partially met through service provision. Forder touches on this concept of need defined through service provision but looks at the process of meeting needs rather than assessing if the needs have been met.

2 Concept of 'need as a 'hierarchy of need'

An alternative classification of need has been put forward by Maslow (1968). In his analysis of need, he developed a classification which he describes as a 'hierarchy of needs' and a 'motivational pyramid'. In this hierarchy or pyramid he recognises 5 stages and stresses that the bottom stage of need must be met to some extent before higher stages can

be satisfied. These 5 stages are: -

- 1 Stage Five - Self-actualising needs
- 2 Stage Four - Esteem, respect, status needs
- 3 Stage Three - Social needs
- 4 Stage Two - Safety needs
- 5 Stage One - Basic physiological needs

A criticism of Maslow's model stems from the simplicity of the classification. It is not either possible or applicable to the real world to imagine that 1 need must be met before another can be addressed. The exception to this is the bottom layer of the pyramid as it is essential that physiological needs are satisfied. Above Stage One, needs are interlinked and the meeting of 1 can create another. Smith's 'Needs Study' for The Spastics Society (1988) gives an example of the dependence of needs on each other. She explains that the provision of educational opportunities cause school leavers to raise their expectations of life and lead to needs which are not met when they leave school. Another problem with over-simplifying needs is that any person can be partially satisfied and partially unsatisfied at every level in the 'pyramid'.

Maslow's classification differs from the 2 previous contributions as it takes the individual as being at the centre of the needs analysis. He moves from considering basic physical needs through to considering the mental needs of the individual. These needs are the need a person has to feel self-fulfilled and content. The inclusion of these needs brings Maslow's model into the sphere of 'quality of life'. It could be argued that if an individual's needs at all 5 levels are satisfactorily met

then that person can experience a high quality of life. However if only needs at level 1 are met then a person will only experience a low quality of life because so many of their other needs are not being addressed.

3 Concept of 'need' in a legislative context

In a legislative context needs are rarely defined precisely. For example Social Work (Scotland) Act (1968), Section 12 states:-

'It shall be the duty of every local authority to promote social welfare... as may be appropriate for their area to provide or secure the provision.....as they may consider suitable and adequate, and such assistance may be given to....a person in need requiring assistance....'

Another example is the Chronically Sick and Disabled Persons (Scotland) Act (1972). This act imposed 2 duties on Local Authorities. Firstly, the duty to inform themselves of the number and needs of people with disabilities living in their area and secondly, to publicise available services. However at no point is the term 'need' explained so the Authority would know what needs to cater for.

The Seebolm Report (1968) recognised social services as 'large scale experiments in ways of helping those in need'. Again what needs were to be helped is left to open interpretation.

This failure to define need in more exact terms is perhaps responsible for the traditional fashion of defining need according to different groups of service users. Legislation uses the device of categorising people in relation to eligibility for services/benefits to limit liabilities.

Silburn (1988) strongly disputes the assumption that people with similar disabilities belong to a 'group' and have similar needs. He states 'people with physical disabilities constitute as varied and diverse a population as any group of able-bodied'.

As typified in the legislation governments have also been lax in defining

clearly their perception of need. The DHSS (1978) defined need 'as much a relative concept as handicap or disability'. It supports the view that the term 'need' is defined according to values rather than objective facts. Such a position makes for a more confusing situation as what values are adopted and do these alter with changing circumstances?

Some researchers (Walker 1981; Townsend 1981) have criticised the Government's lack of response to meeting 'relative' need and associate this with the concept of need being perceived as a 'right' belonging to the person with disabilities. They believe that the issue of needs is not fully addressed because the rights of the person with disabilities are not accepted.

Literature taking up this point list the following needs that were perceived as rights: -

- 1 right to adequate income
- 2 right to employment
- 3 right to live in community independently and inter-dependently with adequate service provision
- 4 right to full participation in the community so no longer isolated and stigmatised
- 5 right to social and political equality

Throughout the mid 1970s various campaigns were launched to publicise and persuade the Government to take on board the rights of people with disabilities, for example, DIG. The International Year of the Disabled Person followed the United Nations declaration of rights in 1975. However, the declaration of rights was not matched by a declaration of obligations. According to Walker the lack of response were threefold. Firstly, there was an under-estimation of the numbers of people with disabilities. Secondly, officialdom lacked the empathy and understanding of the needs

felt by people with disabilities and the rights they possessed and thirdly because of this lack of understanding, there was confusion between the social and economic policies which could play a significant role in addressing needs. These 3 reasons all stem from the inadequate definition of need in legislation to assess numbers and recognise needs.

4 Concept of 'need' in terms of service provision

Embodied in this concept, is the provision of services to meet 'needs', so this concept moves away from the individual to the service provision and the delivery (eg. Silburn, 1988). A possible explanation for considering 'need' in terms of service provision lies in the problem of trying to define and grasp an abstract notion. It is easier to consider more tangible issues that are real such as specific services. Another explanation stems from the view of social services to be 'institutions of a democratic-welfare-capitalist state' (Forder 1974). In such a state, social services are aiming to distribute resources through recognising 'need'.

If 'needs' are service-led, people, seen in terms of 'client groups' are allocated to services instead of the services tailored to the 'needs' of the individual. Emphasis on client groups leads to a lack of acknowledgement of the 'needs' of the individual in preference for blanket service provision. The approach is exacerbated by the Government's continual referral^r_^ to client groups in legislation. Client groups have evolved through the official and medical conceptions of disability (Walker, 1981). It is probable that the latter has influenced the former as medical classifications have caused artificial divisions of need to arise. People are divided according to 'type', age, origin of disablement and according to this grouping assigned a set list of 'needs' yet many of the 'needs' are common to all 'client' groups including the 'able-bodied'.

The DHSS (1978) argues in defence for interpreting 'needs' in terms of service provision stating that 'if needs are to be met, it is necessary to translate them in terms of effective services and facilities and resources...'. However, they do qualify this statement by saying that 'the relationship between the ascertainment of a need and planning/delivery of a service to meet it is therefore tortuous being influenced by many considerations'.

An additional dimension in the discussion on defining and classifying 'need' is the time factor as 'needs' vary over time and with changing circumstances and so service provision requirements likewise change. 'Needs' experienced by an individual can fundamentally change throughout the life span from childhood, adolescence and adulthood. Turnball, Brotherson and Summers (1983) suggested an adult classification of 'needs' using 8 broad areas of family functioning. Such a classification could be adapted to accommodate different phases of a person's life as the areas of functioning alter in importance and priority according to age. However in this research study the time factor is not of overriding importance as the study focuses on the needs of the school-leaver age group and so considers 'needs' at one point in time.

2.32 Indicators of Personal and Social Development

From studying the literature on 'needs', no concept or classification of 'need' was found to be applicable to the research. An alternative concept and classification was evolved and called, 'Indicators of personal and social development' (IPSD). These can be used to assess the independent and autonomous personal and social functioning of YPWMD. The indicators reveal the level of development of a young person in terms of the skills and capacities and access to and control of material resources required to lead a full, quality life.

Seven indicators have been recognised:-

- 1 Basic - essential skills for independent functioning and access to basic facilities for independent functioning.
- 2 Social - capacity to negotiate social relations in differing contexts.
- 3 Stimulation - exposure for the development of experientially based social awareness. General and specific learning experiences.
- 4 Personal - self worth and bases for personal autonomy both essential factors in experiencing quality of life.
- 5 Physical environment - access to and control over facilities for independent functioning.
- 6 Support - access to disability related resources, human and material.
- 7 Adolescent - capacity to recognise and deal with physiological, psychological, social and environmental changes within the context of leaving school.

2.33 The Rationale of IPSD

The rationale incorporates 3 factors:-

1 Focus on the individual

Central to the IPSD is the focus on the individual. For this reason the concept is unlike the contribution made by Forder and Bradshaw. It does support 1 of the Jay principles outlined in the report (1979) where it is stated that 'Disabled People have the right to be treated as individuals' (1.2). Indicators can be drawn up for every individual and these 'lists' will vary between YPWMD.

2 Support of the Principle of Normalisation

2 main goals of the Normalisation Principle according to Wolfensberger (1973) are the 'enhancement of social images' and the 'enhancement of personal competencies'. The Principle indicates that for YPWMD to achieve an acceptable quality of life, there must be the enhancement of personal

competencies. Hence self-development is important because 'personal competency' is valued, not only at the level of the individual and his/her social networks, but as a general cultural principle. If a person is perceived as personally competent, any 'de-valued trait' which is interpreted as implying disabilities, becomes a ground for positive expectations and support. In addition, there is the argument that personal competencies can compensate in areas of disability and tend to greater social interaction which is vital in all avenues of daily living.

3 Development of common and additional skills and capacities

Silburn (1988) assumes that people with disabilities wish to lead a 'normal' life. He argues that everyone in society has 'needs' and that people with disabilities have these 'needs' 'more insistently'. The IPSPD accepts that everybody of whatever ability and disability, require the development of the same skills, capacities and access to and control of material resources and that certain people with multiple disabilities require additional skills and capacities specific to the individual which allow that individual to participate fully in daily living.

2.4 Indicators of Quality of Life

The term, 'quality of life' can be difficult to define and measure (Kind et al, 1982) because the concept can be highly subjective. Baldwin, Godfrey, Propper (1981) accept that quality of life is a multi-dimensional concept and that interests in quality of life can be motivated by different concerns and requirements, eg in terms of commodities (Culyer, 1976), in terms of the environment, of culture and through the accomplishments of the individual (O'Brien, 1985).

Kind et al (1982) introduces the idea of a quality of life continuum and through measurement it is possible to establish a relationship between a person and a point on a continuum. Whatever descriptive system is set up

to define quality of life, it will be composed of indicators and these indicators will establish the dimensions of the system. From the dimensions established a scale can be evolved and positions on the scale identified leading to a quality of life continuum. This is a useful basis for which to define the term 'quality of life' in such a way that it can be measured and different levels of quality can be identified.

In this study, 'quality of life' is conceptualised in terms of the potential independent and autonomous personal and social functioning of the individual taking account of the support and development opportunities provided and delivered in the formal service network. Formal services providing support and development opportunities are an essential part of the input producing quality of life. The overall quality of life experienced by SLWMD will be dependent on informal as well as formal service networks. However, the research concentrates specifically on formal services and so the IPSD used, focus primarily on formal provision. By using the IPSD to discriminate between 'needs' which are being met from those which are not, a means of assessing the extent to which formal service provision and delivery contributes or fails to contribute to potential quality of life is guaranteed. For YPWMD to achieve independent and autonomous personal and social functioning 7 areas of personal and social development are relevant. These may be facilitated through formal service provision and delivery. Therefore, the quality of life indicators are service provision and delivery to develop: -

- 1 essential skills for independent functioning and access to basic facilities for independent functioning
- 2 capacities to negotiate social relations in differing contexts
- 3 experientially based social awareness and general and specific learning experiences

- 4 self-worth and bases for personal autonomy
- 5 access to and control over facilities for independent functioning
- 6 access to disability related human and material resources
- 7 capacities to recognise and deal with physiological, psychological, social and environmental changes.

2.5 Planning and Provision of Formal Services for YPWMD

This section aims to review the contributions from relevant literature on the planning and provision of formal services to YPWMD and draw upon the literature on relevant legislation and policies to establish the immediate background and context of the present study.

The literature was generally found to be critical of provision. SLWMD are faced with inadequate post-school formal service networks and there is a gap between current policy and practice (SHARPEN report, 1988; Beardshaw, 1988; Scottish Health Service Planning Council, 1989). This situation has remained unchanged for over the last decade (Court report, 1976; Warnock report, 1978; SHAPE report, 1980). The implications for the SLWMD is that delays, gaps in provision and inadequate^a services can cause regression in levels and areas of functioning and a decrease in the quality of life (Rowan, 1980).

Problems with the planning and provision of services have been identified by many researchers. Finkelstein (1981) and Oliver (1983) suggest that 'needs' are defined by service providers rather than service users. Wilding (1982) goes further in suggesting that services are built around professional skills which meet the 'needs' of the service provider and not the service user. Oliver (1983) also argues that services are provided by large, well distanced, bureaucratic organisations which cannot respond to individual 'needs'. This is a point supported by Blaxter (1980). She

identified lack of prompt service provision and the overlap between service providers a problem further exacerbated by the transition from child service provision networks to adult service provision networks.

Linked to these 2 issues is the problem of co-ordination and the distinct lack of it. While the young person is at school, it is possible and therefore very likely that all the services utilised are co-ordinated.

Many factors attribute to this happening and the fact that the school can provide a central link between the individual and the service providers is undoubtedly important. However, when the young person leaves school the link is broken resulting in provision being delivered in an ad-hoc manner. This leads to an inefficient system and diminishing opportunity for high quality of life.

2.51 Planning of Formal Post-School Services

The planning of formal post-school services takes place throughout the school leaving process and in particular through the FNA procedure. This process is described as 'an interface between a range of systems' (COSPEN, 1987) and it is acknowledged that it takes place at a time of transition for the young person from childhood into adulthood when provision of services can be problematic. The FNA was made mandatory in the 1980 and 1981 Education Acts. The Education (Scotland) Act 1980 was a gathering together of many pieces of old legislation and Reports for the purpose of being amended by the 1981 Education (Scotland) Act which was implemented in January, 1983.

The background to the legislation came in part from the Warnock Report (1978). It was the 1st major review into the area of special education for a considerable period of time (Fish, 1981). 1 major influence of the Report was to move away from the idea of 'handicap' to 'need' (Brennan, 1987) and the term 'special educational need' was used.

1 of the priority areas of the Report looked into the provision of young people, over 16, with special educational needs and changes in assessment procedures to identify needs. There was an emphasis for multi-disciplinary assessment including active involvement and participation with parents. This approach had been endorsed by the Court Report (1976); National Development Group for the Mentally Handicapped (1977); Mittler (1979). The Report also examined the transition period, between school and adult life, and concluded that skilled support to be available to the young person and carers, referred to as the 'Named Person'.

Following on from the Report, the 1981 Education (Scotland) Act embodied a lot of the recommendations. For example, it detailed the procedures for assessment incorporating the recognition of the Record of Needs, without which there cannot be a FNA; the need for FNA; the need for a multi-disciplinary approach with parent participation and the need for a 'Named Person'. The Act did not detail post-compulsory school age provision which the report did recommend. The FNA procedure will be briefly summarised.

2.52 The Future Needs Assessment Procedure

The intention of the FNA is to consider and assess the post-school 'needs' of school-leavers. In particular, the assessment is to enable the Education Authority, responsible for the young person, to consider the range of possible provision, including school provision, which would benefit the young person when he or she reaches school leaving age. The assessment has to be carried out within the 2 year period before the pupil reaches school leaving age and at least 9 months before that date. The school leaving age for a young person in Scotland is, by statutory definition, aged 16 or 17 years. For this reason education legislation does not provide clear and unequivocal rights to continued full-time education post 16 for a young person with a Record of Needs. Although the

Act gives parents the right to request continued school education between 16 and 18 years Local Authorities are also given the right to refuse requests. The decision depends ultimately on the Education Authority. The assessment is reported and a statement made of the Authority's opinion on whether the young person would benefit from continued school education after the person has reached school leaving age and if the conclusion is that the person would benefit, then the report must state whether or not the Record should be continued. The Record is the Record of Needs as the FNA procedure only applies to pupils with a Record. This concept and process of making the Record is laid out in the 1981 legislation (Sections 60, 61 and 62).

The 1981 (Scotland) Act outlines the FNA procedure but without specific detail. Consequently, individual Regional Authorities have interpreted the guidelines differently. The guidelines state that for an Education Authority to make a 'consideration', the young person must undergo a process of assessment including a medical examination, a psychological examination and a report by any teacher in contact with the young person. The report to be produced by the Education Authority must include their recommendations as to the following: -

- 1 if the child would benefit from continued school education post 16,
- 2 if the child is to continue school education it must be stated if the Record of Needs is to be continued.

If it is decided that the Record will remain open, it is necessary in the course of the review process to consider whether the existing named person should continue or another person more appropriate to the post-16 situation should be appointed.

The Act goes on to instruct the Education Authorities that copies of the Report should be sent to the local Social Work Department, the Health Board for the area in which the child resides and with parental consent any other

body offering provision and from which the parents think the young person would benefit. These copies have to be sent not later than 6 months before the young person is expected to stop full-time school education.

The Report can only recommend what should be done as the Record of Needs is the only means of saying what the Authority must provide. Parents are to be consulted about their thoughts on the 'future' needs of the young person and parents should be invited for discussion. The legislation details the machinery for parents to appeal against any decisions and comments.

There are no clear guidelines as to how a FNA should be conducted. The only people with a mandatory right to be involved are those carrying out the assessments, the Educational Psychologist, Medical Officer, Careers Officer and Headteacher or Assistant Headteacher. It is recognised that the inclusion of parents and carers is good practice and on keeping with the trend towards 'parents as partners' recommended by Warnock. It is also considered good practice to invite representatives from Social Work Departments, from Further Education establishments and from Voluntary Organisations depending on the type of post-school provision being considered to be involved. These representatives however do not have a statutory right to be present. However, Social Work Departments do have a general duty to attend under Section 12 of the Social Work (Scotland) Act 1968 when it is read in conjunction with Section 94(2). This duty also extends to making an assessment of needs for Social Work services and providing support.

A guidance note by the Scottish Education Department states that the FNA is a very important assessment and therefore the needs assessed should not be confined to 'educational' needs but the Report should comment on vocational guidance, training, career service reports and reports made by the Social Work Department and the Health Board. The guidance note suggests that

comments from these sources should focus on the identification and assessment of need and the availability of post-16 provision as this would make the statements more effective.

Within the legislation, Education Authorities are obliged to give notice to the Social Work Department where they considered that the Department would have an interest in the young person's welfare and where services may be required.

Since the 1981 Act, another piece of legislation has been enacted which has implications for the process. This is the Disabled Person's (Services, Consultation and Representation) Act 1985 and in particular Section 13 which concerns school leavers. This section was implemented in February 1988 and applies to young people reaching school leaving age in the summer 1990. Consequently, due to the timescale of the fieldwork, this Act does not directly affect the research study but it does have implications for the research recommendations.

2.53 Future Needs Assessment Procedure in Practice

The previous section described the procedure for assessing post-school needs as outlined in legislation. However there is evidence in the literature to suggest that individual Educational Authorities have responded in different ways (Adams, 1983; COSPEN, 1987; Scottish Consumer Council, 1989) and that within 1 Authority individual schools may follow different procedures albeit without radically breaking the law. The principal reason for any discrepancies is due to the legislation failing to give specific practice guidelines.

This situation is the focus of a small working party set up by the Committee on Special Educational Needs (COSPEN) to examine and report on the provision for young persons aged 16+ with pronounced, specific or complex special educational needs.

Their findings concluded that:-

- 1 some regions were more preoccupied with 'allocation procedures' than with careful assessment which could give rise to the acceptance and recommendation of provision that was not specifically suited to the individual young person's needs.
- 2 The timing of the meetings was found to vary greatly between regions.
- 3 A very problematic issue was the participants attending meetings and the absence of parents and young people.
- 4 There was significant ignorance concerning post-16 provision on the part of professionals, parents and pupils.

These issues are examined through the fieldwork and commented on in Chapter 5. Having discussed the planning of formal post-school provision, attention is turned to reviewing the contributions in the literature on the provision of formal post-school services.

2.54 Current Provision of Formal Post-School Services

The following discussion reviews the literature describing the formal post-school service provision available to SLWMD at the time the fieldwork was being carried out. Included is literature describing services and their development within the Scottish or national context and current legislation and policy guidelines.

The provision is described in terms of the type of setting in which it is delivered. Various types of settings have been identified and classified (Baranjay, 1976; Blaxter, 1980; Kings Fund Institute report, 1988; Scottish Health Service Planning Council, 1989). The research recognises 3 formal service provision settings available to SLWMD and provided by Statutory, Voluntary and Private agencies. They include the 'day and work centre setting', the 'residential and hospital setting' and the 'Further Education setting'.

The development of service provision is briefly reviewed as it puts provision into the context of legislation and policy guidelines as well as describe present provision. Since 1945 there have been many changes in the organisation of service provision and delivery and the development of provision is reviewed from that date. The positive trends that can be identified include, the move away from institutionalisation, the recognition of the rights of people with disabilities, the setting up of joint planning and resource arrangements leading to support and development package availability, recognition of the individual at the centre of provision and the recognition of community integration. Negative trends that can be identified include, the shortage of placements in terms of choice and number, increased bureaucracy in service organisation, the channelling of people into service areas with availability of provision dictating distribution, continued unawareness of the strengths and aspirations of service users and continued difficulties with funding. These topics will be touched upon in the review of different types of provision. These trends are also explored through the fieldwork.

2.55 Service Provision within the Day Centre Setting

Service provision within the day centre setting can be organised by Statutory, Voluntary and Private agencies within different types of placements labelled as 'day centres', 'day hospitals', 'adult training centres', 'work centres', 'day training centres' and 'sheltered workshops' (Carter, 1981). The label, 'social educational centre' has also been recognised by the National Development Group for Mentally Handicapped Adults (1977) and Seed (1988). All these placements are non-residential and located within the community or attached to a residential type centre. The services are offered to service users who are referred to as 'trainees', 'members', 'clients' and 'students' (Seed, Thomson, Pilkington and Britten

1984). They suggest that the term adopted reflects the aims of the centre. Carter (1981) describes the service users as 'economically inactive' with the majority becoming long term users of 1 placement. Her comprehensive investigation of day services revealed that the average size of a placement was 43 places with an average ratio of staff to service users as 1:8.

The development of present day centre provision arose from the way the Government gradually came to accept and extend responsibility for people with disabilities. Consequently there was no overall plan but provision resulted from a series of piecemeal reforms.

From 1945 the development of day services began slowly with an enormous expansion in the 1960s. According to Carter (1981) only a tenth of day units were in existence in 1976 were open at the end of the 1950s with the 'golden years' between 1960 and 1976. She adds however that despite the growth in numbers there still existed shortage of places.

Traditional types of day service emerged in the 1940s but with the expansion in numbers so there was a growth in 'new' types of provision. Originally the goals of a centre were to 'occupy and care' and by the mid 1970s onwards development slowly took place to encourage services which were 'active, positive, rehabilitative and educative' (Kilbrandon 1966; Central Council for Education and Training in Social Work 1975).

In the early 1970s there started the trend to move away from occupation and training to education and self-development. The Education (Mentally Handicapped Children) (Scotland) Act (1974) gave Education Authorities the responsibility for children with mental disabilities. Centres known as 'occupational centres', which as the name suggests, had the aim to 'get the individual out of the house' and provide some activities that would 'keep them occupied until home time', became known as 'Adult Training Centres' (ATC) (Zaklukiewicz, 1984). In their survey of Scottish 'Adult training centres', Jackson and Struthers (1974) identified that these centres were

modelled according to practices in industry. Their overall conclusions were that centres were offering inadequate provision. Although there was now an emphasis on the development of skills, changes did not take place overnight. Changes in staffing, buildings, equipment and practice occurred over a period of time that varied with each individual centre so that there was no uniformity in provision or quality of provision (Jackson and Struthers 1974; Scottish Home and Health Department 1979).

Both the Central Council for Education and Training in Social Work (1975) and the National Development Group for the Mentally Handicapped (1977) produced working papers to set down guidelines for the newly emerging centres as there were no clear government directives. In 'An Action for Training' (CCETSW 1975), the suggested model of practice was to aim for individual development through a functional approach. Seeing the 'needs' of the individual as a starting point for service planning was endorsed by the National Development Group with particular emphasis on the educational function of centres. They wanted the term 'student' to be used instead of 'trainee' and ATC replaced with 'Social Educational Centre'. This educational model of practice was strongly endorsed by the Warnock Report (1978). Tuckey and Tuckey (1981) argue for the 'encouragement of the maximum degree of independence and self help' which they want to see through the promotion of skills development with strong community integration. These objectives are supported by Bender (1987).

Following the expansion and development of services within the 'day centre' setting, there is still no standard model of provision and delivery with set standards of practice and agreed strategy to achieve the Principles of Normalisation (Zaklikicwicz 1984; Seed 1988). Due to the lack of clear government guidelines, different Local Authorities and different placements have different priorities (Seed et al 1984). This situation can change with the current community care legislation (1990) which will have

implications for the growth and policy of day centres. The implications cannot be judged as the legislation will not be fully implemented until April 1993 and did not affect the YPWMD during the research.

Without any clear policy guidelines, current service provision and delivery exhibit a diversity of aims and practices. 2 recent, Scottish surveys provide an insight into present provision and suggest current models of practice.

Goda (1981) presented his findings, 'A Training for Life' in which he concluded that provision was inadequate in many areas. The main aim of the survey, which took a random sample of day centres from 4 different geographical areas, was to analyse the flow of 'trainees' through the centres in relation to the characteristics, the features and the policies of the centres.

Regarding the throughout put of 'trainees', Goda found that people, especially those with multiple disabilities and school leavers, tended to remain at 1 centre for a long period of time. This then caused a shortage of places to develop. Another important repercussion of this trend is that the centre will play significant role in the life of each 'trainee' so that emphasis on quality is paramount.

Other areas of inadequacy included record keeping with implications for planning and monitoring individual development programmes. Communication was also found to be poor, particularly between centres and schools so that continuation of development programmes from schools could not happen.

Seed, Thomson, Pilkington and Britten (1984; 1988) conducted an 'evaluation of the Local Authority contribution to day care services for adults with mental handicaps in Scotland' between 1984 and 1987. 2 reports were produced, 'Which Best Way?' (1984) and 'Day Care at the Crossroads' (1988). 146 service users, called 'clients' and 15 centres, referred to as 'Adult training centres' (ATC) were included. Results from the study describe the

provision available to SLWD. It would appear from this study that there are many areas of inadequacies and gaps in provision. For example: -

- 1 The aims of the ATCs were rather vague and generalised and a discrepancy existed between the views of the managers and the service users as to the purpose of the centres.
- 2 Only in a few cases was the 'trainee' and parent invited to attend the 'referral and admission' procedure. Usually, the panel was made up of the ATC manager, the field Social Worker and the District or Divisional officer from the Social Work Department. It was accepted that there are a shortage of day placements and a lack of appropriate placements so the admissions panel made their selection of potential service users according to what they saw as the main aim of their centre.
- 3 There were limited facilities offered to an individual with 'profound handicaps'.
- 4 The ratio of staff to 'trainees' was found to vary from between 1:3 to 1:13 with an average of 1:8. Staff came from a variety of backgrounds with a significant number coming from trade and industry. Only a small proportion had any professional Social Work qualification with more having teaching or nursing qualifications. However, training appeared to be very limited because if a person attended a course there was a shortage of extra staff available to cover. 53% of staff stated that they would wish for more training.
- 5 There was a wide range of activities available at the centres but at only a few of the centres were activities linked to individual programmes.
- 6 Contact with outside professionals was found to be very limited. Only 1 ATC had a field Social Worker attached. For the majority the Social Worker was only involved in the admissions process. Access to Speech Therapists and Physiotherapists was minimal and this trend applied to

other visiting professionals.

7 Community involvement was found to be limited. Contact with local amenities was generally encouraged although not always achieved. Most of the ATCs claimed to be promoting integration but the research showed that the large majority of visits were in groups of more than 3 people and very often involved mixing with people with 'mental handicaps'.

This review of the literature of day provision and its development, would suggest that YPWMD in the study will have available to them varying types of day services of differing standards and practices and which contain gaps in provision. This will contrast significantly with school based service provision. Informal discussions with YPWMD and Carers showed that more were interested in the provision of post-school services within a residential setting.

2.56 Service Provision within the Residential Centre Setting

Various terms are used to refer to residential centres. These include, 'institutions', 'homes' and 'residential establishments'. Whatever term is adopted, the centre will offer accommodation on a long term basis to a larger number of people than the usual family size (Douglas, 1986). It is likely that the service user or the 'resident' will adopt a less private lifestyle than if they were living in the famial home (Goffman, 1961). Douglas (1986) identifies different types of residential centres with variations in physical size, location, facilities, numbers of 'residents', activities, organisation and aims and policies. He then lists 7 common characteristics:-

- 1 the institution offers a 'living in' situation,
- 2 the residents have no 'ordinary relationship to each other', they share common needs,
- 3 the institution imposes rules, limits choice and 'defines boundaries

and access',

4 the institution 'process people' through 'operational goals',

5 the institution provides for all basic needs

6 the institution makes the distinction between staff and residents,

7 many institutions are 'part of a much larger system or organisation
which has wider and more diffuse goals than the residential unit'.

The majority of the literature on the development of residential centres focus on the provision for people with 'mental handicaps' and little reference is made about service provision for people with multiple disabilities. However, it is relevant to trace the development of these centres as it explains the current models of provision available to YPWMD and outlines the move away from institutionalisation to community living which was a developing trend at the time the fieldwork took place.

Developments in service provision have been influenced by reaction against institutionalisation (Baker and Urquhart, 1987). The following account of the development of residential type service provision and the policies that dictated it, highlight the 2 different patterns of service delivery, institution oriented and community oriented which are available to YPWMD. Clarke (1982) describes them as 'segregated' and 'integrated'. Within the former lies the 'medical model of care' whereas the latter encompasses the Principles of Normalisation. Between the 2 extremes lies a continuum with a variety of different provision and delivery and the types of provision available to SLWMD will reflect this.

Prior to 1948, there was a range of residential institutions, organised and administered by different groups. All centres were isolated and segregated from the general public. Little concern was given to the rights of residents. In 1948 the National Assistance Act replaced the existing Poor Law and made provision for the National Assistance Board together with Local Authorities to make residential provision. The National Health

Service was also tasked with making provision. The Act recognised the need for different types of provision but in reality the range of provision remained very limited to long term 'hospital' type 'institutions'.

Various reports were published to highlight the need for alternative provision and improved quality of provision (Barton, 1959; Morris, 1969; King, Raynes and Tizard, 1971; Raynes and King, 1974; Mc.Cormack, 1979;). There had been no major reform for over 60 years and centres were poorly equipped^P_A, overcrowded and understaffed. Daily life was regimented in a hospitalized fashion and residents were living in wards segregated from society in self-existing, isolated communities.

The situation began to change when frequent incidents of cruelty and maltreatment were reported in the media in the 1960s, (Report of the Official Enquiry at Ely Hospital, 1969). Books such as 'Put Away' by Morris (1969) highlighted the appalling conditions that were found in some hospital wards. Oswin (1978) found similar standards in services for children and young people living in long-stay hospitals. The medical model of residential provision was under scrutiny and increasingly being criticised including the conditions in institutions and the policy of institutionalisation (Townsend, 1962; Goffman, 1968; Howe Report, 1969; Watkins Committee, 1970; Payne Report, 1972). The debate between institutionalisation v de-institutionalisation and community care started in earnest with the gap between theory and practice enormous. The Seebolm Report (1968) considered community provision with an emphasis on provision by the community rather than just in the community. However, a major criticism of the report is that it failed to provide adequate guidance as to how policy could be achieved in reality.

Following the criticism of institutions, the Government made a study of the hospitals and as a result, a checklist of minimum standards was devised which became the White Paper, 'Better Services for the Mentally Handicapped' (1971). The paper intended long stay hospitals to cease being custodial institutions but it was thought necessary for children and young people who were 'multiply handicapped' to remain permanently in a hospital environment with the 'medical' model dominating.

Due to the lack of clear objectives and specific deadlines and funding arrangements (Bayley, 1973), improvements were slow. The most important recommendation was the intention to move people out of hospital provision and into the community. This was to be a shift in the 'balance of care' away from the health service to the personal social services (Clarke, 1982). It was planned to take place over a 20 year period with in-built targets but improvements were extremely slow. Baker and Urquhart (1987), reporting on 'quality of life' in hospitals and residential institutions in Scotland, found 96% of hospital 'residents' lived in wards with limited stimulation, activity and access.

At the same time as the publication of the White Paper was the passing of the Chronically Sick and Disabled Persons Act (Scotland) 1972 which focused on the needs of those with physical disabilities. It supported the intentions of community care and it endeavoured to curtail the admission of anyone under 65 years with a physical disability to long term care in 'geriatric accommodation'. An immediate consequence of the Act was a building programme including new residential homes and day centres. Coinciding with the significant changes in policy thinking were very significant changes in public service administration. In 1968 Departments of Social Work were formed and the NHS was re-organised in 1974. Following on from these changes was a more sociological approach and orientation to community service provision (Glampson, Scott and Thomas, 1975).

Miller and Gwynne (1971) describe 2 contrasting models of practice that existed at the time within Local Authority and Voluntary sector residential provision. The models are named as the 'warehousing' model and the 'horticultural' model. The former encompasses the 'medical' model of provision with an emphasis on care and disability with 'batch processing' the key approach to service delivery. This model is seen by Miller and Gwynne as the conventional approach to be found in centres. The 'horticultural' model recognises the service user as an individual with skills and capacities to be developed. Their findings fuelled the debate against institutionalisation.

The Jay Report (1979) supported the movement towards 'community care' by proposing a 'model of care' based in small residential units sited in local communities and run by Health or Local Authorities. Emphasis was made on the rights of individuals, personal choice and 'normal' daily living experiences. The concept of a 'life-plan' was introduced so that support could be on-going and co-ordinated. This 'model of care' was only accepted in principle by the Government and further debates continued into the 1980s when there was still a substantial reliance on institutions despite the findings of the report, 'Progress, Problems and Priorities (DHSS, 1980) and the reaffirmation of the principles of the 1971 White Paper in 'Care in Action' (1981) and 'Care in the Community' (1981).

An important development, since the White Paper (1971), came with the DHSS report (1984), 'Helping Mentally Handicapped People with Special Problems', which reviewed the current approaches to meeting the needs. The report stressed the needs for joint planning of service provision, with multi-disciplinary teams, between different service providers. The report focused particularly on people with profound mental disabilities, those with multiple disabilities and included school leavers and the lack of facilities. With joint planning can come joint provision of services

making up a comprehensive package of support that can be tailored to individual needs with greater consideration being given in choosing residential placements. These recommendations were built into the developments in community care policies.

In the late 1980s, several important documents were published that affected residential service provision. All are related to the issue of 'community care' and contributed to the community care legislation (1990). These reports and the legislation are only very briefly commented upon as they were published towards the end of the research and so their implications have no significant impact on the provision available to SLWMD during the fieldwork period. They do however, help to describe current provision and they have implications for the research recommendations.

The Wagner Report, 'Residential Care : Positive Choice', (1988), wanted to see a move away from resource-led to individual needs-led service provision and for residential provision to be a positive choice and a spectrum of support provision. The disadvantages of institutionalisation were highlighted together with evidence of bad practices.

The Griffiths Report, 'Community Care: Agenda for Action' (1988) was commissioned by the Government following an unfavourable report by the Audit Commission (1986). Griffiths was asked to review community care policy and its funding. The Report was primarily concerned with England and to a certain extent Wales but with implications for Scotland. It states that the responsibility for community care lies with Local Authorities who can 'contract out' services to other organisations. A 'Care Manager' would be appointed to assess and oversee the provision of 'care packages' for each individual requiring support including residential care.

The Government's White Paper, 'Caring for People - Community Care in the Next Decade and Beyond' (1989) set out the Government's proposals for

implementation with focus on the reform of the organisation and funding of social care and which culminated in the National Health Service and Community Care Act (1990). This legislation will not be fully implemented until 1993. The key elements of the legislation are reviewed in Chapter 6. In preliminary discussions with YPWMD and Carers about the research study, a significant number expressed their concern for continued education opportunities to be available on leaving school. This has been documented by Baranjay (1976), Warnock (1978). Such opportunities are discussed in the following section.

2.57 Service Provision within the Further Education Setting

The service provision discussed in this section is the educational opportunities made available to school leavers (post-16 years) through the formal further educational system based primarily in college type institutions. Such provision should be part of a continuum of provision (Pankhurst, 1981) which offers life-long educational opportunities for continued development in all areas of functioning so an individual can achieve their true potential. In addition to offering the school leaver self-development, further education can ease the transition between school and the adult world (GLAD, 1982; Baranjay, 1976) and provide them with the time to gain appropriate skills and develop maturity (GLAD, 1982; Brown, 1984). For many YPWMD they develop at a stage behind their chronological age and so although they have reached compulsory school leaving age they still benefit from continued education and to prevent any regression in functioning.

The development of further education opportunities for YPWMD was led by the Voluntary sector who tended to target specific types of disability and gave emphasis to vocational training.

Thomas (1963) recommended the need for Local Authorities to offer provision

for the large numbers of school leavers with 'unsatisfactory standards of education'. The emphasis was again given to technical and vocational training provided within a segregated setting. The specialist and separate facilities which appeared were not well developed and only available in a limited number of areas. Both the Chronically Sick and Disabled Persons (Scotland) Act (1972) and the Snowdon Report (1976) recommended a move towards positive integration of SLWMD into the further education system but neither met with a great deal of success.

Various studies carried out in the 1970s highlight the lack of adequate further education provision (Tuckey et al, 1972; National Innovations Centre, 1973; Gunn, 1976). A detailed report produced by the National Council for Special Education (1975) showed that not only was provision poor, it was particularly inadequate for YPWMD and in some areas non-existent.

Towards the end of the 1970s following the Warnock Report (1978) and surveys of Further and Higher Education (NATFHE, 1978) the increase of further education provision for YPWMD was to become a priority for Local Authorities. Emphasis was no longer to be on vocational and technical training but to include and expand all areas of continued education for personal and social development.

Evidence from recent research suggests that the situation present in the 1970s has not improved to any significant extent (Panckhurst and McAllister, 1980; GLAD, 1982). Complaints include the patchy availability of provision, the shortage of purpose built accommodation and the lack of choice of courses and facilities.

Several publications have been put forward offering recommendations leading to a 'good model of practice' (National Bureau of Handicapped Students, 1977; Panckhurst, 1980; GLAD, 1982;). They include the need for education to be seen as a 'right' for all students and for this to be provided within

an integrated setting; a commitment by Government and Local Authorities for adequate grants and funding; a network of provision on a geographical basis and the model to contain 7 essential components - effective, non-discriminatory admission policies, wide ranging curriculum and courses, appropriate and flexible resources, adequate access facilities, appropriate and flexible examinations and assessments, advice and counselling support and outreach facilities.

From a review of college prospectuses it was found that Scotland was served by a network of local provision with each region providing within its colleges certain courses designed for SLWMD. The degree to which each college responded to the demand and requirements of students varied with many unable to offer appropriate access, support and facilities. There was also a limited choice of suitable courses and limited places. Due to the lack of residential accommodation SLWMD were restricted in their choice of provision. Only 1 college offered an attached residential unit for students with multiple disabilities. It also offered the support and resources of a well equipped 'Special Needs' department and students with disabilities were integrated into the college. Funding arrangements can be complicated. Students in receipt of financial benefits can have additional problems if they embark on a full-time course of study. The '21 Hours Rule : Part-time Education and Supplementary Benefit' (Scottish Education Department, 1982) stated that students lose their supplementary benefit if they engaged in the college for over 21 hours per week. These problems can limit choice. There was no college catering specifically for YPWMD as exists in England.

2.58 Summary of the Review of Formal Post-School Service Provision

The literature reviewed on the provision of formal post-school services for YPWMD failed to address several issues which are explored in this research. Firstly, none of the literature focused specifically on YPWMD leaving special education and following the school leaving process laid down by educational legislation within the Scottish context. Rather, studies have been conducted that describe and examine the issues surrounding services provided within a certain type of setting for people with mental disabilities (learning disabilities).

There was also a failure to evaluate provision using a 'needs-led' approach and determine if the provision would meet the developmental and functioning needs of YPWMD. There was also no evaluation of the provision in terms of the quality of life that would be offered to the young person who had just left school and who had undergone the transition from school-based provision to adult-based provision.

Finally, no distinction was made in the contributions between service provision and delivery. This distinction is important for it is necessary to see the provision and delivery of services as 2 separate activities. Throughout the literature, the term 'provision of services' was widely used. This study makes a clear distinction between the provision of a service and the delivery of a service. Service provision is defined as being the components of the support and development package and service delivery is the manner in which the package is administered and the type of setting in which it is offered. Both activities are contributing factors to meeting needs and quality of life. They are used throughout this study. The final section of this chapter reviews the literature on YPWMD. Some of the above criticisms are applied to these studies.

2.6 Previous Research Conducted on SLWMD

This final part of the review aims to summarise the research findings on SLWMD.

May and Hughes (1986) conducted a study on the transition from school to adulthood for a group of school leavers with a 'mental handicap'. This study focuses on the same age group as this research but it failed to include YPWMD. Furthermore, the fieldwork took place prior to the implementation of the 1981 Education (Scotland) Act which dominates the transition process.

The same comments are directed at a study undertaken by Corrie (1984) of Scottish school leavers. He looked at the prospects facing young people with 'mild mental handicap' or a 'physical handicap' leaving special education. Corrie and Zaklukiewicz (1987) reported on a group of young people, 16+, with special educational needs. No distinction was made for YPWMD. They focused only on educational provision and concluded that the young people wanted to remain at school post-16 and continue their educational development.

Seed (1986) examined the quality of life of pupils at school and their post-school experiences. However, the sample was made up of young people with 'severe or profound mental handicap'. He also investigated the issue of employment opportunities which was found not to be relevant in this research. Seed did endorse the need for opportunities for continued education which is an important issue in this research and compatible to the findings of Corrie and Zaklukiewicz.

At the end of the fieldwork period and the writing up of the research, 2 separate projects were reported. 'Still at School' (1989) looked at educational provision for young people aged 16+ years but confined itself to school based provision and to young people with 'moderate learning difficulties'. 'Post-school Outcomes for Recorded Pupils' (Riddell, Thomson

and Ward) was presented in 1990. This was an interim report of a project finally reported to the Scottish Office in 1991 and entitled, 'The transition to adulthood of young people with recorded special educational needs' (Ward, Riddell, Dyer and Thomson). The project could not be used to provide a background context to this research and it differed from this research in that it included a survey of 618 pupils which may include SLWMD. No attempt was made to study how services were planned during the school leaving process and post-school service provision was not examined in terms of meeting individual 'needs' and quality of life. This research makes an important contribution to these studies.

CHAPTER THREE
RESEARCH STRATEGY AND METHODS

3.1 Overview of the Research Strategy and Design

The research problem was tackled by an empirically grounded, in-depth, exploratory study. The study was designed with 5 separate strands of investigation. Table 3.1, overleaf, summarises the overall research strategy by listing the strands, stating the research methods adopted, identifying the aims of each strand and the point in the fieldwork timetable when the fieldwork was carried out.

The initial sample used throughout each strand of the research strategy was drawn from a specific sub-population of the total population of YPWMD in Scotland, involved in the school leaving process. The sub-population constituted those YPWMD who were receiving education under the auspices of the Scottish Council for Spastics and who were involved in the school leaving process during the fieldwork period, October 1986 to July 1989. The Scottish Council for Spastics education facilities for children and young people comprises of 2 combined day and residential schools located in Strathclyde region and 1 day school in Lothian. All 3 schools cater for pupils aged 5-18 years.

Table 3.1 Overview of the Research Strategy

STRANDS OF THE RESEARCH STRATEGY	FIELDWORK METHODOLOGY	AIMS OF THE INVESTIGATION	TIMETABLE
1 Development of an information base in the form of a survey of the abilities/disabilities of the Young People in the sub-population	Compilation and execution of a profile questionnaire	1 To define the population and select a sub-population for exploratory research 2 To develop a functional classification	Months 3-5
2 Systematic and objective analysis of the FNA procedure	Participant observation of FNA meetings and consultation of the minutes of FNA meetings	1 To give an explicit account of the structure and organisation of FNA meetings 2 To monitor the role of the meetings in identifying post-school needs and securing service provision 3 To give an explicit account of the differences between meetings	Months 3-24
3 An exploration of the extent and influence of Carer involvement and Carer perception of their influence on the form and content of formal post-school provision	Semi-structured interviews with Carers of the Young People in the sample	To collect data on:- - Carers' perspective of the FNA procedure - Carers' perspective of post-school needs - Carers' opinion of formal post-school provision - Services currently provided - Social background variables	Months 8-12 and 20-24
4 Investigation into the formal post-school provision available to SLWMD	Semi-structured interviews with service providers and observation of service provision and delivery	1 To examine the nature and range of formal services to meet the IPSD of SLWMD 2 To examine the potential quality of life of SLWMD	Months 20-24
5 Investigation into SLWMD and Carer response to formal post-school service provision	Semi-structured interviews with SLWMD and Carers	To collect data on; - opinions on post-school placements - the transition from school to post-school placements - future aspirations - the 'ideal' placement	Month 33
6 Application of analytical findings	Inductive reasoning given the stated aims	To develop recommendations grounded in the research findings with implications for the planning and provision of formal post-school services for YPWMD	Months 33-36

3.2 The Functional Classification

As previously indicated, the original intention was to find an existing classification for use in this research (p.4). In the event, the following classification was generated and is used throughout the research. It is meaningful and useful in the assessment of IPSD and it can be used to give an operational definition to the term 'multiple disability'. This functional classification lists 5 categories, each representing a different level of functioning. Another way of looking at the classification is to translate the 5 levels into 5 degrees of dependency. These 5 categories are as follows:-

- 1 low level of functioning - very severe degree of dependency
- 2 low to medium level of functioning - severe degree of dependency
- 3 medium level of functioning - moderate degree of dependency
- 4 medium to high level of functioning- appreciable degree of dependency
- 5 high level of functioning - slight degree of dependency

The categories incorporate a judgement made on the individual's ability to perform in 6 areas of functioning:-

- 1 mobility skills-independent inside or outside
- 2 motor skills-gross/fine/perceptual
- 3 communication skills-verbal and conventional/non-conventional non-verbal
- 4 comprehension skills-understanding/recognition of basic objects, basic colours, basic shapes, basic words, basic pictures, basic numbers, size
- 5 social interaction skills-with carers, school staff, classmates, young people, strangers
- 6 life skills-washing, toileting, dressing, undressing, eating, drinking

Table 3.2 summarises the 5 levels of functioning and the relative performances in the 6 areas of functioning.

Table 3.2 The Functional Classification

Level of functioning	Mobility skills	Motor skills	Communication skills	Interactive skills	Comprehension skills	Life skills
Low	Wheelchair dependent	None	None	None	None	Doubly incontinent Complete assistance required
Low - Medium	Independent inside Dependent outside	Poor-variable gross only	Non-verbal only	None - limited	None - limited	Doubly/ singly incontinent Significant assistance required
Medium	Wheelchair independent	Poor-variable quality	Limited verbal and/or limited conventional non-verbal	Low	Poor	Singly incontinent Some help required
Medium - High	Ambulant indoors Wheelchair outdoors	Variable quality	Limited verbal and/or competent conventional non-verbal	Good	Variable	Assistance with washing dressing and undressing
High	Fully ambulant	Competent	Conventional speech	Good	Competent	No assistance required

In the context of this study, the term school-leaver refers to pupils who are between the ages of 15 and 19 years. These age limits follow present educational legislation. This dictates that the school-leaving process

commences when the Young Person has reached his/her fifteenth birthday. At the onset of the study, some Young People aged 13+ were included in the initial sample and described as 'pre-school leavers'. This was because as the project was carried out over a 2-3 year period, these pupils would become school leavers during the course of the study. In addition, some members of the initial sample become 19+ during the investigation and they are described as 'post-school leavers'.

It is generally accepted that a person who experiences physical and intellectual disabilities can be described as having multiple disabilities. For the purposes of this research project those Young People in the sub-population who experience problems of functioning in at least 2 of the areas of functioning, listed in the functional classification, were included in the initial sample.

The criteria were set so that for the individual to achieve a self-determined, high quality life-style, he/she will require access and provision of extra resources. The degree of difficulty experienced by the Young Person in the areas of functioning will have resulted in the Young Person being recorded according to the 1981 Education (Scotland) Act and so will be receiving special educational provision.

3.3 Strand One - Development of an Information Base

The development of an information base was to define the population, to whom in principle, later research findings should apply and to select a sub-population for exploratory research. The identification of a relevant sub-population, was in the form of a survey of the abilities and disabilities of the Young People receiving formal education through the Scottish Council for Spastics and who would be in the process of leaving school for the duration of the project.

3.31 Definition of the Initial Sample

Taking information from registers belonging to the Scottish Council's 3 schools, it was determined that when the project commenced, 77 Young People made up the sub-population of potential SLWMD (including those pre-school leavers). These Young People ranged in age from 13 - 19 years and will be referred to as the 'initial sample'. The following table describes the age and sex of each member of the initial sample. It gives the age at the end of the principal fieldwork period (month 24).

Table 3.3 Age and sex of the initial sample

Age	Male	Female	TOTAL
15-16	5	7	12
16-17	11	9	20
17-18	12	13	25
18-19	7	1	8
19-20	2	4	6
20-21	4	2	6

8 regions are represented as the home areas of the members because 2 of the 3 schools offer residential educational provision for children throughout Scotland. 48 of the pupils in the initial sample attend on a residential basis, with 29 being day attenders. Borders Region and the Island Authorities are not included.

To define the initial sample, a questionnaire survey was conducted in each of the 3 schools to collect data on the abilities and disabilities of the 77 Young People in 6 areas of functioning:-

- 1 Mobility
- 2 Motor skills
- 3 Communication
- 4 Interaction
- 5 Comprehension
- 6 Life skills

School staff, including Teachers, Speech Therapists, Occupational

Therapists, Physiotherapists, School Nurses and House Staff completed the questionnaire forms. The fieldwork was carried out between months 3-5 of the research project.

3.32 The Questionnaire

The questionnaire (Appendix 3.1) was organised under 7 main headings which were labelled as follows:-

- | | |
|-----------------------|-----------------|
| 1 General information | 5 Interaction |
| 2 Mobility | 6 Comprehension |
| 3 Motor skills | 7 Life skills |
| 4 Communication | |

The 1st section asked general questions about the Young Person and includes a description of the diagnosis and prognosis to allow the researcher to compare the findings with the medical classification. The following 6 sections sought information on the level at which the Young Person functioned.

3.33 Recording and Processing the Data

The responses to each question were coded into 3 levels of functioning, high, medium and low (Appendix 3.2). The responses for the questions in each section were then brought together so that a level of functioning was

established for each area of functioning. This was achieved as follows:-

<u>Responses in the section</u>	<u>Level of functioning in the section</u>
All high	High
High and medium	High - Medium
All medium	Medium
High/medium/low	Medium
High and low	Medium
Medium and low	Medium - Low
All low	Low

The overall level of functioning, putting together all the levels for each area was achieved by allotting a score to each level of functioning so that

High	= 5	Medium - Low	= 2
High - medium	= 4	Low	= 1
Medium	= 3		

The 6 scores for each section were then added together and an overall level determined

27 - 30 = High	10 - 15 = Medium - Low
22 - 26 = High - medium	6 - 9 = Low
16 - 21 = Medium	

3.34 Piloting the Questionnaire

The profile questionnaire was piloted in the 3 schools in the 2nd month of the research project. 10 pupils from each school took part in the 1st pilot and 12 pupils from each school in the 2nd. This resulted in some changes being made to the schedule. Certain questions were eliminated because they did not sufficiently discriminate a level of functioning and others provided information not required. The revised questionnaire and method of coding and processing the data was piloted and found to be acceptable. The final questionnaire was distributed at the end of month 4.

3.4 Strand Two - Analysis of the Future Needs Assessment procedure

3.41 Aims of Strand Two

This strand of the research strategy was designed to analyse the FNA procedure. The aims were:-

- 1 to develop an explicit account of the structure and organisation of FNA meetings
- 2 to monitor the role of FNA meetings in identifying post-school needs and securing service provision
- 3 to give an explicit account of the differences experienced by the individual in different FNA meetings.

3.42 Fieldwork Methods

This fieldwork was carried out during months 3 to 24. It took 2 forms:-

- 1 participant observation of selected FNA meetings
- 2 consultation of the minutes of meetings taking place during the 21 month period.

It was anticipated that there would be severe problems in comprehensive coverage through direct participant observation. The problems encountered are described in detail (p.63). It was therefore decided that to ensure a comprehensive coverage the minutes of all meetings would be consulted and selected meetings would be targeted for direct observation. 2 factors determined which meetings were to be targeted:-

- 1 Each different type of meeting was to be observed. From background reading and discussion with Headteachers, it was anticipated that the structure and organisation of meetings changed depending on whether it was a 1st, 2nd or subsequent meeting for an individual
- 2 Consecutive meetings of individual Young People were observed. 3 Young People were included in part 2 of the fieldwork.

Headteachers agreed to pass on the arrangements of all scheduled meetings taking place between November 1986 and September 1988 and indicate the type

of meeting. The fieldwork was planned from this information.

The minutes of the meetings were made available by the Headteachers and consulted within the schools. During the meetings that were observed, the researcher maintained a low profile and sat on the edge of the room.

Detailed notes were made both from the minutes and during the observations.

Information was collected under the following headings:-

1 Timescale

All the YPWMD were expected to experience at least 1 FNA meeting.

Preliminary observation and discussions suggested that YPWMD normally experience at least 2 meetings. Discussion with Headteachers suggested that for many YPWMD, they will experience more than 2 meetings before finally leaving school. The fieldwork established the ages at which YPWMD were involved in meetings and how that fitted in to the school-leaving process.

2 Venue

Information on the venue of each meeting was collected. This was considered to be important because it could influence the dynamics of the meeting. There is no indication given in legislation about the venue of the FNA meeting. As a number of different professionals can be present at the meetings it can therefore be assumed that the venue could be at a variety of locations.

3 People present and the basis for their participation

The range and interests of the people present shape and determine both the processes and outcomes. Different professionals have different responsibilities for the Young Person and have independent contributions to make. Each participant comes to a meeting from a different professional background. Professionals may find it difficult to relate and co-operate with each other and Carers may find it difficult to establish their position within a body of professionals.

These issues are to be explored through the fieldwork. To gain some insight into the dynamics of the FNA meeting, information was recorded on the interaction between participants including:-

- who dominated the inputs and outcomes
- the extent to which each participant was active or passive
- the relationship between professionals
- the relationship between the professionals and the Carer

4 Content of Discussions

The fieldwork collected data on the meetings' discussions in an attempt to find out how present school needs and post-school needs were identified and how present and post-school formal service provision was planned.

5 Conclusions

At the end of each meeting the Chair is expected to draw a meeting to a close by stating the conclusions reached. These conclusions are important because they map out who is expected to take what action and provide an agenda for the various steps to be taken in the school leaving process. All the members of the meeting can be involved in carrying out the actions of the meeting.

3.43 Fieldwork Data Collection

Data for both parts of the FNA fieldwork were collected simultaneously over the 21 month period. Before any meeting was observed, the Carer, the Young Person, the Educational Psychologist responsible for the Young Person were consulted and their permission sought. It proved impossible to included details on every single meeting for every individual pupil in the

sample. Several factors limited the availability of information: -

- 1 Limitations of time and finance
- 2 Involvement with other fieldwork
- 3 Meetings arranged and cancelled at the last minute
- 4 The minutes of some meetings had been mislaid
- 5 Copies of the minutes were not always sent to schools and the Headteachers did not always minute the meetings
- 6 There were occasions when the Headteachers failed to inform the researcher when meetings were taking place
- 7 Some meetings took place towards the end of the fieldwork period and the minutes were not available to the researcher.
- 8 For certain YPWMD minutes of the relevant FNA meetings were unavailable as they had been passed ~~on~~ to post-school placements together with other personal reports and documentation
- 9 Minutes often became confused with reports from Social Work Department reviews as on occasions the review and the FNA meeting were held in conjunction with ~~each~~ other. In addition some minutes became mixed up with the Record of Needs and annual reviews of the Record of Needs. As permission had not been sought with the Secretary of State for Scotland to have access to this information, it was not possible to extract the data.
- 10 The information content of some minutes was very sparse and so only a limited amount of data could be collected. This was sometimes due to the fact that for the older pupils the FNA meeting and reporting procedure was very new and no general agreement had been reached on format and content.
- 11 If the meeting was classified by the Education Authorities as an update a full meeting was not held and the minutes were extremely brief.

3.44 Fieldwork Coverage Achieved

The total number of meetings that took place between November 1986 and September 1988 was 76 (Table 3.4). The upper part of the table shows how many of these meetings were 1st, 2nd or subsequent meetings for the YPWMD. The lower part shows the percentage of those meetings observed and the percentage of meetings whose minutes were consulted.

Table 3.4 Fieldwork coverage rate

	Type of FNA meeting							TOTAL
	1st	2nd	3rd	4th	5th	6th	7th	
Total in sample	26	26	14	7	1	1	1	76
Percentage minuted	65	54	43	29	0	0	0	51
Percentage observed	35	46	57	71	100	100	100	49

Table 3.4 shows that 49% of the FNA meetings that took place throughout the fieldwork period were observed and the minutes consulted at 51% of the meetings. There were more 1st and 2nd FNA meetings (26 and 26 meetings respectively) taking place than subsequent meetings. This is because the majority of YPWMD experienced at least 2 meetings during the school leaving process. In addition, the frequency of decisions to seek further schooling combined with the distribution of ages in the research sub-population meant that all the members experienced at least 1 meeting during the fieldwork period. A smaller percentage (35%) of 1st FNA meetings than 2nd or 3rd meetings were observed because many of the 1st meetings took place when

other strands of the project's fieldwork were under way, or in a few cases, before the commencement of the research.

3.5 Strand Three - An Exploration of the Extent and Influence of Carer Involvement in and Carer Perceptions of Their Influence on the Form and Content of Post-School Provision

3.51 Aims of Strand Three

This strand of the research was designed to investigate Carer opinion on how the post-school needs of YPWMD are assessed and what formal support provision is made available once the Young Person has left school. There were 5 objectives of the interviews, namely to collect information on:-

- 1 Carers' perspective of the FNA procedure
- 2 post-school needs of YPWMD as perceived by their Carers
- 3 Carers' understanding of formal post-school provision
- 4 services currently provided to YPWMD and their Carers
- 5 social background of the YPWMD.

1 Carers' perspective of the FNA procedure

The FNA meeting affords an opportunity for the present and post-school needs of YPWMD to be discussed by those with the responsibility of meeting them. Carers have a legal responsibility and they are recognised as having an interest and concern for the quality of life experienced by the Young Person. Carers should therefore be closely involved throughout the FNA procedure along with the professionals. This objective is to collect data on Carers' sense of involvement and their views and opinions on the organisation, the discussions, and the conclusions of the meetings. This information can be used to answer the following questions:-

- 1 to what extent are Carers involved in the FNA procedure?
- 2 do Carers believe that the process is an effective method of ensuring that the YPWMD receives appropriate post-school provision?

3 do FNA meetings identify the post-school needs of YPWMD and the provision required to meet those needs?

4 what differences are experienced by Carers attending meetings?

5 what improvements can be made to the FNA process?

2 Post-school needs of YPWMD as perceived by Carers

It is important to find out what post-school needs YPWMD have in order to assess the formal service provision required to offer a high quality of life. Carers are able to supply this information from their perspective, they know the individual concerned and they see 'need' in pragmatic contextual terms which may not coincide with what is available through formal services. This information can be used to answer the following questions: -

1 do Carers perceive the needs of the YPWMD differently to service providers?

2 do Carers perceive a greater number of needs and type of need than those identified at FNA meetings?

3 what post-school needs were most frequently identified by Carers?

4 does Carer perception of post-school needs change throughout the school leaving process?

3 Carers' understanding of post-school provision

This objective concerned collecting data on the post-school provision required and the provision being offered in the discussions at FNA meetings. Preliminary and casual conversations with Carers showed that Carers see post-school provision as a residential or daily placement. The aim was to investigate what real choices Carers and YPWMD were being offered and their ideal placement. Central to this aim is to ascertain Carers' judgements on services offered, the manner of service delivery and lack of provision. This information can indicate the quality of life offered to YPWMD.

4 Non school-based services currently provided to YPWMD

The 4th objective was to investigate the current non school-based service provision received by the YPWMD and their Carers during the school leaving process. This involved listing the actual services received and noting the service providers, in addition to finding out how satisfied Carers were with the service provision and delivery. At the same time, gaps in service provision could be identified by listing the services Carers were not receiving.

5 Social background variables of the YPWMD

The purpose of collecting background information on the YPWMD was to substantiate the data collected through the profile questionnaires. A brief description of the home circumstances allows for a greater insight into understanding the post-school needs of the YPWMD and it can help to put information into context. This data can also be used to build up background material for case studies.

3.52 Fieldwork Methods

Data was collected through semi-structured interviews with the Carers between months 8-12 and 20-24. The interview schedule and information on data collection and processing is given in Appendix 3.3 and 3.4.

5 pilot interviews were carried out in month 8. Throughout the early stages there had been many informal discussions with Carers in their homes and at schools. Information from these dialogues also contributed to the planning, setting up and execution of the fieldwork. The 5 pilot interviews were all carried out in the Edinburgh area because of limited access to transport. They were chosen so that the YPWMD involved represented differing levels of functioning. The piloting of the interviews provided the following information:-

- 1 The average time required for each interview was 1½ hours with 45

minutes required for recording the responses and 45 minutes required to establish a rapport with the Carer and answer their questions.

- 2 Both recorded and non-recorded interviews provided information to meet the fieldwork objectives.
- 3 Some questions in the interview schedule were re-phrased to facilitate the interviewee.
- 4 The method of data recording was found to be appropriate in meeting the fieldwork objectives.

3.53 Fieldwork Procedure

All Carers of the 77 YPWMD in the initial sample were to be included in 2 phases of the interviewing fieldwork. Any non-respondents were followed up and included in a later phase of the fieldwork. Before making any approaches to the Carers the relationship between the YPWMD and their Carer had to be established and the number of full-time main Carers responsible for the YPWMD. This information was sought from the schools and is shown in Table 3.5.

Table 3.5 The relationship between the YPWMD and the Carer

Number of main Carers	Relationship between Carer and Young Person	Initial sample
2	Mother and father	57
1	Mother only	10
1	Father only	1
1	Grandmother	2
1	Sister	1
2	Mother and stepfather	3
2	Mother and father separated	2
1	Local Authority S. W. Dept.	1

The majority of Carers in the initial sample are parents with a significant number of YPWMD having 2 principal Carers, Mother and Father / Stepfather. There are 14.3% of YPWMD with only 1 principal Carer and that is their Mother or Father living on their own. 6.5% of Carers had a different familial status and where parents were separated the Young Person could spend time with both.

The fieldwork was carried out in 2 phases. Phase 1 took place between months 8 - 12 and phase 2 took place between months 20 - 24. Those YPWMD who had not experienced a FNA meeting before month 12 were included in the 2nd phase because Carers were only asked to take part if the YPWMD had been involved in a FNA meeting.

3.6 Strand Four - An Investigation into Formal Post-School Provision

This part of investigation was designed and carried out to develop an account of the nature and range of formal post-school provision for SLWMD and the way in which such services are delivered. There were 2 evaluative aims: -

- 1 to examine the nature and range of formal services aimed to meet the post-school needs of SLWMD
- 2 to examine the potential contribution of such services to quality of life of SLWMD.

3.61 Aims of the Strand Four

Formal post-school services are provided and delivered by Local Authorities and Voluntary organisations in different types of settings. To collect information on the nature and range of formal post-school services, the fieldwork aimed to answer the following questions: -

- 1 Are the 7 IPSD addressed in post-school placements?

- 2 Do placements provide - Enabling support supplied by specialist and non-specialist personnel
 - Services related to the physical environment
 - Equipment and resources
 - Access and transport services
 - Financial services
- 3 Do post-school placements ensure that services are delivered while promoting the concepts of - service user independency
 - service user autonomy
 - service user privacy
 - service user self-development and self-determination
 - service user self-dignity and self-esteem
 - meeting individual needs
 - service user advocacy
 - integration with the community

In reviewing the relevant research literature, models of service provision and delivery were examined. Different models approach the meeting of individual personal and social developmental needs of SLWMD in different ways which offer different levels of quality of life to the individual. From these models, 2 quality of life continuumms were developed to be used to examine aim 2, the potential contribution to quality of life of SLWMD offered by the service provision and delivery in post-school placements. The 2 quality of life continuums were developed with 4 different styles of provision and delivery:

1 Independent-enabling and individually-centred style

The SLWMD is enabled to be independent through support, facilities and resources. They fully participate and take responsibility for their

decisions and self-development. SLWMD and placement staff are inter-dependent. The focus of provision and delivery is the individual's personal and social developmental needs. SLWMD develop their full potential with the focus on holistic self-development and self-determination. Privacy and personal rights are respected at all times.

2 Informal living style

This style of provision and delivery can apply to residential accommodation which should be informal with a homely setting of small size and full community integration.

A combination of these approaches would, in theory meet the IPSD needs of SLWMD. The following 2 styles are opposite in approach:

3 Dependent-Care and Group-centred style

The SLWMD are cared for and cast into a dependent role, with no autonomy. Their life-style is dictated to them with little or no control over it. There is no opportunity for self-development and self-determination. Facilities and resources are limited so restricting independency. The SLWMD are seen as a group and personal and social developmental needs are common to all members. The meeting of these needs are within a group setting, instigated by the placement staff and non-specific to the individual so that development is limited. Privacy is minimal.

4 Formal living style

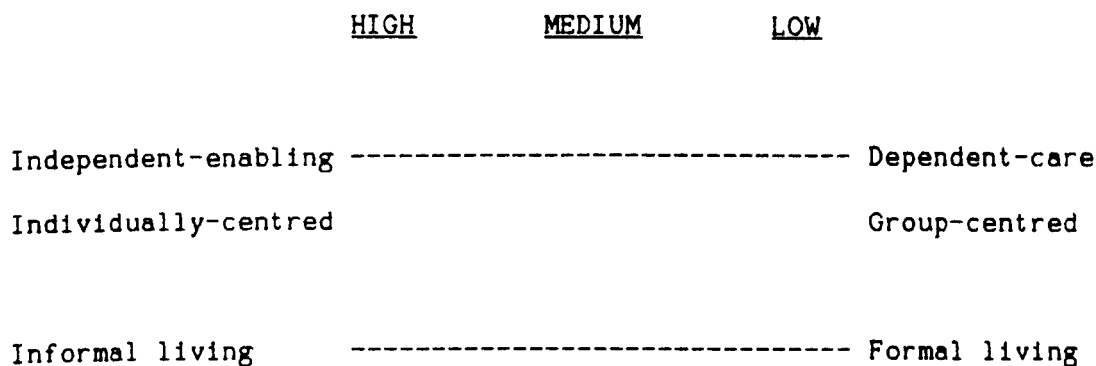
The SLWMD live in an institutionalised setting with a lack of homeliness and privacy. The setting will have a large number of residents with set daily routines laid down. Community involvement is minimal.

A combination of these styles would not, in theory, result in the meeting of IPSD needs.

The 2 quality of life continuums are shown in figure 3.1 The potential for high quality of life is found at the left side of the continuum line where the styles of provision and delivery incorporate the Principles of

Normalisation, the social model and the 'horticultural' model. The potential for low quality of life at the right side where the styles incorporate the medical model and the 'warehousing' model and do not accept Normalisation Principles. Medium quality of life is found inbetween the 2 ends of the continuums where elements of all the styles are apparent.

Figure 3.1 The Quality of Life Continuums



An examination of the service provision and delivery of a post-school placement can show where on each continuum the placement is and the quality of life it can offer the SLWMD. These continuums are used in examining the results from this fieldwork.

3.62 Fieldwork Methods

The fieldwork took place during months 20-24. It was designed to collect information on service provision and delivery in the post-school placements by: -

- 1 using a semi-structured interview with a senior member of staff from the placement
- 2 making detailed observations of service provision and delivery.

The interview schedule and information on the conduct of the observation together with the recording and processing of the data is given in Appendices 3.6-3.10.

3.63 Piloting the Fieldwork

6 placements made up the 'pilot' group and they are identified by letter/number for reasons of confidentiality - R=residential, D=day, and F=Further Education. 3 placements were residential placements - R10, R12, R13; 2 were day placements - D6, D7; and 1 was a Further Education placement - F4. No hospital or work centre placements were included in the pilot group as there were only 1 of each of these in the total sample. The fieldwork was piloted in 4 stages and its aim was to ensure that it produced information that satisfied the aims and the method of recording the data was appropriate. Each stage will be outlined briefly.

Stage 1

During the 1st 3 months, 6 placements were visited - R10, R12, R13, D6, D7, F4. These visits included discussion with senior staff, informal conversation with staff and service-users and a 'guided tour' of the establishment and the activities taking place. The fieldwork notes contributed to the construction of the interview schedules and observation checklists.

Stage 2

The interviewer spent 5 days 'employed' as a member of the support staff in placement R12 (a residential centre with a day centre attached) and experienced working on each shift. This allowed for substantial checking to be carried out on the interview schedules. The method of recording the data was also piloted and examined to ensure that the method provided the results to meet the aims of the fieldwork.

Stage 3

Further checking of ideas and data took place when the researcher participated as co-presenter in 'Quality of Care' workshop sessions carried out in placements R12, R10 and D6. These workshops were staff training sessions and they were designed on the basis of the placement evaluation framework. It involved detailed discussions with staff about the services

provided, the way in which they were delivered and the quality of life being offered to service-users. As part of the workshop session in placement R12, a mixed group of YPWMD and staff were brought together to discuss the needs and meeting the needs of SLWMD and the problems of transition from school to an adult placement. The outcome of the discussion was used to check on whether the range of placements and services encountered in the fieldwork covered what would, in practice, normally be available. Minor modifications were made after the 1st workshop session at placement R12 and these were piloted during the session at placement D6. After this exercise, the results from stage 3 of piloting were positive. The information collected from the amended schedules and the list of points for observation allowed the checklists to be completed and data recorded satisfactorily.

Stage 4

Following on from stage 3, the 6 placements in the 'pilot' group were visited. Further checks were carried out and no modifications were made to methods of data collection and data recording.

3.64 Fieldwork Sample

A total of 32 placements made up the sample. Placements were included if they were discussed as a 'serious' possible placement for the YPWMD at FNA meetings and if they had been taken up by SLWMD. A placement is defined as 'seriously considered' if arrangements have been made for visits by the Young Person and Carers in addition to assessments being carried out by placement staff. Table 3.6 shows the number of post-school placements and the type of placements. Placements are categorised according to the types as recognised by the Carers in the Carer interviews and notes the administering bodies involved. The table also indicates which of the 32 placements have been taken up by SLWMD between August 1986 and August 1988.

All the 32 placements with the exception of 1 are located in Scotland, the majority in the Central Lowlands. 8 regions are represented excluding the Island Authorities and Grampian Region.

Table 3.6 The characteristics of the placement sample

	Type of Placement					
	Residential	Day	Further Education Day	Residential	Hospital	Work
Total number of placements in the sample	15	9	2	3	2	1
Administrative L. A. Body Vol.	1 14	6 3	2 0	2 1	2 0	0 1
Location:						
Lothian	2	3	0	1	2	0
Strathclyde	7	2	2	1	0	1
Central	1	1	0	0	0	0
Fife	0	3	0	0	0	0
Dumfries+Galloway	1	0	0	0	0	0
Highland	1	0	0	0	0	0
Borders	2	0	0	0	0	0
Tayside	1	0	0	0	0	0
England	0	0	0	1	0	0
Places taken up by SLWMD between Oct. 1986-Oct. 1988.	7	6	2	2	1	0

3.7 Strand Five - An Investigation into SLWMD and Carer Response to Formal Post-School Service Provision

3.71 Aims of Strand Five

This strand was designed to investigate what SLWMD and their Carers felt about the formal post-school service provision they were receiving. All the Young People involved had officially left school for at least 1 year. This time gap between the school leaving date and the period of fieldwork allowed for the Young Person and the Carer to have come to some definite opinion of the post-school placement. There were 5 objectives, namely to collect data on:-

- 1 the post-school placements taken up by the SLWMD and the judgement made on the package
- 2 the transition from school to the new placement(s)
- 3 the future aspirations of the SLWMD and the Carers
- 4 the opinions of SLWMD and Carers of 'ideal' post-school placements
- 5 the opinions of SLWMD and Carers of services provided outwith the placements.

1 The Post-School Placement Packages

Post-school services can be provided and delivered in 1 placement, referred to as the 'principal placement' or in a variety of placements which constitute the placement package. For purposes of the research, it was important to determine how appropriate the placement packages are for SLWMD and find out details about service provision and delivery. Comparisons could then be made between provision and delivery at school and at post-school placement(s).

2 Transition from school to post-school placements

The interviews aimed to find out what events and experiences of SLWMD which take place during the 'transition period'. This starts from the time that the Young Person decides to go to a particular placement and the end of the settling in period into the placement. There are 4 components:-

- 1 securement of the placement through formal applications and after assessments have taken place and admission procedures carried out
- 2 the Young Person makes preparations for leaving school
- 3 the time lapse between the final school leaving date and the starting date of the principal placement
- 4 the 'settling in period' which on average lasts for 3 months and referred to as a 'trial period' for both SLWMD and staff after which the decision is made if the placement continues.

3 Future Aspirations of SLWMD and Carers

The fieldwork aimed to find out if SLWMD saw the placement package as 'permanent' or if it was regarded as a stepping stone to somewhere else and what type of placement package they then wanted.

4 Perceptions of 'ideal' post-school placements

In order to make comparisons between 'real' and 'ideal' placements gaps in provision identified, information was collected on perceptions of 'ideal' placements. For some SLWMD and Carers, the 'ideal' placement is seen in terms of an actual placement or combination of placements that exist. For others it is an imaginary placement.

5 Service provision outwith post-school placements

SLWMD and Carers may require formal services that are provided outwith the placements. It was important to find out if such services were provided and what was thought about them. Apart from support and respite care, which is worthy of treatment in its own right, the services proved to be of minimum significance for purposes of this research. These services are not considered further in this thesis.

3.72 Fieldwork Methods

Information was collected by conducting semi-structured interviews. The interview schedule was designed to collect data to meet the 5 objectives. It is given in Appendix 3.5 together with notes on the collection and processing of the data (Appendix 3.3).

3 sets of SLWMD and their Carers were selected to make up the pilot interviews. Each Young Person had competent and independent methods of communication that were fully understood by the interviewer so there was no possibility of mis-interpreting the information and jeopardise the validity of the results. All interviewees agreed to be recorded but it was deliberately decided that 1 set of responses would not be recorded to allow the interviewer to assess the validity of information from a non-recorded interview. The results of all 3 pilot interviews showed that only very minor modifications had to be made.

The average time for conducting the interviews was 1 hour. This avoided tapes having to be changed during the course of the interview and so interrupt the flow. Both recorded and non-recorded interviews provided information to meet the objectives as did the method of data recording. Before the pilot interviews were carried out, the schedule had been looked at by members of a Parent Support Group. This included Carers of Young People who had left school but who were not part of the research. Their comments were very valuable as were the interviews carried out with the Carers in months 8-12 and 20-24.

3.73 Fieldwork Procedure

A sample of 36 SLWMD and their Carers was taken from the sub-population of 77. These were Young People who had left full-time education between Christmas 1986 and Summer 1988. The reason for applying these dates as limits to inclusion in the sample are related to the restraints imposed by

the research timetable and Educational legislation. Pupils are able to leave school education between the ages of 16-18 years and it is Local Authority practice that depending on when the pupil's birthday falls, he or she will leave school at Christmas or at Summer. Therefore the 1st possible school leaving date after the beginning of the project was Christmas 1986. The planned completion of the fieldwork was Autumn 1989 and taking into account that the Young Person had to have been away from full-time school education for 1 year, the last leaving date for inclusion in the sample was Summer 1988. The fieldwork was carried out during a 2 week period in month 33. 4 sets of SLWMD and their Carers were not included because they lived too great a distance away from the research base and insufficient finance was available and 1 Young Person and Carer were not included because it proved impossible to trace their new address. 31 sets of SLWMD and their Carers were interviewed.

3.8 Strand Six - Application of Analytical Findings

3.81 Aims of Strand Six

This final strand of the research aimed to develop and generate a series of recommendations to be presented within the content of current legislation. These recommendations aimed to focus on the planning and provision of formal post-school service provision.

3.82 Fieldwork Methods

Throughout the course of the fieldwork, data was collected, processed and analysed. The content of the recommendations was then derived by inductive reasoning within the stated aims. The recommendations are therefore pragmatic and empirically based. This work was conducted during months 33-36 of the research and they are presented in Chapter 6.

CHAPTER FOUR **FIELDWORK RESULTS**

This chapter sets out the results from the 5 strands of fieldwork presented in Chapter 3:-

- 1 - results from the Profile Questionnaire
- 2 - results from the observation of FNA meetings and the consultation of written reports
- 3 - results from the interviews with Carers
- 4 - results from the interviews with placement staff and the observation of post-school placements
- 5 - results from the interviews with the YPWMD and the Carers on formal post-school provision

An operational definition of the population to which the research is, in principle, applicable has been generated. Because the sub-population was used in the formulation of the definition, and there is no survey material available which identifies even the number of YPWMD to which the criteria apply, the sub-population can in no sense be thought of as representative. Application of the profile questionnaire serves to define, by means of a functioning/dependency index, whether a Young Person is sufficiently multiply disabled to be included in the population.

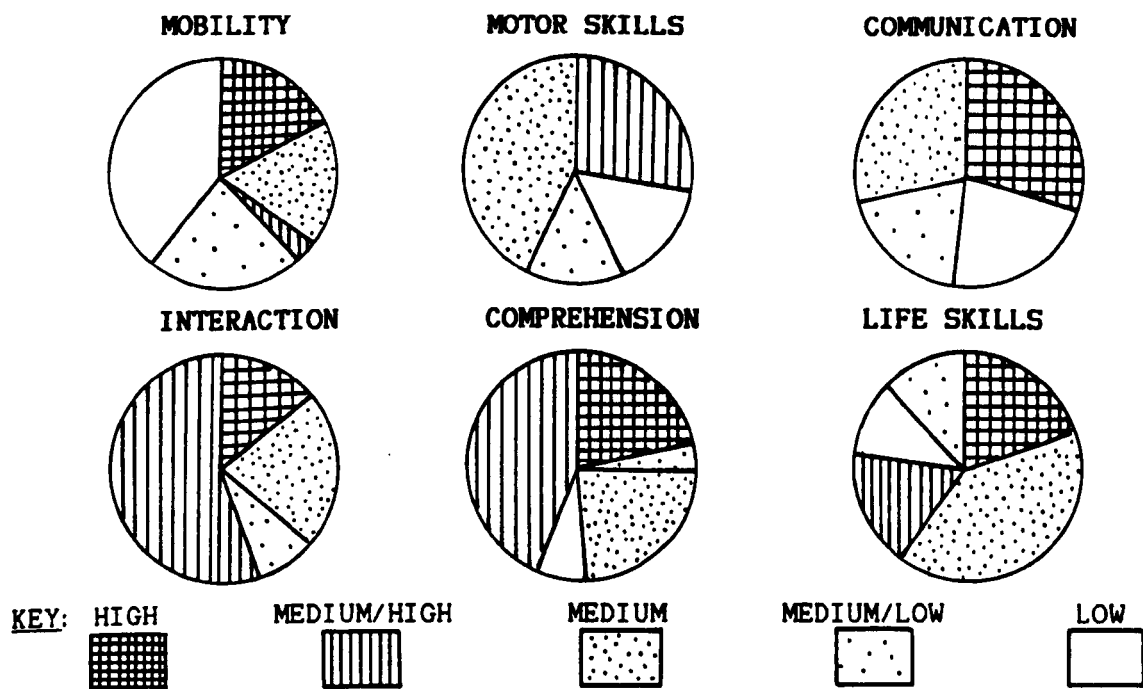
4.1 Results from the Profile Questionnaire

The aims of the profile questionnaire were to define the initial sample and determine the levels at which the YPWMD functioned. There was a 100% response rate to the profile questionnaire survey.

4.11 The Levels of Functioning of the Initial Sample

Figure 4.1 shows the level of functioning in all 6 areas of the initial sample.

Figure 4.1 The levels of functioning attained by the Initial Sample



The pie-charts show the predominantly low level of functioning in the area of mobility and the predominantly medium level of functioning in the areas of motor skills, communication and life skills. In the areas of interaction and comprehension higher levels of functioning were achieved. From the results of the processed questionnaire data, the overall level of functioning of all the members in the sample is shown in table 4.1.

Table 4.1 The levels of functioning of the initial sample

Level of functioning	Number of members
High	4
High - Medium	28
Medium	24
Medium - Low	18
Low	3

4.12 Individual Profiles

The individual profiles of 12 Young People from the initial sample are presented to provide an insight into individual levels of functioning. 5 profiles are presented here and 7 are included in Appendix 4.1. The information was taken from the data collected from pupil observations in addition to the questionnaires.

Profile 1

Age when survey conducted : 15.1 Sex : Female
Home region : Fife School : Day pupil at School B
Functional classification category : High

This young person is non-ambulant but has independent wheelchair mobility and good quality motor skills. Communication is conventional speech and she is can be easily understood. D interacts well with school staff, peers and non-familiar people. Her comprehension is good though she finds computational skills harder to achieve. School records report a mental age of 5.0 years and a reading age of 7.0 years. The assessed I.Q. is between 40 and 50. D is continent and requires only a little assistance for dressing/undressing and washing. Care has to be taken incase D takes an epileptic fit which is controlled by medication.

Profile 2

Age when survey conducted : 14.0 Sex : Female
Home region : Strathclyde School : Residential pupil at School C
Functional classification category : High/Medium

G follows a secondary school level course of study and is very interested in using computers and word processing. School records show a mental age of 13.9 years. She requires a little assistance with dressing/undressing and washing but otherwise she is independent and can manage self-transfers most times. G has independent wheelchair mobility inside and outdoors but her fine and gross motor skills are of variable quality depending on the situation. Her posture tends to be poor. Communication is by conventional speech but at times G has difficulty being understood although this partly

due to excessive dribbling. She interacts extremely well with parents (she is the only child), with school staff and peers but she tends to be less enthusiastic when with strangers and other children.

Profile 3

Age when survey conducted : 16.6 Sex : Male
Home region : Central School : Residential pupil at School A
Functional classification category : Medium

I is ambulant both in and outdoors. The quality of motor skills is variable for gross motor skills with no fine and perceptual motor skills. Communication is using conventional speech which can be understood. He interacts well with parents and school staff but this decreases with peers and is non-existent with strangers. I's level of comprehension is very low apart from the names and uses of basic objects. His mental age is recorded at 3.0 years. He is continent and only requires some assistance with dressing although he needs supervision. I is on medication for seizures and he experiences some hearing loss.

Profile 4

Age when survey conducted : 18.0 Sex : Male
Home region : Strathclyde School : Residential pupil at School C
Functional classification category : Medium/Low

A has no controlled movement other than with his head and eyes. He uses these in a most expert way for communication through Bliss. He attains great speed when carrying out a conversation. Gross and fine motor skills are non-existent and he has variable quality perceptual skills. A has dependent wheelchair mobility inside and outside and requires to be frequently positioned to prevent stiffening and pressure sores. Comprehension is very good and A follows a secondary school level course of studies including preparation for external examinations. A can become very frustrated and has screaming fits and temper tantrums. Medication controls mild epilepsy. Interaction is good with familiar persons. Regarding personal skills, A requires complete assistance with everything.

Profile 5

Age when survey conducted : 17.1 Sex : Male
Home region : Lothian School : Day pupil at School B
Functional classification category : Low

S has dependent wheelchair mobility both indoors and outdoors. He requires to be frequently positioned. He has no motor skills but makes attempts to reach out and grasp objects. Communication is non-verbal, using smiles and pulling at things to indicate his needs. S suffers from several health problems including epilepsy, diabetes and a hiatus hernia. School records report a mental age of 2.6 years and comprehension would appear to be virtually non-existent. He interacts at a low level with familiar people such as school staff and parents but there is no degree of interaction with strangers. Complete assistance is required for all daily living tasks and S is doubly incontinent. He can exhibit inappropriate behaviour patterns including grabbing and self-induced vomiting.

4.2 Results from the Fieldwork on the FNA Procedure

The results from the fieldwork on FNA procedure is presented in 2 parts:-

- 1 Results from the consultation of written minutes and direct observation
- 2 Results from the observation of consecutive meetings of 3 YPWMD.

4.21 Results from the Consultation of Written Minutes and Direct Observation

76 FNA meetings are included in the results which are presented under the following 5 headings:-

- 1 the timescale of the FNA meetings
- 2 the venue of the FNA meetings
- 3 the people present and their participation in the FNA meetings
- 4 the content of the discussions
- 5 the conclusions reached at the FNA meetings.

4.211 The Timescale of the FNA Meetings

To gain some insight into the timescale of the FNA meetings and how that relates to the overall school leaving process data was collected on the ages of the Young People when the FNA meetings were held. This is presented in table 4.2.

Table 4.2 The age of the YPWMD when FNA meetings were held

Age of the YPWMD	Type of meeting						
	First	Second	Third	Fourth	Fifth	Sixth	Seventh
<14	1	0	0	0	0	0	0
14.0-14.6	2	0	0	0	0	0	0
14.7-15.0	9	0	0	0	0	0	0
15.1-15.6	8	5	0	1	0	0	0
15.7-16.0	4	4	0	0	1	0	0
16.1-16.6	1	9	2	0	0	1	1
16.7-17.0	0	3	6	2	0	0	0
17.1-17.6	0	2	4	3	0	0	0
17.7-18.0	0	1	1	0	0	0	0
18.1-18.6	0	0	1	1	0	0	0
18.7-19.0	1	1	0	0	0	0	0
19.1-19.6	0	1	0	0	0	0	0

Table 4.2 shows that the majority of YPWMD had their 1st FNA meeting between the ages of 14.7 and 15.6. These figures comply with legislation but the table shows that 7 Young People had their 1st meeting outwith the stated time period. 1 reason for this pattern is the relationship between

the actual birthday of the Young Person and the recognised school leaving date and another reason is that for some Young People, the legislation had not been implemented in time. For another individual, the 1st meeting took place when she was over 17.0 as she had just been recorded following a serious head injury.

The table shows that 2nd FNA meetings take place between 15.1 and 19.6 with a significant number between 16.1 and 16.6. This is because most YPWMD want to continue at school until their 18th birthday and to do this they need to apply to the Local Education Authority for a year's extension to their education.

24 meetings are 3rd and subsequent meetings, taking place when YPWMD are approximately 17.0. This trend is because as the Young Person approaches the final school leaving date, meetings are required to determine post-school service provision. The Young Person who did not follow this trend experienced his 4th to 7th meetings between the ages of 15.2 and 16.5 because of difficult home circumstances.

Data on the timescales of the meetings can show the length of time YPWMD waited until the next meeting. This is presented in table 4.3.

Table 4.3 The time lapse between FNA meetings

Time lapse between meetings (months)	Type of FNA meeting					
	1st-2nd	2nd-3rd	3rd-4th	4th-5th	5th-6th	6th-7th
0-3	0	2	1	0	0	1
4-6	2	4	4	0	1	0
7-9	5	5	1	1	0	0
10-12	11	3	1	0	0	0
13-15	4	0	0	0	0	0
16-18	3	0	0	0	0	0
19-21	1	0	0	0	0	0

These results indicate that the period of time between 1st and 2nd meetings is likely to be longer than the period of time between subsequent meetings because later meetings are held nearer to the final school leaving date.

4.212 The Venue of the FNA Meetings

The majority of the meetings, regardless of the type of meeting, are held in the schools, with 3 held in Child Guidance offices and 3 in Social Work offices. This pattern exists because it is the Headteacher who arranges the meetings and it allows School Staff to take part. A consequence of this arrangement is that the FNA meeting is often held in conjunction with the annual review meeting for the Record of Needs. The 3 meetings were held in Child Guidance Offices because of regional policy. The 3 meetings held in Social Work Offices were 3rd and 4th meetings taking place shortly

before the final school leaving date with Social Workers taking on a more prominent role in organising post-school provision.

4.213 The People Present and their Participation in the FNA Meetings

1 The number of people present

The number of people present at the different types of FNA meetings ranges between 4 to 12. The numbers include the Carer who is counted as 1 person. The average number of people present was 6. There is no obvious pattern to indicate a relationship between the number of people present and the type of FNA meeting.

2 The different professions present

The different professions present at FNA meetings fall into 2 groups:-

- 1 School staff employed by the Scottish Council for Spastics
- 2 Other professions.

Group 1 - School Staff

- | | | | |
|---|-------------------------------|----|-----------------------------|
| 1 | Headteacher (HT) | 6 | Speech Therapist (ST) |
| 2 | Assistant Headteacher (AHT) | 7 | Physiotherapist (P) |
| 3 | Class teacher (CT) | 8 | Occupational Therapist (OT) |
| 4 | Educational Psychologist (EP) | 9 | School Nurse (SN) |
| 5 | Social Worker (SW) | 10 | Houseparent (HP) |

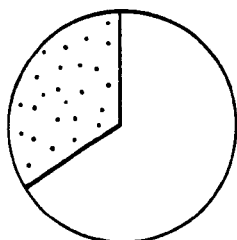
Group 2. - Other Professions

- 1 Local Authority Educational Psychologist (LAEP)
- 2 Local Authority Social Worker (LASW)
- 3 Local Health Authority Community Doctor (CD)
- 4 Local Authority Occupational Therapist (LAOT)
- 5 Staff from post-school placements (PPS)
- 6 Local Authority Special Careers Officer (SCO)
- 7 Local Authority Co-ordinator of Special Needs (CSN)

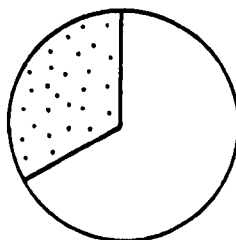
The following pie-charts in figure 4.2 illustrate the proportion of group 1 (school staff) members to group 2 (other professions) present and the type of FNA meeting.

Figure 4.2 Pie-charts to show the proportion of professions present and the type of meeting

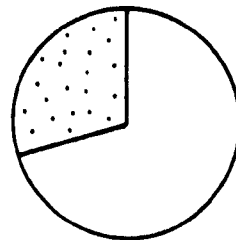
1st FNA meeting



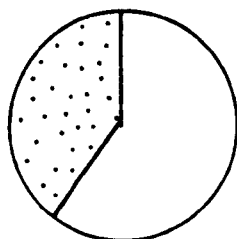
2nd FNA meeting



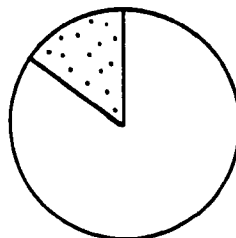
3rd FNA meeting



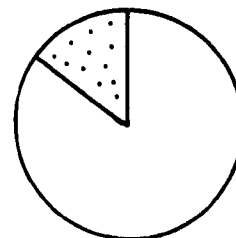
4th FNA meeting



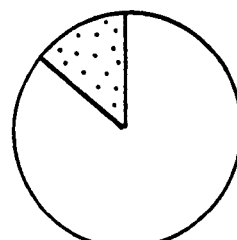
5th FNA meeting



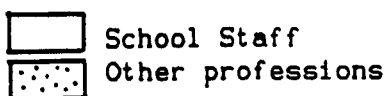
6th FNA meeting



7th FNA meeting



KEY:



In all types of meetings there is a significant proportion of school staff present compared to the other professions. Table 4.4 shows in more detail the percentage of meetings, according to type, attended by each profession from the 2 groups. Each profession is presented by the letters shown in brackets in the previous lists of the 2 groups.

Table 4.4 The percentage of FNA meetings attended by each type of profession

Type of profession	Type of FNA meeting						
	First	Second	Third	Fourth	Fifth	Sixth	Seventh
<u>Group 1</u>							
HT	92%	85%	79%	71%	100%	100%	100%
AHT	8%	15%	21%	0%	0%	0%	0%
CT	61%	58%	64%	36%	100%	100%	100%
EP	27%	19%	14%	14%	0%	0%	0%
SW	73%	65%	86%	36%	100%	100%	100%
ST	35%	15%	7%	14%	0%	0%	0%
P	50%	19%	0%	14%	0%	0%	0%
OT	23%	11%	0%	0%	0%	0%	0%
SN	58%	69%	71%	36%	100%	100%	100%
HP	31%	11%	0%	14%	0%	0%	0%
<u>Group 2</u>							
LAEP	96%	92%	71%	71%	0%	0%	0%
LASW	54%	80%	86%	100%	100%	100%	100%
CD	27%	23%	14%	14%	0%	0%	0%
LAOT	8%	0%	0%	0%	0%	0%	0%
PPS	4%	15%	0%	0%	0%	0%	0%
SCO	19%	19%	0%	0%	0%	0%	0%
CSN	4%	8%	0%	0%	0%	0%	0%

These results show that 5 out of the 17 different professions attended all the types of meetings and the same 5 attended the most number of meetings. They are recognised as the key people taking part in the FNA process and include:-

- 1 Headteacher (attended 85% of all meetings)
- 2 Local Authority Educational Psychologist (attended 75%)
- 3 Local Authority Social Worker (attended 73%)
- 4 School S.W. (attended 67%)
- 5 Classteacher (attended 63%)

Table 4.4 shows a trend in the attendance of particular professions at different types of meetings. At only approximately 1/4 of the 1st FNA meetings (54%) was there the presence of a representative from the Local

Authority Social Work Department. The attendance improves with subsequent meetings. The opposite trend occurs with the attendance of the Local Authority Educational Psychologist which was found to decrease throughout the FNA process.

3 Participation

Data on the participation of the different professions present at the meetings was collected both from the minutes of the meetings and from the observed meetings. Group 1 will be described 1st followed by Group 2.

Headteacher - 2 important roles performed by the Headteacher is to chair and minute the meetings, especially meetings held at school. They also had the responsibility to convene the meetings.

Assistant Headteacher - on the occasions when the Headteacher was unable to attend meetings the Assistant Headteacher took over the role of the headteacher.

Classteacher - Class teachers informed the meeting about the progress and general overall development of the YPWMD. They also commented on post-school needs and service provision. In many cases the Classteacher had discussions with the YPWMD prior to the meetings and they conveyed the feelings and comments of the YPWMD.

School Educational Psychologist - the School Educational Psychologist was found to make a very small contribution to the meetings commenting briefly on current performance.

School Social Worker - the Social Worker played a significant part in the FNA proceedings. One Social Worker was responsible for meetings held in ~~2~~ of the schools. They took responsibility of finding out about post-school placements and available service provision. Evidence suggests that in many cases they performed the role that should have been played by the Local Authority Social Worker.

The Therapists, School Nurse and Houseparent - participation by these professions was primarily making comments about present work programmes, progress and problems. Very little comment was made on post-school needs or on post-school service provision. In many cases, they only attended a small part of the meetings when discussion centred on the present circumstances of the YPWMD.

Local Authority Social Worker - the role played by the Social Worker varied greatly between meetings. Generally performances were unsatisfactory and a variety of factors were responsible: -

- 1 the personality of the individual Social Worker
- 2 the nature of the post-school needs of the YPWMD
- 3 Social Worker lack of knowledge about YPWMD and the Carers
- 4 little or no opportunity given to the Social Worker to become acquainted with the YPWMD and Carers
- 5 Social Worker inexperience in the FNA process and their function
- 6 Social Worker inexperience in multiple disability
- 7 different Social Workers attended meetings leading to a lack of continuity
- 8 shortage of placements restricted discussion and choice
- 9 problematic relationships developing between the Social Worker and other professionals and between the Social Worker and the Carers
- 10 when meetings became tense, professional rivalries became prominent and the Social Worker was more concerned about exacting authority and protecting professional status than focusing on the post-school needs of YPWMD
- 11 Social Workers failed to fulfil duties following meetings.

There were however examples where the Social Worker was well informed.

This was very often a Senior Social Worker who attended meetings because of pressure put on the Social Work Departments by the Carers and the schools

for more active participation and support.

Local Authority Educational Psychologist - the Local Authority Educational Psychologist was found to chair and minute many of the FNA meetings. They played a significant role in discussing whether the YPWMD would benefit from continued education and in the discussions on applying for extensions. They played a less prominent role when the discussions turned to post-school placements with the exception of a few who were well informed about certain placements and who negotiated and arranged funding for Further Education courses. There was evidence of the Educational Psychologist being absent from later meetings when the focus of the discussions was on post-school placements.

Community Doctor - the Community Doctor was not found to make a significant impact on the FNA process either by their attendance or through their contribution in the meetings. On a few occasions, they gave medical advice on dieting and offering the YPWMD assistance in managing their own health care. There was 1 example where the Doctor took on the role of finding out about a hospital placement and making arrangements for visits and assessments. This YPWMD and Carer were without the support of a Local Authority Social Worker. At 1 meeting where the Community Doctor was absent, the Local Authority Educational Psychologist made the point that the meeting could not be valid.

Local Authority Occupational Therapist - the Local Authority Occupational Therapist attended very few meetings and they played a minor role when discussing aids and adaptations for the Carer's home. In all cases they were addressing present needs with no example of post-school needs being discussed or arranged.

Special Careers Officer and Co-ordinator of Special Needs - for those YPWMD who belonged to Fife Region, it was usual for the Special Careers Officer and the Co-ordinator of Special Needs to attend 1st FNA meetings. They had

not met the Young Person before these meetings, so the meeting was an opportunity to meet the Young Person and the Carer and make an assessment as to whether they had a future role to play in securing locally available post-school provision. At 1 meeting the Special Careers Officer was used to mediate between the carer and the Local Authority Social Worker.

Post-school Placement Representatives - the meetings that were attended by Post-school Placement Representatives were found to be later meetings and they made a positive contribution. They were invited to talk about the placement or if the transition arrangements had been completed, they liaised with other professionals to ensure that the transition went as smoothly as possible. At 1 meeting staff from a day centre in Grampian travelled to the school because it had been decided that the Young Person would be moving onto this placement when she left school in 2 years time. This is the only example of such planning. At another meeting, the representative of a local day placement was invited to attend a 3rd meeting. All previous meetings had discussed this placement which was thought to be the most appropriate. However, on meeting the Young Person, the representative advised against the placement. This caused a great deal of disappointment for the Young Person who had accepted the placement and was looking forward to attending it.

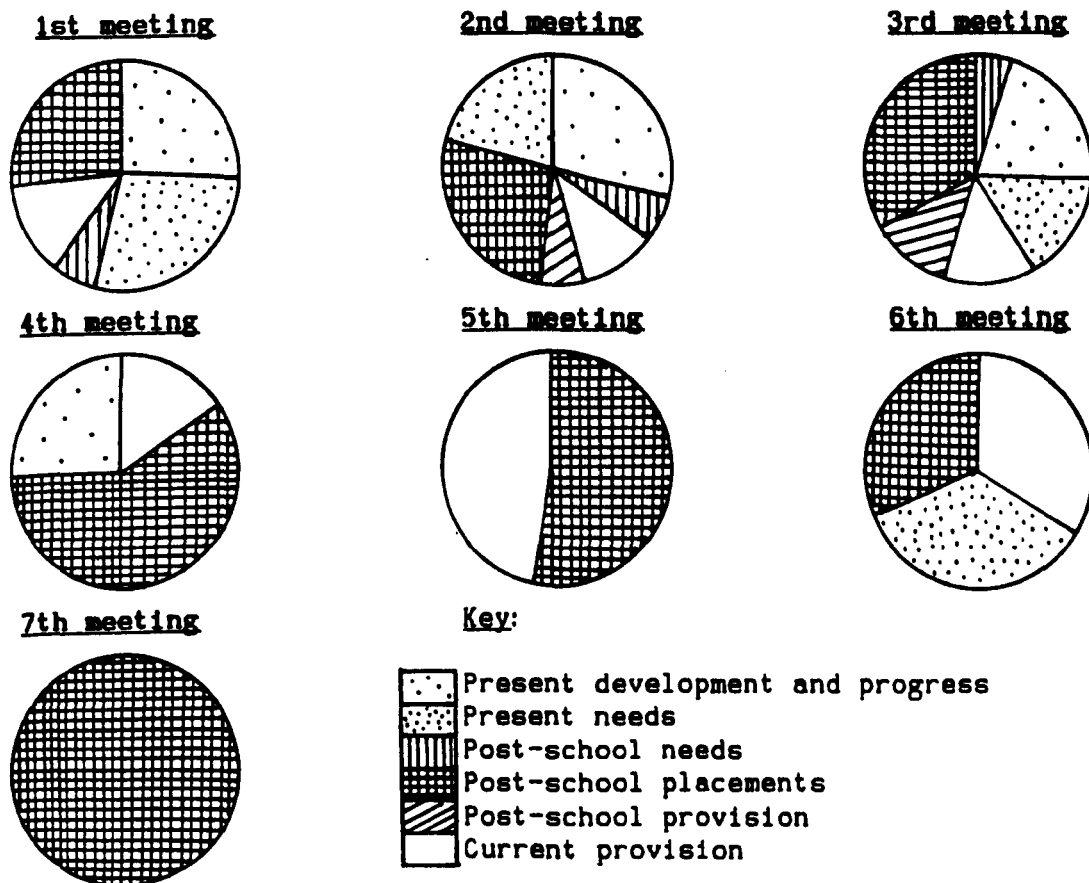
4.214 The Content of the Discussions

The content of the discussions of the FNA meetings covered 6 different areas: -

- 1 the present development and progress of the YPWMD
- 2 present needs of the YPWMD between 16-18 years
- 3 post-school needs
- 4 post-school placements
- 5 formal post-school service provision
- 6 current formal service provision

The following 6 pie-charts, each representing a different type of meeting, show what proportion of the discussion was on each of these 6 areas.

Figure 4.3 The discussion at different types of meetings



The pie-charts indicate the lack of discussion concerning post-school needs at all stages of the FNA procedure and a predominant emphasis on discussing post-school placements. Each of the 6 areas of discussion will be examined in turn: -

1 Present development and progress

The 1st topic to be discussed at the majority of FNA meetings was current work programmes. Problems and progress were discussed. School staff played a big part in these discussions with each member of staff making an input. Carers were asked to comment. Such discussion allowed other members of the meeting to find out strengths and weaknesses. Decisions on alterations to current programmes were often discussed

2 Present needs

Discussions under this heading focused on the needs of the YPWMD in the latter stages of schooling and were a continuation of the above discussions determining if present work programmes should continue and if they should be adapted. A very important point of these discussions was to decide whether the YPWMD was to leave school at 16 years or remain until 18 years. If it was decided to continue at school, the meeting would agree for an application to be made. On very few occasions did the consensus of meeting result in a non-recommendation.

3 Post-school needs

The results shows that very little discussion took place. It was usual for only 1 need to be discussed. Table 4.5 shows, for each type of meeting, the number of post-school needs discussed.

Table 4.5 The number of post-school needs discussed

Type of meeting	Number of different post-school needs					
	1	2	3	4	5	6
First	11	4	0	0	0	0
Second	7	2	2	2	1	1
Third	3	0	0	0	0	0
Fourth	3	0	0	0	0	0
Fifth	1	0	0	0	0	0
Sixth	1	0	0	0	0	0
Seventh	1	0	0	0	0	0

The table illustrates that at only the 1st meetings and particularly at the 2nd meetings was there discussion of more than 1 post-school need. For subsequent meetings, only 1 type of post-school need was discussed. The post-school needs discussed were seen in terms of formal service provision and they focused on: -

- 1 the type of placement or actual placement wanted
- 2 the therapeutic service provision required
- 3 other service provision

Table 4.6 shows the number of times each of these areas were discussed at the different types of meetings.

Table 4.6 The number of times each type of 'need' was discussed

Discussion on post-school 'needs'	Types of meeting						
	First	Second	Third	Fourth	Fifth	Sixth	Seventh
1. Placement settings							
Any Day	2	5	1	0	0	0	0
Any Residential	8	2	1	2	1	1	1
Any Day/Residential.	1	2	1	0	0	0	0
Actual Day/Residential	2	2	0	0	0	0	0
2. Therapy services							
Physiotherapy	1	3	1	0	0	0	0
Occupational therapy	0	2	0	0	0	0	0
Speech therapy	0	3	0	0	0	0	0
3. Other services							
Community facilities	0	1	0	0	0	0	0
Enabling support	2	3	1	0	0	0	0
Health services	1	2	1	0	0	0	0

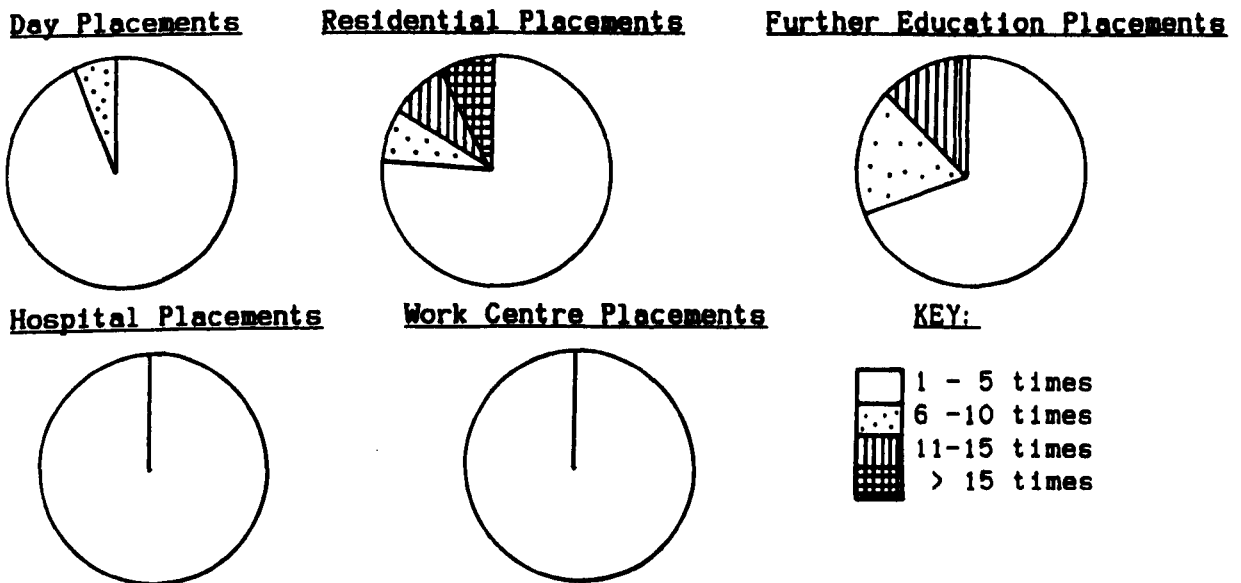
The table highlights the emphasis on placements at all types of meeting and as only 1 post-school need is likely to be discussed, the topic of discussion will be placement oriented. Carers were particularly vocal in stating what type of placement setting they wanted.

4 Post-school placements

Discussion on post-school placements was very prominent in FNA meetings, especially at 2nd and subsequent meetings. Participants saw a prime aim of the meeting to decide on 'the place' the YPWMD would take on as their principal placement. A total number of 61 operational post-school placements, located throughout Scotland, were discussed with 22 'day' placements, 25 'residential' placements, 5 hospital placements, 7 Colleges of Further Education and 2 Work Centre placements. It was possible from the data to find out how often each of these 61 placements were discussed at the meetings and find out which type of setting was most often discussed. The

pie-charts, in figure 4.4 represent each type of placement setting and the number of times placements within these settings were discussed.

Figure 4.4 The types of placements discussed at meetings



The pie-charts show that residential type placements were most frequently discussed at meetings followed by Colleges of Further Education. The individual residential placements which were mentioned on at least 5 or more separate meetings were placements R1 (18 times), R16 (5 times), R4 (10 times), R7 (14 times), R8 (8 times), R11 (35 times), R12 (12 times). The individual Colleges of Further Education that were mentioned on at least 5 meetings were F1 (14 times) and F4 (8 times).

When examining the discussion on placements, the following observations were made: -

- 1 the lack of knowledge by professionals about the placements being discussed and the suitability for the YPWMD. The Headteacher, the School Social Worker and the Carer were most informed. Discussions therefore tended to be very limited with only superficial details mentioned.
- 2 Local Authority Social Workers suggested possible placements on the basis that other young people with a similar disability

attend. This shows that no account was made for individual levels of functioning and dependency and a lack of knowledge about the YPWMD.

- 3 2nd and subsequent meetings held close to the final school leaving date discussed only 1 placement and gave no choice to the Carer to discuss others even though they had expressed concern and doubt.

Carers were persuaded that the placement would be adequate and if it was not accepted there may be no alternative.

The following example highlights the situation many carers found themselves in: -

The carer had a residential placement suggested at the 3rd meeting. This was visited and for many reasons it was considered inappropriate. Despite voicing concern, the same placement was discussed at the following meeting and the carer was persuaded to accept the placement by being told that if the placement was not accepted then there was a significantly high possibility that there would be nowhere available for the Young Person on leaving school. For a variety of reasons including concern about her personal health, the Carer was very anxious about coping with the Young Person should he have to return home on a full time basis. The Carer finally agreed to the Young Person being assessed.

- 4 discussion on placements stopped if Carers would only agree to 1 particular placement. Such a stand 'held up' the proceedings.
- 5 the final stage of discussions on placements when arrangements were to be made for visiting and assessment, very often took place shortly before the Young Person finally left school. This allows no time for adequate planning and preparation to take place and it causes stress and anxiety. Several YPWMD moved into their new post-school placement only a few days after knowing that it was to happen and 1 Young Person only heard about the new placement 2 days before he left school.

5 Post-school service provision

Only a small part of the discussions focused on post-school service provision. This took place in 2nd and subsequent meetings. The discussion centred on provision of aids and adaptations to the Carers' homes, provision of therapy services, transport provision between the Carers' homes and the principal placement, availability of community facilities and provision of home support.

Participants were particularly concerned about the importance of continuing physiotherapy and speech therapy. For many YPWMD these services were not offered in the post-school placements and not at the same level as at school. Great concern was voiced about the consequences of this lack of provision to the YPWMD, especially if significant progress was being achieved at school.

Community facilities were considered to be important to address YPWMD social needs, especially if they lived at home. Local Authority Representatives were asked to give information, or at least find out information, about the types of social and leisure facilities available to YPWMD in their home area.

Home support was of particular importance to Carers who wished for respite care arrangements. Many Carers were already receiving respite care and they wanted this to continue where the Young Person was to be living home for a significant period of time. Other home support included the need for a home help service which might include housekeeping support and assistance which offers personal support to the Young Person.

6 Current service provision

Discussion on current service provision took place at 1st and 2nd meetings. The types of service provision discussed were the same as for post-school services and the discussion was also very similar.

4.215 The Conclusions Reached at the Meetings

Every FNA meeting finished with a list of conclusions which included courses of action to be taken by certain members of the meeting. 8

particular conclusions were reached regularly at meetings. These were: -

- 1 Date for the next meeting (A)
- 2 Decision about continuing the Record of Needs (B)
- 3 Arrangements to make applications for extensions to schooling (C)
- 4 Details concerning placement arrangements -
visits, investigations, applications, assessments, funding (D)
- 5 Attention to current school work programmes (E)
- 6 Present/Post-school service provision arrangements (F)
- 7 Decision to involve outside agencies and making arrangements (G)
- 8 Courses of action to be taken concerning medical needs (H).

Table 4.7 shows the frequency with which these different conclusions were reached at different types of meetings. The types of conclusions are shown by a capital letter corresponding to the list above.

Table 4.7 The number of times the different conclusions were reached

Type of meeting	Type of conclusion reached							
	A	B	C	D	E	F	G	H
First	15	4	18	29	1	10	3	1
Second	14	0	16	32	0	8	2	2
Third	9	0	5	28	0	3	1	1
Fourth	6	0	2	13	0	7	2	1
Fifth	1	0	0	1	0	1	0	0
Sixth	1	0	0	1	0	1	0	0
Seventh	0	0	0	1	0	1	0	0

The table shows that the type of conclusion most frequently reached is concerned with post-school placement arrangements at all types of meetings.

These figures support the trend already observed that FNA meetings are primarily placement oriented with discussion on placements dominant. Conclusions concerning applications for extensions and conclusions about fixing the date of the following meeting were also frequently reached but more so at 1st and 2nd meetings because of the stage the YPWMD had reached in the school leaving process. No conclusions were reached that incorporated the safeguard that a further meeting would be arranged should the extension not be granted.

The number of times conclusions were stated concerning continuing the Record of Needs is low. Although a decision is legally required, the data suggests that this issue is not seen to be important by participants of the meetings and to be stated in the conclusions.

Conclusions concerning school work programmes are also infrequently reached even though this topic, particularly at 1st and 2nd meetings, is frequently discussed.

In addition to the 8 principal categories of conclusions listed, there was a small group of conclusions that appeared at times at different types of meetings and which were concerned about the lack of adequate Local Authority Social Worker representation. For example: -

- 1 On 3 separate occasions it was stated in the conclusions that a Social Worker had to attend the following meeting
- 2 1 meeting concluded with the statement that it was of vital importance to the future of the Young Person for a Field Social Worker to be allocated
- 3 A conclusion was noted from a 4th meeting that stated it was imperative for the Social Worker to arrange to meet both the Young Person and Carer for the 1st time
- 4 The conclusions of 1 meeting stated that it was necessary for both the Social Worker and the Carers to inspect their relationship as the

present situation was 'detrimental to securing a placement.

7 participants were regularly assigned to act upon the conclusions reached and to have completed these duties before a subsequent meeting. They were: -

- 1 the Headteacher
- 2 the School Social Worker
- 3 the Local Authority Social Worker
- 4 the Local Authority Educational Psychologist
- 5 the Community Doctor
- 6 the Young Person
- 7 the Carer.

Looking at all the conclusions with an action put on them for all 76 meetings, it was found that the Headteacher and School Social Worker together ~~were~~ asked to carry out 31% of the conclusions, the Local Authority Social Worker 32%, the Local Authority Educational Psychologist 21 %, the Community Doctor 3% and the Young Person and Carer together 13%. These figures do not show if the duties were accomplished. The Community Doctor is not involved in taking actions as much as the others as the attendance at meetings is relatively low. The percentage figure for the Local Authority Educational Psychologist is lower than for the School staff and the Local Authority Social Worker because 1 of their main duties is to make an application for an extension and the demand for this decreases towards the end of the school leaving process when 3rd and subsequent meetings are held.

The person most often required to carry out a particular role after the meetings is the Local Authority Social Worker. This is because they have the duty to make arrangements concerning the post-school placement package. The Headteacher was given the duty to arrange meetings and the School Social Worker was given tasks related to securing post-school

placements and therefore they both have a significant role to play in meeting the conclusions. Due to the problems associated with the representation of the Local Authority Social Work Department at meetings, the burden of carrying out actions frequently fell on the shoulders of the School Social Worker instead of the Local Authority Social Worker. The YPWMD and Carers did not play a significant role in carrying out tasks and their role was confined to visiting post-school placements although many Carers took it upon themselves to find out about possible placements through frustration at the lack of progress.

4.22 The Results from the Observation of Consecutive Meetings of Individual Young People

3 Young People were chosen to develop 3 vignettes which illustrate the dynamics of the meetings and in particular follow the Young Person through a series of meetings to give an insight into the longitudinal dimension of the FNA process (Appendix 4.2). The 3 Young People were chosen because they represent 3 different levels of functioning and because they experienced several meetings during the fieldwork period, all of which were observed by the researcher. The age of the Young Person was a critical factor in selecting the case studies. If the Young Person was in the later stages of the school leaving process they could not be considered for inclusion because they were a subject of a limited number of meetings during the fieldwork period. Likewise, for the YPWMD embarking upon the process they had only experienced 1 or possibly 2 meetings in the fieldwork period. It was not possible to include a Young Person functioning at a low level or at a high level as no more than 1 meeting was observed for the YPWMD functioning at these levels and as the aim of this part of the results is to follow a series of meetings, this being at least 2 meetings, then only the other 3 levels could be included.

4.3 Results from the Interviews with Carers

48 Carers were interviewed over 2 phases of fieldwork. The presentation of findings follows the 5 headings of the interview schedule (Appendix 3.3):-

- 1 the FNA meetings
- 2 the post-school needs of the YPWMD
- 3 post-school placements
- 4 current formal service provision
- 5 Social background variables on the YPWMD.

Throughout this presentation, the term Carer will be used to refer to the 1 principal Carer and where there are 2 main Carers responsible for the Young Person.

4.31 The Respondents

1 Interview coverage achieved

The interview response rate is shown in table 4.8 with a total of 48 Carers were interviewed in the 2 phases.

Table 4.8 Interview coverage achieved

Interview reponse	Numbers responding	
	Phase 1	Phase 2
Possible number of Carers invited for interview	61	16
Carers living too great a distance to be invited	8	0
Carers who refused to be interviewed	3	1
Carers not invited on the advice of the schools	3	0
Carers who could not be contacted	7	7
Total number of Carers interviewed	40	8

A certain number of Carers were excluded. It was deliberately planned to exclude those who lived a considerable distance from the research base in

Edinburgh because of funding constraints. A small number of Carers were deliberately excluded on advice given by school staff. 2 other reasons for Carers not taking part were anticipated but not deliberately planned. Some Carers refused to take part and communicated such replies straight back to the researcher. Other Carers after being approached by letter and followed up by telephone calls could not be contacted and after several attempts it had to be concluded that their views could not be represented.

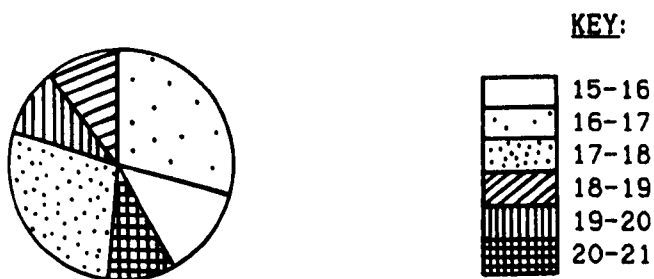
2 Relation of the Carer to the Young Person

In phase 1, 26 mothers were interviewed, only 1 father, 12 sets of parents together and 1 grandmother. In phase 2, 6 mothers were interviewed and 2 sets of parents.

3 The age of the YPWMD at the time of interview

Carers' perceptions and opinions could change throughout the school leaving process so the age of the YPWMD was recorded when the Carers were interviewed. Figure 4.5 presents the proportions of the YPWMD aged between 15 - 21 when the 48 Carers were interviewed.

Figure 4.5 The ages of the YPWMD at the time of interview



4.32 Carers' Perceptions of the FNA Meetings

The interviews collected information on Carer opinion of FNA meetings with reference to:-

- 1 the organisation of the meetings
- 2 the content and discussion of the meetings
- 3 the outcomes and conclusions reached at the meetings
- 4 Carer reaction to the FNA meetings.

Carers' opinions can change throughout the FNA process as they attend more meetings. Of the 48 Carers interviewed, 56% (27) had attended 1 meeting, 13% (6) had attended 2 meetings and 17% (8) had attended more than 2 meetings. 8% (4) Carers had only attended the 1st meeting and 6% (3) had not attended any meetings.

Of the 27 Carers who attended 1 meeting, 16 were mothers on their own, 1 was a father on his own, 8 were sets of parents, 1 was a grandmother on her own and 1 mother attended with her sister. Of the 6 Carers who attended 2 meetings, 3 were mothers, 1 a father, and 2 were sets of parents. Of those Carers who attended more than 2 meetings, 4 were mothers, 1 a father and 3 were sets of parents.

The following results reflect the experiences and opinions of the Carers concerning the last meeting they attended.

4.321 The Organisation of the Meetings

In describing the organisation, the Carers commented on the following:-

- 1 Invitation to the meeting
- 2 The venue
- 3 The people present at the meeting
- 4 The procedure.

1 Invitation to the meetings

All the Carers received a letter from the Headteacher inviting them to attend the FNA meeting with the date and time stated. Those Carers who were not present at some or all of the meetings did not say that they had requested an alternative date and/or time. Either they did not wish to attend or they felt that the date/time although inconvenient could not be changed for their convenience. Some did say that they felt the previous meeting(s) to be a waste of time and that they therefore did not wish to experience another. 6 Carers recalled being invited to meet the

Headteacher before the meeting took place in order to discuss personally what the meeting was about and what was involved.

2 The venue

For the majority of Carers, the venue for the FNA meetings was the Headteacher's office. 9 Carers had meetings held in another venue within the school building. These 9 Carers described the venue as the dormitory, the Assistant Headteacher's office and the physiotherapy room. The reason they gave for these locations was because of the large number of people present. 4 Carers attended meetings outwith the school. 3 of these meetings were held in Child Guidance Clinics in the home region of the Young Person. The other Carer described the location of the meeting as being the District Social Work Department offices.

3 People present and their roles in the meetings

Approximately ½ of the Carers interviewed (20) considered the meetings to be too large in terms of the total number of people present. They stated that this led to feelings of anxiety and increased nervousness, especially when it came to feeling able to discuss issues. It also raised doubts about whether so many people knew their child. The following quotes are representative of the feelings of many of the carers about the size of the meetings: -

1 (Mother attending 1st FNA)

"I feel because there were so many, I found it difficult to remember what to ask and who to ask."

2 (Mother and Father attending 1st FNA)

"We felt there were perhaps too many people there but at least we knew some of them from school."

3 (Mother and Father attending 1st FNA)

"Such an arrangement with big meetings is very daunting for parents not used to meetings."

4 (Mother attending 1st FNA)

"I feel 18 is just too many."

5 (Mother attending 1st FNA)

"I remember alot of people there and (at) times I felt there were too many ... it inhibits what you can say...don't know how to express myself."

The following quotes show the doubts raised by Carers over how well the members of the meeting were acquainted with the Young Person: -

1 (Widowed mother attending 1st FNA)

"I felt alot of people there didn't know D."

2 (Mother attending 1st FNA)

"I felt everyone there didn't know K except for two."

3 (Mother attending 1st FNA)

"I felt sorry for those who were at the meeting but didn't know J...they couldn't have got a correct assessment of him."

4 (Mother attending 1st FNA)

"I would have preferred the meeting to be more informal and with people who knew J rather than strangers reading off case notes."

Carers found it difficult to accurately recall everyone who attended the meetings and they were not aware of who should be present. They found the terminology used to describe the professions confusing, particularly between 'Psychologist' and 'Psychiatrist'. There was a lack of understanding of the roles of the different professionals. Carers find it easier to recall the School Staff present as they knew these people and they are familiar with their personal names and professional titles. Professionals invited to attend from outwith the school were less familiar to the Carers and if it was the 1st FNA meeting then it was unlikely that

the Carer would have met them before. These points are illustrated in the following quotes: -

1 (Mother attending 1st FNA)

"I think there two or three were missing from P's meeting...I don't think there was anyone there from Social Work or an Educational Psychologist."

2 (Mother attending 1st FNA)

"I was confused about the different people present...who was who."

3 (Mother attending 1st FNA)

"I don't think anybody from Social (Work) was at the meeting but I'm not sure because (they) didn't make any contribution and (there) is so many other people."

Although Carers relate how they were formally introduced to everyone present, they described this introduction taking place at the beginning of the meeting when they felt 'keyed up', especially if it was the 1st meeting. They said it was difficult to remember names and job titles. Only 18 of the Carers interviewed felt they could accurately recall the people present.

Carers were very vague about the roles the different professions should perform at the meetings if they were not School Staff, who they felt made a valid contribution to the discussions because they knew the YPWMD.

Regarding the Local Authority Social Worker and Educational Psychologist, Carers felt they played a passive role. Carers were critical of the Local Authority Social Worker who they felt did not know them or the Young Person. The following quotes indicate the tone of the responses received from Carers about the roles of the 'outside' school professionals: -

1 (Mother attending 1st FNA)

"The fellow (L. A. Social Worker) was like a fly on the wall."

2 (Mother and Father attending 1st FNA)

"We had never seen the Social Worker before."

3 (Mother attending 1st FNA)

"The first time I had one (L. A. Social Worker) was at the meeting and he wasn't prepared.... (he) had no notes."

4 (Grandmother attending 1st FNA)

"He (L. A. Social Worker) doesn't know Y that well."

5 (Mother attending 1st FNA)

"I met the Social Worker for the first time at the Future Needs."

6 (Mother attending 1st FNA)

"Date for meeting already cancelled because he (L. A. Social Worker) wasn't there, yet he still didn't turn up."

7 (Mother attending 1st FNA)

"The Future Needs meeting was the first time I had contact with a Social Worker."

"Social Worker had little to say at the Future Needs...he didn't know H, the case or places available. He told me that he didn't know why he was there..didn't know anything about it and only given a few hours notice of the meeting."

8 (Mother attended several FNA)

"I've had many meetings and the Social Worker has not attended one meeting apart from the last after I myself asked for one."

9 (Mother attended 2 FNA)

"Social Worker said little as he hadn't seen R for a while."

10 (Mother attending 1st FNA)

Referring to the Local Authority Occupational therapist -

"She didn't know anything."

11 (Mother attended 2 FNA)

"I feel incensed by the Educational Psychologist...she just sat there (the meeting) and when she did the assessment at home before the meeting the test was based on verbal response to pictures...she only spent half an hour...I feel she can't have made a judgement especially for recommendations for extensions."

Carers felt that they themselves played a minor role in the meetings. 47% felt they had not been involved in discussions, 42% felt they had been and 11% were undecided. Carers described themselves as feeling 'insignificant and superfluous'. 1 mother commented:-

"At first I found the meeting too overpowering...being the mother of a mentally handicapped child and at home so much you lack the ability to discuss things."

They felt unable to make a contribution because they were uninformed about post-school placements:-

(Mother at 2nd FNA)

"How can I say something about the place when it could be in Timbucktoo for all I know."

Carers felt they could make a greater contribution when the meeting was discussing the present needs of the Young Person.

In only 7 of the meetings was the Young Person invited to attend and then it was only at the end of the meeting.

4 The procedure

Carers described the meetings, whatever the type and venue, as following a similar pattern. Carers were invited into the Headteacher's office or the alternative room and briefly introduced to all present. The meeting started with the chair, usually the Headteacher bringing the meeting to order. No Carers commented on an agenda being stated and they felt attempts were made to keep the situation as informal as possible.

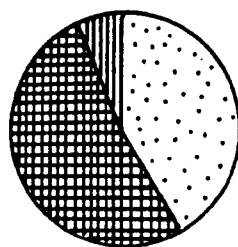
4.322 The Content and Discussion of the Meetings

The discussion focused on 3 main areas:-




- 1 the present progress and present needs of the YPWMD
- 2 the post-school needs of the YPWMD
- 3 the post-school placement

Figure 4.6 shows what proportion of the discussions was given to each topic.

Figure 4.6 The discussion at meetings



KEY:

	Present needs
	Post-school needs
	Placements

The pie-chart shows that the discussions are dominated by 'present needs' and 'post-school placements'.

The focus of the discussions was found to change with the type of meeting.

This is shown in table 4.9

Table 4.9 Discussion and the type of meeting

Type of discussion	Type of meeting		
	First	Second	Subsequent
Present needs	20	3	1
Post-school needs	1	0	1
Post-school placements	6	3	6

The table shows that in 1st FNA meetings, the discussion focuses on the present needs of the YPWMD whereas in later meetings, post-school placements dominate. The issue of post-school needs is not seen by Carers to ever feature as the main subject in discussions. The following quotes illustrate Carers' perception of the meetings' discussions:-

1 (Mother and Father attending 1st FNA)

"The meeting narrowed down quickly to L's immediate needs for next two years, but not future, after she's 18."

2 (Mother and Father at 1st FNA)

"We felt there was not enough time spent on future needs...too much emphasis on the present."

3 (Mother and Father at 1st FNA)

"A lot of the meeting was about present progress and what was going to happen next term at school."

4 (Mother at 1st FNA)

"Discussion at it (the meeting) really about now."

4.323 The Outcomes and Decisions reached at Meetings

1 Decisions reached at 1st meetings

27 of the Carers interviewed had attended only 1 FNA meeting and 25

described that the decision reached at the end of the meeting was to make

an application to the Local Education Authority for an extension for

another year's full-time education at school. All the Carers were

satisfied with this decision. For the other 2 Carers, both were told that

an application would not be made and that a hospital placement was available. This was rejected by both Carers who demanded another meeting so alternative placements could be suggested.

Although a decision is reached by the meeting to make an application for an extension, the Carers leave the meeting unsure of whether the application will be accepted by the Education Authorities. They are not sent confirmation or otherwise of the Authority's decision until several months later. This is a matter of worry and concern for the Carers.

1 (Mother attending 1st FNA)

"I get so worried that her education will stop if we don't get an extension."

2 (Mother and Father attending 1st FNA)

"The application is in as far as we know...she (Scottish Council Social Worker) is seeing to it for us."

3 (Grandmother attending 1st FNA)

"I'll be delighted for her to stay on...she has been so happy since going there (School)."

2 Decisions reached at 2nd meetings

6 of the Carers interviewed had attended their 2nd FNA meeting. Of these 6, all described the outcome of the meetings to be twofold. Firstly, a 2nd extension was applied for to the Local Education Authority for schooling to 18 years. This decision pleased the Carers but several voiced their disapproval that yet a 2nd application had to be made and that 1 extension should be given for 2 years instead of having to make 2 separate applications and the uncertainty and worry was repeated.

1 (Mother and Father attended 2nd FNA)

"We are worried about the present position when G would leave in December with no provision unless she gets an extension."

2 (Mother attended 2nd FNA)

"It is discrimination...a normal child doesn't have to go through this to stay on at school."

3 (Mother attended 2nd FNA)

"I've already gone through this once, why do I need to worry all over again."

Secondly, Carers were asked to consider various placements. Some of these placements may have been very briefly mentioned at the 1st meetings so that the Carers may be aware of the names. In some cases, Carers had visited these placements. They were asked to express their views and discuss secondary visits or alternatively dismiss the placement as being inappropriate. Arrangements were made at these meetings for assessments to

be carried out of the YPWMD in a possible post-school placement and for the YPWMD to see what they thought of the place.

All 6 Carers expressed dissatisfaction with this part of the meeting's conclusions. They described feeling inadequate in making any decisions about placements as they lacked detailed information about them and they felt pressurised into accepting places they already felt to be inappropriate. Carers commented on feeling disillusioned and that "they seemed to be getting nowhere". They stated that arrangements for visits were suggested but not actually made, only the promise of a Social Worker "getting in touch" was made at the meeting. In some cases, Carers recalled that members of the meeting promised to look into a possible placement to determine its suitability and some agreed to try to find a placement.

1 (Mother and Father attending 2nd FNA)

"We are sure the place won't be suitable but we have been been told so little...we'll visit it anyway."

2 (Mother attended 2nd FNA)

"She (L. A. Social Worker) is suppose to be getting back to me..I'm still waiting."

3 (Mother and father attended 2nd FNA)

"If its like after the first (FNA) we'll end up looking ourselves...we need to know where to start."

4 (Mother attended 2nd FNA)

"Its always B (Name of a residential establishment) that comes up..yet when I voice doubts I'm told there is nowhere else."

3 Decisions reached at 3rd and subsequent meetings

The conclusions reached centred around making decisions about different placements in addition to making visits to places already previously mentioned. Many Carers expressed dissatisfaction with the conclusions reached at these meetings. They were angry about the shortage of suitable placements for their child and worried about the lack of certainty over the future which causes distress and anxiety. To quote 1 parent - "there are too many ifs, buts and may bes". Carers see time rapidly running out yet nothing is being achieved. They believed that firm offers of places and definite decisions should be presented to them.

1 (Mother attended several FNA)

"I just now feel there is nowhere in Scotland."

2 (Mother attended several FNA)

"Time left at school is so short I wish he could be there longer...where else is there?"

3 (Mother attended several FNA)

"I'll be so much happier when we hear that she is in."

4 (Mother and father attended several FNA)

"We thought by now they would have got their act together."
(Referring to members of the meeting)

Carers generally felt, whatever the type of meeting, that nothing definite was concluded and they found this difficult to accept.

1 (Mother attending 1st FNA)

"(The) meeting passed O.K. but (it) never came up with anything constructive."

2 (Mother attending 2nd FNA)

"Should be able to attend a meeting and be told something definite so can plan ahead instead of left hanging."

3 (Mother attending 1st FNA)

"I would describe the meeting as superficial and I hope the next one will be more nitty gritty."

4 (Mother attended several FNA)

"I feel meetings are too indecisive...nothing ever decided...everything just left till next one, especially when decisions about finance..who pays what."

4.324 Carer Reaction to FNA Meetings

Carers reaction to the meetings are categorised as positive, negative and indifferent but generally dissatisfied.

Carers who felt positive made comments such as:-

" Meetings were informative."

"I felt at ease,I could say what I wanted."

"I got what I wanted."

Carers who felt negative about the meetings, stated:-

"I felt angry because the others (school staff and professionals) were making all the decisions."

"I felt too ignorant."

"I felt overwhelmed."

"It was a waste of time....uninformative."

"I did not get what I wanted."

"Too many were present who did not know S."

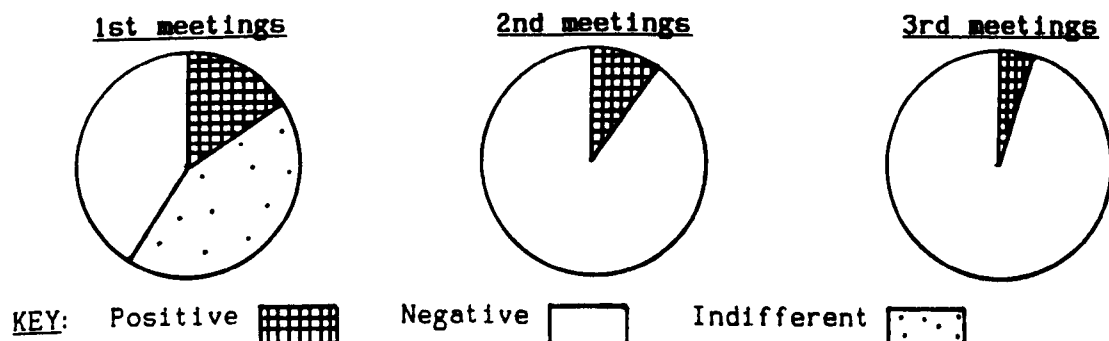
Some Carers were unable to feel positive or negative about the meetings and they made comments such as:-

" The meeting was O.K., just like other meetings held at school." (referring to non FNA meetings)

" No definite suggestions were made so everything (is) as before."

Figure 4.7 illustrates the proportion of Carers in each category and if it was their 1st, 2nd or subsequent meeting.

Figure 4.7 Carer reaction to meetings



Carers who attended more than 1 meeting explained that the procedure changed very little with subsequent meetings but their level of satisfaction decreased and they became increasingly negative in their reaction to the meetings. 1 Carer summed up this attitude:-

" as trying to fight your way out of a wet paper bag."

Carers relied on the FNA meetings to solve their problems and erase their worries but after several meetings they did not see themselves any further forward.

4.33 Carer Perspective of the Post-School Needs of YPwMD

Carers identified 17 post-school needs. Table 4.10 lists these needs and the number of times the needs were identified by the Carers. The needs are listed in order of frequency with the most frequently identified need at the top.

Table 4.10 Post-school needs of YPwMD as identified by the Carers

Post-school Needs	Number of times stated by Carers
1 Stimulation and motivation	38
2 Academic development	33
3 Physiotherapy	30
4 Recreation and leisure opportunities	29
5 Social activity	28
6 Develop independency	28
7 Develop maturity	22
8 High staffing ratio in principal placement	22
9 Speech therapy	17
10 Full-time care + supervision	15
11 Community involvement	15
12 Respite care	13
13 Medically trained staff in placement	9
14 Minimal care + supervision	8
15 Occupational therapy	7
16 Vocational training	6
17 Part-time care + supervision	2

The following quotes provide an insight into Carers' perceptions of post-school needs:-

Need for stimulation -

1 (Mother - several FNA)

"Important she gets stimulated... she gets bored, frustrated... gets tantrums and lazy."

2 (Mother and father - 2nd FNA)

"S can't be at home as she needs so much stimulation.. she will regress otherwise."

The need for continued education -

1 (Mother - 2nd FNA)

"I feel I would regress if education was to stop... I feel he still has potential .. can see regression over holiday period.. (he) starts to revert to being a baby."

2 (Mother - 2nd FNA)

"I really feel money is wasted in education a child then leaving a child to regress when an adult."

3 (Mother - 2nd FNA)

I feel R has alot of potential and needs more than just being occupied... education needs to continue as its taken him so long to get where is now and still has potential to develop."

4 (Mother - several FNA)

"S achieved far more than ever thought..it (education) can't stop now."

The need for paramedical services

1 (Mother - 1st FNA)

"Need for speech therapy to continue because (I) feel the clearer R is the more able he will be to mix socially."

2 (Mother and father - 2nd FNA)

"K has to have it (physio) ..if he doesn't he'll stiffen up."

3 (Mother - 1st FNA)

"If these needs including therapies are not met, (there will have been) much wasted work over past years."

Need for social contact -

1 (Mother and father 1st FNA)

"We really believe K would go backward rather than forward if he hadn't anything to do or people to meet."

2 (Mother and father - 1st FNA)

"J already has so many friends it would be wrong for her not to be able to carry on seeing them."

Need for independency -

1 (Mother - 2nd FNA)

"Prehaps never have complete independence but in their minds can be independent."

The need to mature -

1 (Mother - 1st FNA)

"R has always been behind others of same age...still needs more time to grow up."

2 (Mother - 1st FNA)

"M still needs time to mature...too young to go to an adult placement."

4.34 Carer Opinion on Post-School Placements

Carers gave their opinions on post-school placements that existed and on the provision they wanted to see available.

4.341 Carer opinion of existing placements

Carers commented on existing placements which were discussed at FNA meetings and which were visited. They described how they were reluctant in considering post-school placements and that they waited until the meetings took place. They then relied on the School Social Worker and/or the Local Authority Social Worker to arrange visits but they were critical about the lack of suggestions made and the advice given by the professionals who they felt should have been better informed. Carers themselves felt ignorant about what placements were available and whether they would be appropriate.

"I feel helpless with no information...it seems nobody is interested or cares if can't do anything...I don't know where to start looking...I want places advertised."

(Mother at 1st FNA)

"I feel ignorant....can't voice an opinion."

(Mother at 2nd FNA)

Carers preferred to push the 'future' to the back of their minds despite accepting that the time remaining at school passed quickly and that arrangements for post-school placements took time and had to be planned well in advance. The following quotes sum up the feelings of many Carers when they considered the future for the Young Person:-

"The time isn't appropriate yet, I'll wait another year."

"I've made no effort, I'm pinning my hopes on N-----
(name of placement)."

"Once I'd heard she had an extension, I'm not thinking further into the future."

"I prefer to live from day to day...I'll wait until the next meeting when places are discussed."

"I couldn't cope if I thought about the future."

"I don't want to think about the future...if I think about it I get depressed...worried about the idea of K being a mentally handicapped old person and institutionalised."

"I take each day as it comes...feel I can't dwell on it...push it to the back of my mind."

"I have reservations about planning too far into the future as in two years time circumstances can change."

Before Carers considered a placement they had already decided what type of placement they wanted and very few were prepared to be flexible. Out of the 48 Carers, 23 wanted a residential type placement, 22 a day placement and only 3 were undecided.

The reasons Carers gave for wanting a residential placement included:-

- 1 "Most appropriate place is too far away from home."
- 2 "I cannot cope at home."
- 3 "She is in a routine now being at a residential school."
- 4 "for personal and family circumstances."
- 5 "I am concerned about the future and when I'm not here."
- 6 "Being residential is necessary to meet his needs."

The reasons Carers gave for wanting a day placement included:-

- 1 "I want her to live at home."
- 2 "G wants to live at home."
- 3 "A has always been to a day school."
- 4 "I feel its my job and responsibility to look after him."
- 5 "I want M to come home after being away at school."

The reasons Carers gave for being undecided included:-

- 1 "It depends what the most appropriate place is."
- 2 "I've not yet sorted it out in my own mind."

In addition to being sure about wanting a residential or day placement, 43 Carers had decided what type of placement they wanted. 7 Carers wanted a College of Further Education, 14 wanted a residential centre, 18 wanted a day centre, 1 wanted a work centre, 1 wanted a place in a 'Special Unit' of

a work centre and 2 wanted a sheltered placement. (This terminology was used by the Carers).

When Carers visited placements they found it difficult to make an adequate assessment and decide if the placement was appropriate. Carers complained of being unable to think of and remember questions to ask, especially when in the middle of a 'walk about'. However Carers were still able to get an impression about a placement and come to a conclusion about whether they would want to seriously consider it for the Young Person. The staff and the features of the placement were what Carers noticed and remembered and they used these as pointers to decide if they liked or disliked the placement.

"I didn't like B-----, I felt it wasn't clean and it was smelly."

"Everyone there just seem to be sitting."

"All the staff seemed very pleasant especially the one in charge."

"Quite a few of D's friends are there...it will seem like home from home."

"I didn't like the drab colourings."

"I find it difficult to like places as I've been spoiled with school...I compare everywhere with it."

"Possibly places O.K. when visit but its different if been a few times and know someone there."

Carers were asked to give reasons why they were positive about a placement, negative or indifferent. Below are comments from Carers that can be categorised under these 3 headings:-

Reasons for being positive

- 1 "Good staff ratio"
- 2 "Stimulating activities... plenty to do"
- 3 "Physio, speech (therapy) and O. T. (Occupational therapy) available"
- 4 "Convenient location"
- 5 "R (young person) said he liked it"
- 6 "Fosters independency and maturity"

- 7 "Good social contact and community involvement."
- 8 "K knows other people there."

Reason for being negative

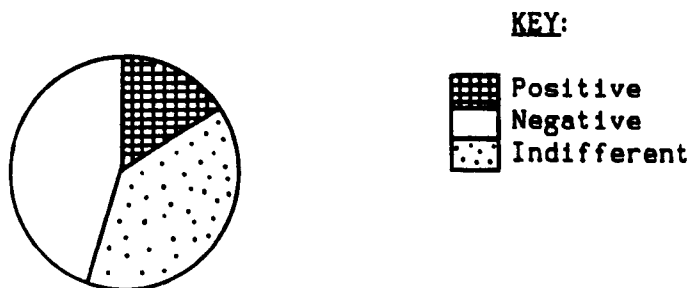
- 1 "No therapies offered."
- 2 "No appropriate stimulation activities... just sit in front of the T.V. all day."
- 3 "Too far away, especially as now I'm redundant."
- 4 "I'm not happy about the other clients there."
- 5 "Understaffed."
- 6 "A didn't like it."
- 7 "I didn't like the building... a smell about it."
- 8 "Poor standard of care."
- 9 "I'm unhappy about the risk of sex."
- 10 "Future seems uncertain... its being run down."
- 11 "It seems too institutionalised, like a hospital."

Reasons for being indifferent

- 1 "There's nowhere else, so I have no other choice."
- 2 "I don't know of anywhere else."
- 3 "At least he will get out of the house."

Figure 4.8 shows the proportion of Carers who were positive, negative and indifferent about the placements they visited.

Figure 4.8 Carer opinion of post-school placements



Carers described how although they felt unhappy about a placement they knew that they may have to accept it because of the shortage of placements for YPWMD.

"I feel I've tried hard to find places but there are just none."

"Because there are not that many places or places to go."

"Nothing locally suitable for G as all for mentally handicapped and more profoundly handicapped."

"He (L. A. Educational Psychologist) also agreed that at the moment there is nowhere she can go to when she leaves school that would be suitable... If she were leaving school next

year, it would be simply the case to get her a place out of the house all day...it wouldn't be a place of any great benefit to her."

Because of the shortage of placements, Carers have said that they feel pressurised into accepting a placement which they do not want either because they are unhappy with it or they see it as suitable but they want the Young Person to stay on at school for longer. Carers describe themselves as being in a 'catch 22' situation. They are told that a place is available but they are not happy about it, however if they do not accept, they will lose the opportunity. If the Carer wants the Young Person to remain at school for as long as possible, and a place is offered before the final school leaving date, they are pressurised into accepting it although they would rather the Young Person remain at school because they are told the placement will not then be available.

"We felt channelled into one place."

"At every meeting I was given the same place and made to feel it was my fault for not wanting it so I had to do the looking."

"We discussed whether G stay on at school or go there (a possible placement)...it was a 'catch 22' situation."

"Its as good as we are going to get...I suppose we have been lucky..there must be a lot of people tearing their hair out."

4.342 Carer Opinion on 'Ideal Post-School Provision

Carers were very satisfied with the quality of life experienced by the YPWMD at school. Consequently, they were expecting the same from post-school provision. Carers were very aware of the disparity between what they wanted to see provided and what they believed to be available:-

"What is required and what is here are two completely different things."

(Mother attended several FNA)

When asked what their ideal placement would be, the majority of Carers who expressed an opinion described an placement similar to the school the Young Person was attending.

"Ideally there should be somewhere like (School A)...

I want the same arrangements as at moment."

(Mother attended 1st FNA)

Carers also wanted 2 additional factors to be included:-

1 a more adult environment to develop greater maturity and independence.

"I want something like school..when children aren't really adult even though aged between 16 and 25."

(Mother attended 1st FNA)

Carers accepted that it was difficult to foster maturity and independency in a school atmosphere particularly if the YPWMD were residential pupils. They felt that pupils were too cosset ed - a criticism not just of the School Staff as Carers admitted that they were guilty of doing too much for their child and not allowing them to take risks and behave as adolescents.

2 a smaller sized placement both in terms of the numbers of people and the physical space. Carers wanted small 'homely' like units, assimilating ordinary, daily living rather than having the appearance of an institutional establishment. It was commented by Carers that although efforts are made in larger places to remove the 'institutional' label it is difficult to throw it away altogether.

"I want it (post-school placement) to be small and homely...not too big."

(Mother attended 1st FNA)

Some Carers described their 'ideal' post-school placement as being a transitional placement - a place where YPWMD could become more mature and independent as well as fulfilling more of their educational potential. Carers felt that then YPWMD would be ready to consider an adult placement.

"What I'd like to see is an inbetween place..to give time to grow up."

(Mother attended 2nd FNA)

4.35 Current Formal Service Provision

Carers commented on the formal service provision they were currently receiving. Many were concerned about the change from 'child' to 'adult' service provision.

"Facilities are sadly lacking when (young people) adults, not so bad when children."

(Mother attended 1st FNA)

"Everything changes after 16...I don't where it all goes."
 (Mother referring to service provision)

Table 4.11 lists the services Carers were receiving and the number of Carers who felt satisfied or dissatisfied with the provision and delivery.

Table 4.11 Carer satisfaction with service provision

Service Provision	Number of Carers receiving services	Number satisfied	Number dissatisfied
1 Financial benefits	48	0	48
2 Aids and adaptations	27	10	17
3 Personal aids	48	21	27
4 Respite care	11	9	2
5 Social activities	3	1	2
6 Support/advice	19	4	15
7 Medical services	48	11	37

The table shows that the Carers were critical of service provision.

"I feel (that) whatever needs have, have to fight for it and scream for it."

"I feel nobody is offering help, or comes to the door to help...just left to cope on own."

The dissatisfaction felt by the Carers arose from the following problems and difficulties with the provision and delivery:-

- 1 carers were critical of late payment of benefits and errors made by the DHSS and the complexity of the forms to be completed.

One mother comments on the DHSS:-

"I'm currently having problems with the DHSS for L's benefits because she is 16 ...I always feel I'm hitting obstacles whenever (I) turnfeel they are not interested...feel I've got enough to do without extra problems."

- 2 the provision of inadequate and unsuitable aids and adaptations.
- 3 the amount of time taken for any alterations to be made:-

"I got the downstairs adapted using the Authority O.T. but only after long waits and much pushing. Eventually the Doctor got things moving...taken four years for toilet adapted."

"I am satisfied with the O.T. but I did have to wait a long time and (I) had to keep asking and shouting...if you make a fuss you get it eventually."

- 4 the time and effort required on the part of the Carer to get any personal aids needed by the Young Person eg. a computer, incontinence pads. Carers resented having to pressurise the Authorities and being made to feel grateful for what was provided.
- 5 criticism was expressed about the types of aids provided, their quality and the way they reinforced the disabilities eg. orthopaedic boots.
- 6 the lack of formal respite care provision
- 7 the poor management of respite care provision
- 8 the lack of appropriate social activities and the inaccessibility of the limited provision available. This was particularly a problem during the holiday periods.
- 9 the lack of appropriate advice and information and the lack of general support and counselling from professionals outwith the schools. A mother described the lack of support she received from her Social Worker:-

"the person who visited seemed very ignorant about what benefits H entitled to and how decide it. I feel this is typical of anyone from the Social Work...they lack training and experience dealing with the handicapped."

With reference to the problems a mother encountered in having a new shower installed:-

"I was quite disgusted with their lack of knowledge and understanding of disability."

- 10 concern about the change in services when the Young Person becomes classed as an 'adult' and gaps in provision became apparent eg. physiotherapy.

11 criticisms were expressed about the lack of contact Carers had with Social Workers and the lack of support and understanding. They also commented on any support being infrequent:-

"I dislike (the) attitude of Social Workers...they don't understand problems or understand what a disabled child is like especially if isn't mentally handicapped."

"I got a Social Worker allocated to me when G turned 16 but I've no contact otherwise."

"We don't use any Social Work services and have no Social Worker...only use the O. T."

12 the attitude of some medical staff to Carers caused feelings of inferiority and the use of technical 'jargon' led to misunderstandings and confusion.

4.36 Social Background Variables on the YPMD

The analysis of the social background data failed to disclose any systematic variations according to home region, number of children in the family, birth position of the Young Person in the family, Carer's occupation, and housing tenure. This is possibly because of the smallness of the sample.

There were 2 sets of variables which merit further consideration. These relate to the Carer's health and to location and design of the home.

20 Carers described themselves as suffering from poor health. These health problems include recent and longstanding conditions of a severity that is sufficient for the individual to feel that it makes their task of caring harder.

The following cases are examples of the problems referred to by the 20 carers:-

- 1 Mother living alone with rapidly growing teenage son, she suffers from acute back pain accentuated by the lifting and transferring.
- 2 Mother suffers from high blood pressure and nervous disorder, father

- recently suffered serious heart attack, Young Person is day pupil, high level of dependency including lifting and transferring.
- 3 Father unable to work due to ill health, mother about to have a major operation, Young Person a day pupil living at home.
 - 4 Mother about to have a major operation, previous operation unsuccessful, father away from home a great deal through business. Mother very concerned about what will happen to her son when she is in hospital. Social Worker said that he would go into a nearby hospital which greatly upset the mother and caused additional health problems.
 - 5 Grandmother living alone and caring for Young Person. She finds it increasingly harder to cope as she becomes older and her grand-daughter becomes bigger. Lifting especially in and out of the car has become impossible and caused the grandmother concern.
 - 6 Mother suffers from severe depression increased with anxiety.
 - 7 Mother about to undergo an operation, has 2 small boys to look after as well as the Young Person. Mother suffers from nervous exhaustion, father is away alot as in the Navy.
 - 8 Mother coping alone is finding it increasingly harder, son (Young Person) is suffering from a degenerative illness, recent marital problems causing mother to suffer from various health problems.
 - 9 Father has long standing illness, mother recently had serious disease diagnosed, many problems within the family.
 - 10 Mother of a large family described how she was putting off having an important operation because of having to look after a dying relative, Young Person lives at home being a day pupil, most of other children also living at home, father away alot.

21 Carers described their home as unsuitable for the Young Person. Factors of unsuitability included:-

- 1 hilly location
- 2 stairs
- 3 limited internal space
- 4 poor to non-existent internal access
- 5 poor to non-existent internal access
- 6 inappropriate kitchen facilities
- 7 inappropriate bathroom facilities
- 8 lack of adequate garden.

4.4 Results from the Fieldwork on Post-School Provision

4.41 Placement coverage achieved

Out of the 32 placements in the sample, fieldwork was carried out in 31 placements. The placements included were:-

- 1 Residential placements - R1, R2, R3, R4, R5, R6, R7, R8, R9, R10
R11, R12, R13, R14, R15
(total 15)
- 2 Day placements - D1, D2, D3, D4, D5, D6, D7, D8, D9
(total 9)
- 3 Further Education placements - F1, F2, F3, F4, F5
(total 5)
- 4 Hospital placements - H1
(total 1)
- 5 Work Centre placements - W1
(total 1)

Placement H2 is not included as permission was not given to conduct the fieldwork.

The data collected on the nature and range of formal service provision and delivery is presented in 5 sections corresponding to the types of post-school placements:-

- | | |
|--------------------------------------|--------------------------------|
| 1 - Residential placements (R) | 4 - Hospital placements (H) |
| 2 - Day placements (D) | 5 - Work Centre placements (W) |
| 3 - Further Education placements (F) | |

This is followed by determining the quality of life each placement offers SLWMD according to the levels of service provision and delivery and using the quality of life continuums.

In addition to finding out about the service provision and delivery available to SLWMD and the potential quality of life, the fieldwork collected data concerning the transition period which begins with a referral being made to a placement and finally a conditional offer being made by the placement. The 5 stages of this process are briefly described in 4.44.

4.42 The Nature and Range of Service Provision and Delivery in Post-School Placements

The pie-charts and circle diagrams illustrate the results from the interview and observation schedules completed during the fieldwork. They show the level of provision offered by the placement to meet the different areas of IPSD. They also indicate what levels of privacy, independency, autonomy and self-development are promoted through the service delivery. The results on service provision and delivery available in the placements which included residential accommodation are illustrated by a circle diagram and pie-charts which highlight the aims of each placement and the service provision and delivery available for:-

- | | |
|-------------------------|------------------------------|
| 1 basic/personal needs | 3 stimulation/personal needs |
| 2 social/personal needs | 4 a 'homely' atmosphere |

For placements not offering residential accommodation, the results are

shown in a circle diagram and pie-charts highlighting the aims of the placement and the provision and delivery available for: -

- 1 stimulation/learning experiences
- 2 basic/personal needs

The following key is applicable to all the pie-charts except for the aims of the placement: -

- P - services delivered promoting privacy
- I - services delivered promoting independency
- D - services delivered promoting personal development
- A - services delivered promoting autonomy

In the circle diagrams, the following key is applicable for the aims of the placement: -

- A - promotes independency
- B - promotes autonomy
- C - promotes privacy
- D - promotes personal development
- E - promotes self-dignity and self esteem
- F - promotes the meeting of individual needs
- G - promotes service user advocacy
- F - promotes integration in the community on locational, social and functional levels.

No placement had a specific policy aimed to meet adolescent needs although the majority stated that they were aware of such needs. Placements with a key worker system attempted to address these needs through personal and social development programmes.

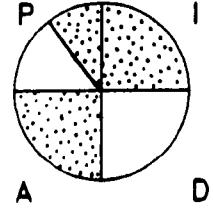
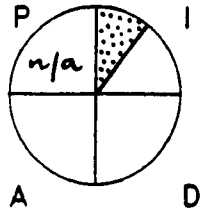
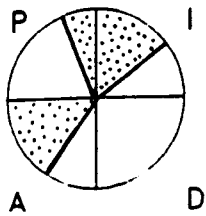
4.421 Residential Placements

The results of placements R4 and R7 are presented in figures 4.9 and 4.10 and the results for the other residential placements are in Appendix 4.3. R4 functions as a residential centre and R7 is a residential centre with a day centre attached.

Figure 4.9 Residential Placement R4

Services for basic/personal needs.

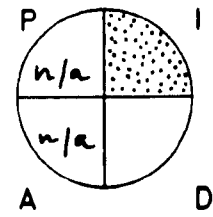
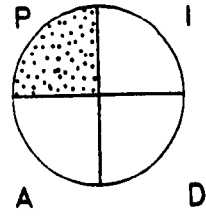
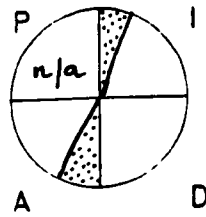
Washing and toileting Eating and food preparation Dressing/undressing



Mobility

Health care

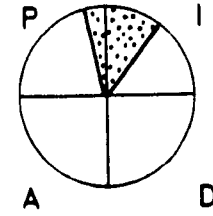
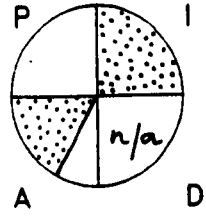
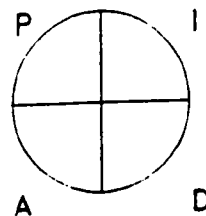
Communication



Finance

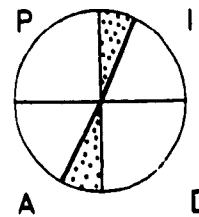
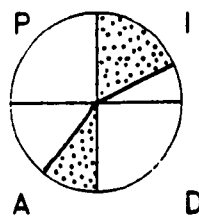
Sleeping

Home-base



Services for : social/personal needs

stimulation/personal needs



Provision for a 'homely' atmosphere

Aims of the placement

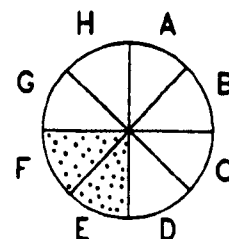
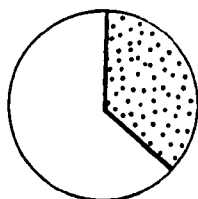
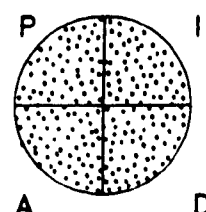
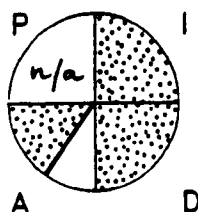
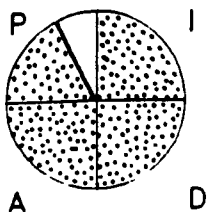


Figure 4.10 Residential placement with day facilities R7

Services for basic/personal needs

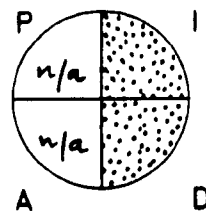
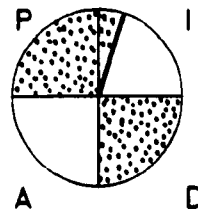
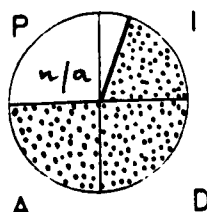
Washing and toileting Eating and food preparation Dressing/undressing



Mobility

Health-care

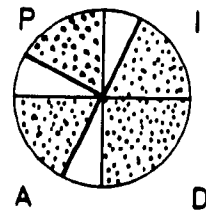
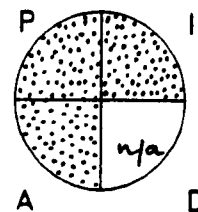
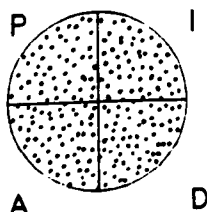
Communication



Finance

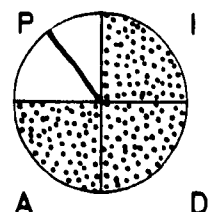
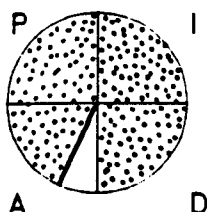
Sleeping

Home-base



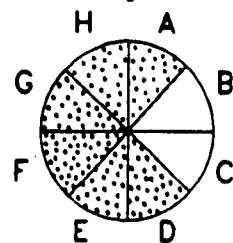
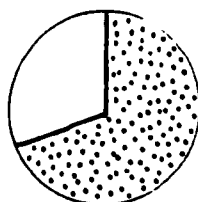
Services for : social/personal needs

stimulation/personal needs



Provision for a 'homely' atmosphere

Aims of the placement



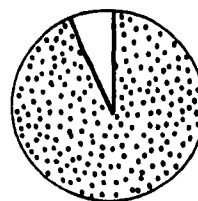
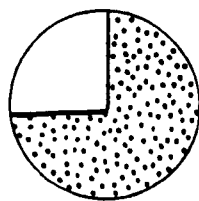
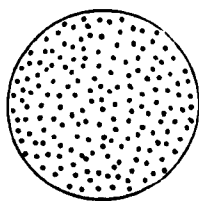
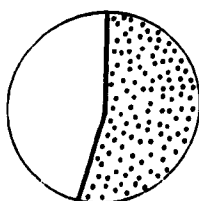
Services for developmental needs :

Facilities

Equipment

Staff

Organisation

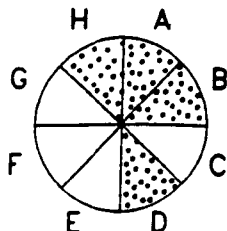


4.422 Day Placements

Results for placement D7 are shown in figure 4.11 and the results for the other day placements are in Appendix 4.4. A 'Special Care Unit' (SCU) was attached to this placement and the services provided in this unit are shown separately in the results.

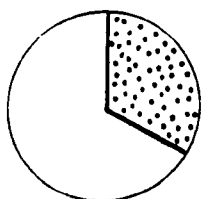
Figure 4.11 Day placement D7

The aims of the placement

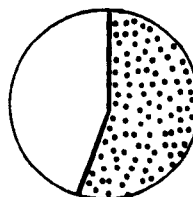


Service provision for stimulation and learning experiences

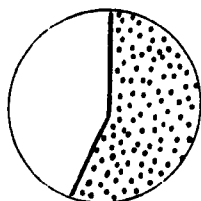
Facilities



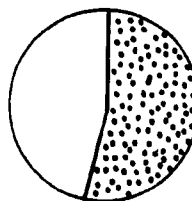
Equipment



Staff

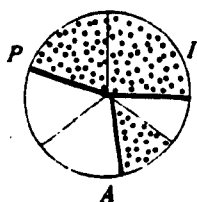


Organisation

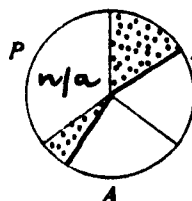


Service provision and delivery for basic/personal needs

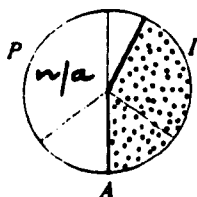
Washing/toileting



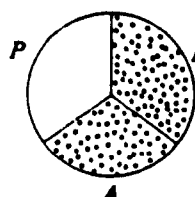
Eating



Mobility



Communication



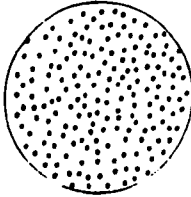
4.423 Further Education Placements

The results for placements, F1 and F3 are given in figures 4.12 and 4.13 with the results for the other Further Education placements in Appendix 4.5. F1 offers residential facilities and F3 offers provision for day students only.

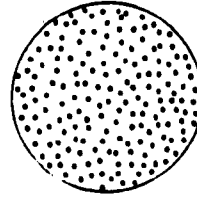
Figure 4.12 Further Education placement with residential facilities F1

Services for development needs

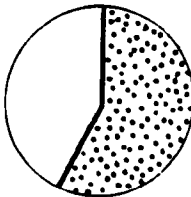
Facilities



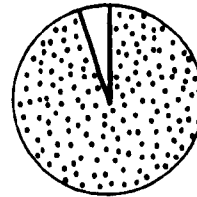
Equipment



Staff

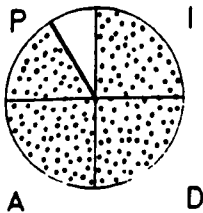


Organisation of activities

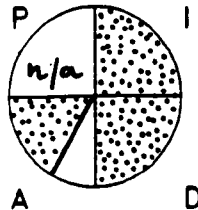


Services for basic/personal needs

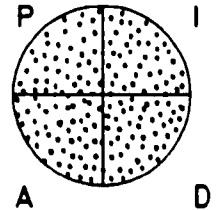
Washing and toileting



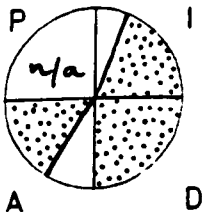
Eating and food preparation



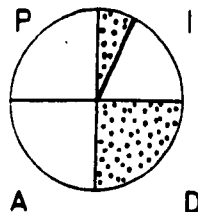
Dressing/undressing



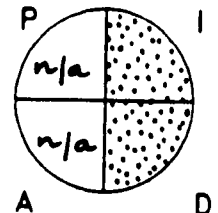
Mobility



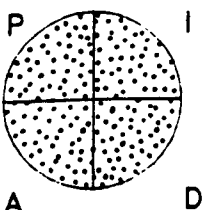
Health care



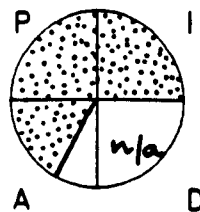
Communication



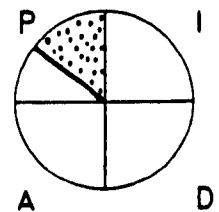
Finance



Sleeping

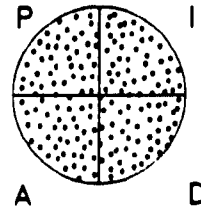
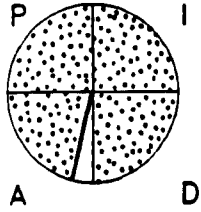


Home-base



Services for : social/personal needs

stimulation/personal needs



Provision of a 'homely' atmosphere

Aims of the placement

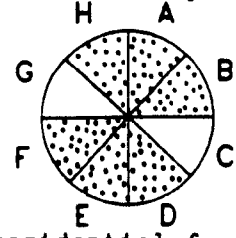
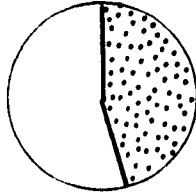
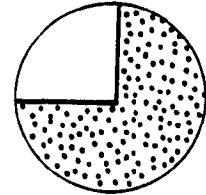
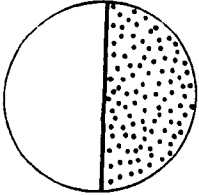


Figure 4.13 Further Education placement without residential facilities F3

Services for developmental needs:

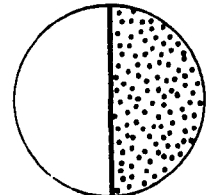
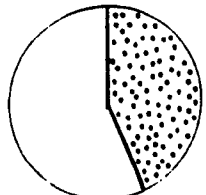
Facilities

Equipment



Staff

Organisation



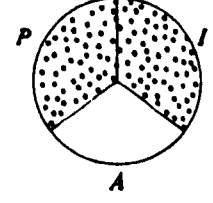
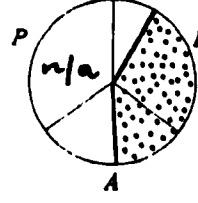
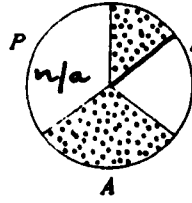
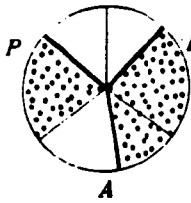
Services for basic/personal needs :

Washing and toileting

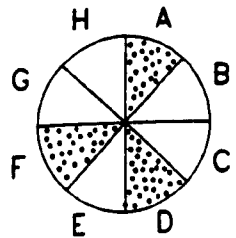
Eating and food preparation

Mobility

Communication



Aims of the placement



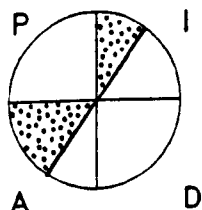
4.424 Hospital placements

The results for H1 are presented in figure 4.14.

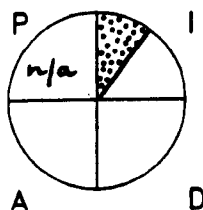
Figure 4.14 Hospital placement H1

Services for basic/personal needs

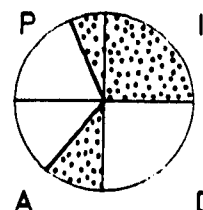
Washing and toileting



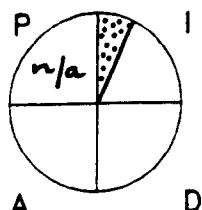
Eating and food preparation



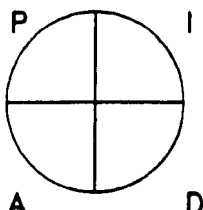
Dressing/undressing



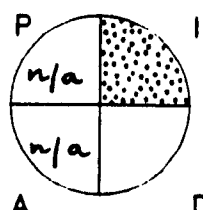
Mobility



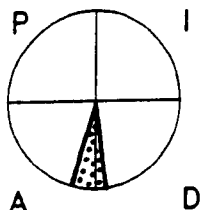
Health care



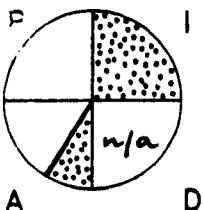
Communication



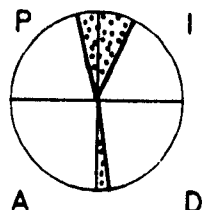
Finance



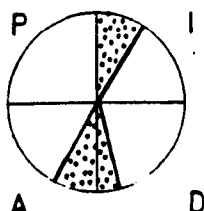
Sleeping



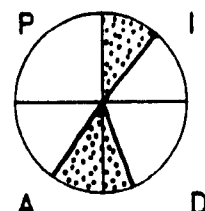
Home-base



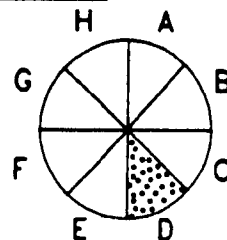
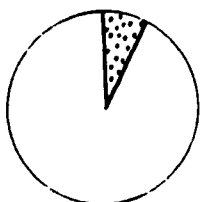
Services for : social/personal needs



stimulation/personal needs

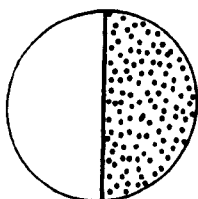


Provision of a 'homely' atmosphere Aims of the placement

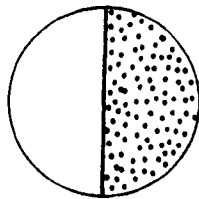


Services for developmental needs :

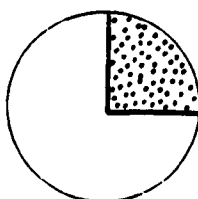
Facilities



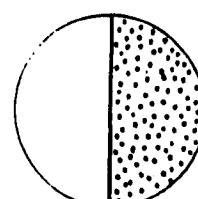
Equipment



Staff



Organisation

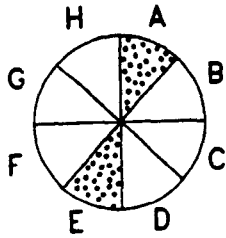


4.425 Work Centre placement

The results for placement W1 are presented in figure 4.15.

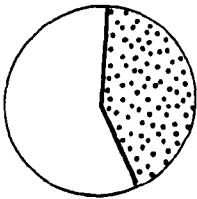
Figure 4.15 Work Centre placement W1

Aims of the placement

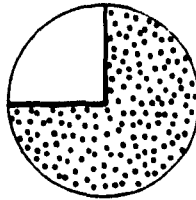


Services for development needs

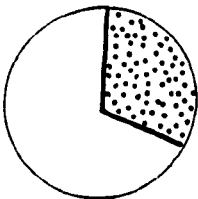
Facilities



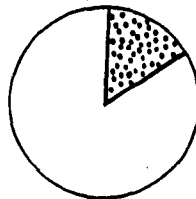
Equipment



Staff

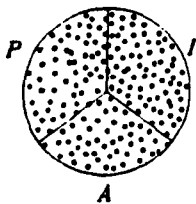


Organisation of activities

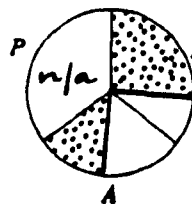


Services for basic/personal needs

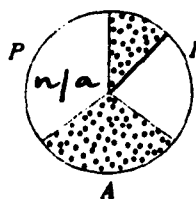
Washing and toileting



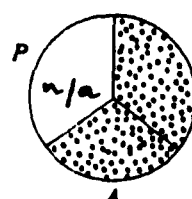
Eating and food preparation



Mobility



Communication



4.426 Summary of the Results on the Nature and Range of Formal Service Provision and Delivery in Post-School Placements

The nature and range of services to meet IPSD needs of SLWMD was found to be limited. For residential placements, in a significant number of placements (13), service provision was limited, particularly in the area of basic/personal needs. There was a slight improvement in the nature and range of services to meet social/personal and stimulation/personal with the latter being better met. However, these improvements are relatively minor and make no impact on the meeting of IPSD needs. Only 2 placements were offering to meet the need for a 'homely' living environment the others were run on institutionalised lines.

For day placements, the nature and range of services the meeting of basic/personal needs was only achieved by half of the placements and only a third of the placements met 50% of developmental needs and 2 placements meeting all developmental needs.

The service provision to meet developmental needs improved slightly in further education centres. Only 2 colleges met 75% of developmental needs. Colleges offering residential accommodation were found to meet basic/personal needs to a greater level than the day colleges where facilities and resources were limited. A higher level of provision to meet social/personal and stimulation/personal needs was found in these placements but the provision of a 'homely' environment was extremely limited.

Services to meet IPSD needs in both the hospital placement and the work-centre placement were found to be very limited, leaving substantial needs unmet. For the hospital placement, services were provided in an institutionalised framework and for the work-centre, according to a factory environment.

The policy aims of the placements can have important implications for the nature and range of service provision and delivery and for the SLWMD. 4

placements were found to have no set policy aims and both the hospital and the work-centre placements had few set aims. For the remaining placements, data shows that the promotion of privacy, autonomy, advocacy and community integration were neglected. The majority of placements, (23), recognised the promotion of independency and 20 promoted the meeting of individual needs. In the area of personal development and the promotion of self-dignity and self-esteem, 21 placements were included. However, despite these policy aims of the placements, fieldwork in the placements found that they did not have significant effect on the nature and range of provision and delivery.

4.43 The Quality of Life Offered at Post-School Placements

The data collected on the service provision and delivery of each post-school placement and shown in the pie-charts can be presented in terms of the quality of life offered to SLWMD along the 2 quality of life continuums. The pie-charts show the level of provision and delivery available to meet different areas of personal and social developmental needs of SLWMD. If the level of provision is high, and therefore IPSD needs are being met, the potential quality of life for the individual will also be high. The opposite situation exists if the level of provision is low, then a potential low quality of life is offered. A medium level of provision will result in potential medium quality of life. The level of quality can vary within a placement depending on the area of need being met. Table 4.12 shows the level of quality of life offered by the along the 2 quality of life continuums for residential placements (R=Residential; F=Further Education with residential facilities; H=Hospital) and table 4.13 shows the level of quality of life offered along the 1 continuum in day placements (D=Day; W=Work Centre).

Table 4.12 The quality of life offered in residential placements

Quality of life Type of placement	HIGH			MEDIUM			LOW		
	R	F	H	R	F	H	R	F	H
Independent/ Enabling/ Individually- Centred	R12 R7	F4 F1		R13 R3 R5 R8 R6 R10	F2		R2 R14 R1 R9 R11 R15 R4		H1 Dependent/ Care/ Group/ Centred
Informal- Living	R12 R3			R2 R6 R15 R7	F1		R13 R14 R1 R5 R8 R9 R10 R11	F2 F4	H1 Formal- Living

Table 4.13 The quality of life offered in day placements

Quality of life Type of placement	HIGH			MEDIUM			LOW		
	D	F	W	D	F	W	D	F	W
Independent/ Enabling/ Individually- Centred	D5 D8			D9 D2 D3 D4	F3		D1 D6 D7	F5	W1 Dependent/ Care/ Group- Centred

The overall potential quality of life offered by each placement according to the levels of formal service provision and delivery to meet individual personal and social developmental needs is shown in table 4.14.

Table 4.14 The overall quality of life offered by post-school placements

Residential placements :	R1 - Low	R9 - Low
	R2 - Medium-low	R10 - Medium-low
	R3 - High-medium	R11 - Low
	R4 - Low	R12 - High
	R5 - Medium-low	R13 - Medium-low
	R6 - Medium-low	R14 - Low
	R7 - High-medium	R15 - Medium-low
	R8 - Medium-low	
	F1 - High-medium	
	F2 - Medium-low	
	F4 - High-low	
	H1 - Low	
Day placements :	D1 - Low	D6 - Low
	D2 - Medium	D7 - Low
	D3 - Medium	D8 - High
	D4 - Medium	D9 - Medium
	D5 - High	
	F3 - Medium	
	F5 - Low	
	W1 - Low	

The results in table 4.14 showing the overall quality of life offered to SLWMD in post-school placements shows that for residential centred placements, 12 of the 15 offer a low or medium-low quality of life but residential Further Education centres offer between medium-low to medium-high. For day centred placements, there is a spread of quality with the average being a medium level. The Further Education centres were not offering the same level of quality as the residential Further Education centres. Taking the post-school placements together, only 6 offered SLWMD a high or high-medium quality of life. Therefore a significant number of post-school placements were not found to offer school-leavers the quality of life they were accustomed to at school.

4.44 The Role of Placements in the Transition Period

Fieldwork data described the role of placements in the transition period which begins with a referral being made to a placement. The referral comes from the Social Worker. Placements 'advertise' themselves through information leaflets. Three quarters of the centres produced information leaflets and $\frac{1}{2}$ of these were a brochure specifically on the placement. The remainder had a general leaflet linked with other placements. Only 2 placements were involved with the FNA process though 2 indicated their willingness to be involved if they had been invited to attend. Over $\frac{1}{2}$ of the placements commented that they had very limited liason with schools. Only 2 day centres had made specific efforts to liase with local schools. 1 of the colleges of Further Education described their relationship with local schools as 'good' and another said they were keen to promote liason. When a placement receives a referral it sends out an application form. These forms varied between centres and nearly a $\frac{1}{2}$ required an input from the Doctor, Social Worker, School Staff and possibly Educational Psychologist. Only 1 centre said that they specifically consulted the FNA Report and another said they referred to the Record of Needs. Visits were then arranged with some centres arranging residential visits. 4 centres carried out home visits. Placements concluded with formal assessments which lasted between 1 day to several weeks. $\frac{1}{2}$ of the placements had assessment panels that met to decide on the applicant after carrying out individual interviews. These interviews included the Carer. 2 placements did not invite the SLWMD to attend until the end of the meeting. In 2 cases there was no formal assessment procedure but the 'suitability of the applicant' was discussed by the management committee of the centre. 5 placements did not hold individual assessments and the application was discussed in the regional

Social Work Department offices along with other applications on a monthly basis.

If a place was offered it was dependent on funding being secured and a trial period being satisfactorily completed. In the majority of cases funding came from the DHSS with additional Social Work Department funding. In the case of the colleges of Further Education the SLWMD was funded by Local Education Authorities.

Trial periods varied from a few weeks to 6 months and often it was incorporated with the assessment. 7 placements did not operate such a system and others were flexible. The aims of the trial period were said to be for the SLWMD and the staff to determine if the placement was appropriate.

The offer of a place depended on where the SLWMD lived as each centre had its own catchment area and if the SLWMD lived outside this area, a place may not be offered. 7 placements catered for the whole of Scotland, 10 operated on a regional level and the others had their own local area. Offers could also depend on the 'waiting list'. 12 placements had a waiting list and 3 operated a 'pool' system whereby the waiting list was not treated as 'first come first served' but a place was offered to a person considered to be in most 'need'. 2 placements gave preference to SLWMD who were members of the local organisation who administered the placement.

4.5 Results from the Interviews with SLWMD and Carers on Post-School Provision

The results are presented under the following headings:-

- 1 the Respondents
- 2 discussion about post-school placement packages
- 3 experiences of the SLWMD and Carers during the transition period
- 4 SLWMD and Carer expectations for the future
- 5 the respondents perceptions of an 'ideal' placement.

4.51 The Respondents

Out of the 31 sets of SLWMD and Carers approached, 22 sets were interviewed. 9 sets declined to be interviewed. 9 SLWMD and Carers were interviewed together, 7 Carers were mothers and 2 sets were parents. The remaining 13 Carers were interviewed without the Young Person: 8 mothers, 2 fathers, 2 parents and 1 mother with a daughter. 11 Carers lived in Strathclyde, 7 lived in Lothian, 2 lived in Central and 2 in Fife. The SLWMD (14 male and 8 female) were aged between 17-22 years, with 11 aged between 18-19 years. The majority, (18) had been Summer school leavers. All 5 levels of functioning are represented in the sample with 1 Young Person having a high level of functioning, 8 high-medium, 9 medium, 3 medium-low and 1 functioning at a low level.

4.52 Results on Post-School Placement Packages

4.521 The Types of Post-School Placements

In the sample, 15 SLWMD had 1 placement package since leaving school and 7 had 2 different placements packages. The 15 SLWMD are referred to as Group 1 and the 7 who have had 2 placement packages as Group 2.

Table 4.15 shows the different types of placement packages taken up by Group 1. The placement packages are described in the terms used by the

SLWMD and Carers. The principal placement is underlined.

Table 4.15 The types of placement packages in Group 1

Type of placement package	Number of SLWMD
<u>Home</u> (FT)	1
<u>F. E. College</u> (Residential)+Home	4
<u>Hospital</u> +Home	1
<u>Day centre</u> (FT)+Home	4
<u>Day centre</u> (FT)+Residential home	1
<u>Day centre</u> (PT)+Home	1
<u>Residential placement</u> (FT)	2
<u>Residential school</u> (FT)+Home	1

N.B. FT= full-time attendance, PT= part-time attendance.

Table 4.16 shows the 2 placement packages experienced by the 7 members of Group 2.

Table 4.16 The types of placement packages in Group 2

Type of first placement package	Number of SLWMD	Type of second placement package	Number of SLWMD
<u>Residential placement</u> (FT) + school	4	<u>Residential placement</u> (FT)	5
<u>Residential placement</u> (FT)	1	<u>Day centre</u> (FT)+Home	1
<u>Day centre</u> (FT)+Home	1	<u>Day centre</u> (PT) +	
<u>Day centre</u> (PT)+Home	1	<u>Residential placement</u>	1

The tables show that in Group 1 the most frequent type of principal placement was a day type placement (6) and a Further Education placement (4). Only 4 were in a residential placement, including a hospital placement and 1 Young Person had no placement outwith the home.

In Group 2 the majority of the SLWMD (5) had a residential placement as their 1st principal placement which increased to 6 SLWMD for the 2nd principal placement. The remaining SLWMD attended day placements.

The following placements are included in the 2 tables. They are referred to be letter/number as in section 4.4.:-

- Residential placements - R1, R2, R3, R4, R7, R11, R12, R15.
- Day placements - D2, D3, D4, D7, D9.
- Further Education placements - F1, F2, F4.
- Hospital placement - H1

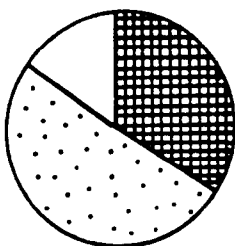
4.522 Satisfaction with the principal placement

The degree of satisfaction expressed by the respondents is shown in figure 4.16. Pie-chart A indicates the degree of satisfaction expressed by Group 1, pie-chart B indicates the degree of satisfaction expressed by Group 2 for the 1st principal placement, and pie-chart C, the satisfaction for the 2nd principal placement.

Figure 4.16 Satisfaction with the principal placement

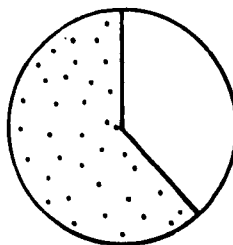
Pie-chart A

Group 1
1st placement



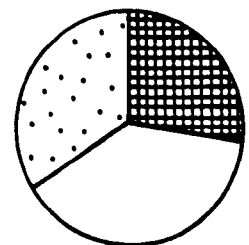
Pie-chart B


Group 2
1st placement



Pie-chart C

Group 2
2nd placement



Key: Positive  Negative  Generally dissatisfied 

The pie-charts show that members of both groups were not satisfied with the principal placement. Members of Group 2 were significantly dissatisfied with the 1st principal placement and only marginally more satisfied with the 2nd placement. Only 2 members in Group 2 stated that they were more satisfied with the 2nd placement. 2 members became increasingly dissatisfied with the 2nd placement and the other 3 felt the same as for the 1st placement.

The following quotes describe how Carers and SLWMD expressed their feelings of satisfaction regarding the placement packages:-

1 "I feel it (Placement F1) has been very successful so far..She (Young person) is always doing different things."
Mother

2 "We are not all happy with the way things have gone .. in fact we are very disappointed and feel let down."
(Reference to F4)
Young Person and Mother

"I am doing everything I did last year again."
Young Person

3 "Ever since (I) left there (School B), I've gone back the way." (Reference to D2)
Young Person and Mother

4 "The place is alright - lets face it, there was nowhere else." (Reference to D7)
Father

5 "They seem to be kind to him...he isn't showing any signs of distress." (Reference to R1)
Mother

6 "I was so grateful he could go there...there was nowhere else." (Reference to H1)
Mother

7 "I often wonder if prehaps A would be better at home.. there is the problem of how to cope." (Reference to R11)
Mother

8 "After initial mix-up everything has turned out very well for us both (Mother and young person)." (Reference to D3)
Mother

9 "R likes ---- (Placement R7)...the only problem is that its too far from us (Mother and Stepfather)."
Mother

10 "We are very disappointed...the staffing levels are low and we are not happy with the standards of care."
(Reference to D7)
Young Person, Mother and Stepfather

4.523 Factors affecting the Satisfaction of Principal Placements

The combination of 4 factors was responsible for the dissatisfaction with principal placements. These were: -

- 1 distance between the placement(s) and the homes of SLWMD
- 2 Carer contact with principal placement(s)
- 3 meeting the IPSD needs of the SLWMD
- 4 the choice of principal placements.

1 Distance from home

The respondents found the distance between the principal placement and their homes to be too far. This was particularly so for SLWMD with residential placements. They complained that the placement was outwith the local community and their local area. The SLWMD found it difficult to settle into a new area as well as a new placement and Carers found problems visiting regularly because of the time and expense involved.

SLWMD at day placements also experienced difficulties. The travelling time was increased because of the way the transport was arranged and because of the location of the Carer's home within the catchment area of the placement. This caused tiredness and discomfort.

The following 3 vignettes describe the problems encountered. 2 are SLWMD with a residential placement, and 1 is a SLWMD with a day placement.

- 1 R is living in a residential home some 250 miles from his parents home. He has strong ties with his mother and had wanted to live near his parents when he left school although not actually with them. R feels that he would have found settling in far easier if he had not been so far away and is angry that there was no choice of placements available that would have allowed him to live nearer to home. He is finding it hard to adjust to fewer visits as his parents are limited

to when they can come as his stepfather works certain weekends. When he was at school, this was not a problem as they were able to visit frequently. R has certain difficulties being understood on a telephone, particularly if the connection is not sound, and he finds having to use the telephone as his main communication link rather frustrating.

- 2 When S left school, he moved into a residential home located in the same region. His mother is an elderly lady, living on her own and with no access to private transport and she finds it expensive, time consuming and tiring to visit. Usually she has to rely on relatives to offer her transport. This restricts the times she can visit and she feels cut off from S. The mobility allowance that S receives is handed over to the residential home. He is able to visit his mother once a month but that involves a long and uncomfortable mini-bus journey as other people are picked up and dropped off at their respective homes on the way. Both S and his mother worry about each other.
- 3 K travelled approximately 5 miles from her home to a day centre which she attended daily on a full-time basis. Arrangements were made for K to be collected each morning and taken to the centre. At first, K was asked to be ready for 8.15 am. K is dependent on her mother for dressing, washing, toileting and for some assistance with eating. It therefore took approximately 1 hour for K to be ready. At the same time as assisting K to be ready, K's mother has other family commitments so that each morning was very fraught and increasingly the mother felt worried that K would be late. She had been told that if K was not ready to leave then she would have to remain at home as they were unable to wait as there were other people

to collect and their Carers had to go out to work and could not afford to wait for K. This situation became worse when the driver started to arrive earlier and refused to help K from the front door into the bus. K's mother comments on how the driver became more and more abusive when K was not ready. She ^sdescribes how she came to dread mornings and suffer from panic attacks. She felt angry that K was not going to the centre as smartly dressed as she would wish and she felt this was her responsibility. The matter was eventually resolved after numerous complaints and a confrontation with the centre manager.

2 Carer contact with the principal placement

3 Carers stated that they made frequent visits to the principal placements and 19 Carers felt that they only rarely visit. Over 1/2 of these Carers (10) felt that the distance was too far for regular visits.

16 Carers described how they found it difficult to accept the lack of contact because they were in the habit of making frequent and regular visits to the schools. They accepted that the SLWMD was becoming an adult and they could not expect to be as closely involved as with the schools. However, they felt that there had to be a period of re-adjustment and during the transition period it was imperative for contact to be maintained. 3 Carers did not object to the infrequent contact because for personal reasons they wanted to reduce the amount of responsibility they felt for the Young Person and treat the Young Person as an adult.

Carers described the reasons for visiting placements other than to be with the SLWMD. These are listed together with the number of times the reason was given: -

- 1 attending assessment review meetings (8)
- 2 attending fund-raising events (2)
- 3 attending activities laid on for Carers (3)

3 Meeting the IPSD needs of SLWMD

Interview data establishes clearly that if the SLWMD and Carers did not feel that the IPSD needs were being adequately met, then they became dissatisfied with the principal placement. The yardstick used by the respondents in their assessment of the adequacy of service provision was to compare the services provided in the principal placement with those received at school and determine whether the SLWMD felt as if they had progressed, regressed or remained the same since leaving school in terms of social, personal and functional development. Table 4.17 lists the needs identified by the respondents and the number of respondents who felt that the needs were being adequately addressed.

Table 4.17 The IPSD needs identified and being met

Needs identified	Group 1	Group 2 First placement	Group 2 Second placement
1 Basic/personal needs	9	4	1
2 Develop and maintain communication skills	5	2	1
3 Develop and maintain mobility skills	4	2	1
4 Develop and maintain academic skills	6	2	1
5 Experience recreation and leisure	13	6	2
6 Stimulation and new experiences	8	2	2
7 Social contact and interaction	2	4	0
8 Community involvement	7	0	2
9 Develop maturity	8	0	3
10 Develop independency	8	0	3
11 High standard of support	0	4	2
12 High level of staff attention	1	3	1
13 Appropriate accommodation	2	3	0
14 Homely living environment	0	0	1
15 Available quiet environment	0	0	0
16 Attention to medical needs	1	1	0

16 different needs were identified by the SLWMD and Carers in groups 1 and 2 and to be met through post-school provision. The results show that a significantly low number of respondents in both groups felt that these needs were being adequately met.

Certain needs are attributed with a low number because a small number of respondents identified the need as being relevant to them eg. 'attention to medical needs' and 'the need for a quiet environment'. Focusing on the needs identified by all the respondents (numbers 1 - 12) the table shows that provision did not adequately meet these needs and this attributed to dissatisfaction with placements. Need 5, recreation and leisure, was found to be the most adequately met need by the respondents in both groups.

Looking at group 2 and comparing 1st and 2nd principal placements there is a decrease in satisfaction in the meeting of all needs except needs 5, 8, 9 and 10. Respondents did not express a difference in the meeting of need 5 (recreation and leisure) and they expressed an increase in satisfaction for needs 8, 9 and 10 although the numbers involved were still small. The main reason for this pattern is that 4 of the SLWMD left the 1st placement package which was a combination of school and a residential centre to 2nd placement package which was only the same residential centre. At this placement they were expected to behave as adults and so the needs for independency and maturity were more fully met. There was also greater opportunity for community involvement. The comparison between the 1st and 2nd placements is explored further in table 4.18 which shows the total number of needs met for each respondent in both placements.

Table 4.18 The IPSD needs met in 1st and 2nd placements

Respondents in Group 2	Number of needs met in first placement	Number of needs met in second placement
1.	7	1
2.	7	1
3.	1	7
4.	9	3
5.	7	2
6.	1	5
7.	1	1

The table shows that for only 2 members in Group 2 is there an increase in the number of needs met, for 1 member there would appear to be no change according to the Carers and for 4 members there is a significant decrease in the number of needs to be adequately met.

The feeling of dissatisfaction with placements is also shown in the comments made by the respondents on the changes in the Young Person since leaving school in terms of their developmental progress. Table 4.19 presents the responses.

Table 4.19 Changes in the SLWMD since leaving school

Developmental changes since leaving school	Number of SLWMD in Group 1	Number of SLWMD in Group 2 First Placement	Number of SLWMD Group 2 Second placement
Young person progressed	6	1	1
Young person regressed	3	2	4
Young person unchanged	6	4	2

In Group 1 a relatively small number of SLWMD have progressed in developmental terms in the post-school placement and this pattern is reflected for the SLWMD in Group 2 for both the 1st and 2nd placements. Indeed, more SLWMD felt that they had regressed developmentally as a result of the 2nd placement than the 1st.

4 Choice of principal placement

When asked about the choice they had about placements, the respondents commented on the lack of choice. 13 members of Group 1 and all 7 members of Group 2 said that they had no choice. The placement that they accepted had been the only placement offered. Only 2 SLWMD in Group 1 had been able to make a choice. Both these Young People were 16 years and the alternative was for them to continue at school. For the other SLWMD, if they had not accepted the placement offered they would have been at home and been totally dependent on the Carer for support and meeting all their needs. The following quotes highlight the respondents' comments on the lack of choice of placements:-

1 "This was the only college that could offer us residential accommodation."

Young Person and Mother, Group 1

2 "H had to come home permanently....I did not want her in a hospital or for to have to go away as far as Aberdeen."

Mother, Group 1

3 "We knew that F1 was the only place for S....it was important for her future and the region admitted this but we still had to fight for funding. I was so worried it (the funding) wouldn't come but I knew we would just have to carry on as always."

Mother, Group 1

4 "We were adamant that G should go to Rudolf Steiner when she left school. She had had a place when she was 8 years old but the region wouldn't fund it. That's why we had to move here and eventually G got a place at School A. However I was told by the Social Worker that there was a shortage of places and as G was on an extension, she could not get onto a waiting list...I was completely devastated. When I applied for a second extension I was panicking as nothing was happening and the future was repeating itself."

Mother, Group 1

The mother goes onto explain how she felt about G having to return home permanently: -

"....it would have been disastrous and what about the waste of all the education she has already had.... building her up for what?"

5 "There was another possibility but it wasn't really in the running because of access problems....I didn't want to have to ask strangers when I wanted to use the toilet."
Youn Person and Mother, Group 1

6 "I always expected D to go to D7 and anyway there seemed to be nowhere else. We didn't know he had a place until just before he left school. I must admit I got worried and began to plan what I would do all day with D on my own and if I could cope...perhaps he would have had to leave home...it was a terrible time for me. I'm just glad there was somewhere to go."
Father, Group 1

7 "The matter came up when I was due to go in for an operation. I really wanted I to go to R11 but I was told there were no places so I had no alternative but to take up R1. At least I knew then that if anything happened then I would be cared for. I think all the worry made me feel more ill."
Mother, Group 2

8 "There really was no other place for R. He liked R12 but they felt he was too young and we liked F1 but that was far too far away, R7 is far enough for R. Really nothing was as we would have wished....you have to compromise and settle for something else."
Mother and Stepfather, Group 1

9 "We have always expected K to go to D7, everybody at School B goes there. K saw his friends go there and so nowhere else was thought about...it was like being channelled into the one place....we did worry about getting a place..we couldn't take it for granted so we lived day by day hoping."
Mother and Stepfather, Group 1

10 "There was only one other place we thought about but they were not wanting to take J. We couldn't cope with J at home especially as we are now in an upstairs flat.... R1 had to do."
Mother and Father, Group 2

11 "I think it is all wrong that just because he is mentally alright and physically all wrong there is nowhere for him to go as A doesn't fit into a category. Its difficult for anyone to get anywhere...you have to push and push and push to get a place and then its not really what you want. It was pure luck we got a place."
Mother, Group 2

12 "There was so little choice to begin with and then after you visit there is even less. There is only 1 place for S but it has no places so we have to wait...what happens in the meantime?"

Mother, Group 1

13 "I had resigned myself when M came home from school to have her at home for years and years...I was getting so depressed...there was nowhere."

Mother, Group 2

4.53 The Experiences of SLWMD and Carers in the Transition Period

This section focuses on the transition period which is defined as the period of time experienced by the SLWMD and Carers from the point that the placement package is formally secured by all parties involved to the time when the SLWMD has completed the 1st initial 3 months at the principal placement.

The following quotes illustrate how the SLWMD and Carers felt about their experiences. These comments are categorised according to whether they are positive or negative. No distinction is made between members of Group 1 and members of Group 2.

It was found that the majority of the respondents (18) described their experiences as being negative:-

- 1 "feeling anxious"
- 2 "being constantly worried about funding"
- 3 "being let down"
- 4 "feeling isolated and having to cope alone"
- 5 "experiencing conflict situations"
- 6 "never feeling confident that decisions will be carried through"
- 7 "lacking trust in the individuals involved"
- 8 "feeling constantly worried about a place being available"
- 9 "worried that after the trial period he will have to leave"
- 10 "depressed about the 'placement' but there is nowhere else"

The feelings of the other respondents (4) were positive: -

- 1 "I felt I could stand back, all was planned by the department (Social Work Department) and A being fostered made sure he was on their books."
- 2 "I always expected J to go to the college and I knew the school would arrange everything."
- 3 "With A simply changing schools I felt everything went smoothly and I seldom worried about it."

4.531 Factors Contributing to Negative Experiences of the Transition

1 Length of the transition period

For 16 SLWMD the transition period lasted between 0-6 months which they found to be too short a time span to make big changes and adjustments in their lives. They wanted more time to make important decisions. Of the 4 SLWMD who were positive about the transition period, 3 had 12-15 months to make the necessary changes.

2 Securement of the placement package

Throughout the whole process the majority of the respondents (19) felt that they did not play a prominent role. This opinion is reflected in the following quotes: -

- 1 "The placement was always expected so I left the school to see to things, they knew what was wanted."
Mother, Group 1
- 2 "With the Social Work being so much involved with A, I left it up to them to see to things."
Father, Group 1
- 3 "I left it up to X (Scottish Council Social Worker) and the local one (Social Worker). I didn't know what to do and they know best."
Mother, Group 2

The 3 Carers who felt they did play a significant role commented: -

- 1 "It was a matter of having to push and push, no-one else would, it was up to me."
Mother, Group 2
- 2 "I had to take the bull between the horns otherwise M would still be with me."
Mother, Group 2

3 "If we had'nt made a fuss and got going she (young person) would never have gone to F1...it was a matter of fighting all the way and checking up on everything."
Mother, Group 1

The process of securing a placement package involves:-

- 1 visiting the placement(s) within the package
- 2 assessments carried out by staff in the placement(s)
- 3 assessments of the placement(s) made by SLWMD and Carers
- 4 determining funding arrangements

83% of the respondents visited the principal placement but 81% of them only made 1 visit. They found that this did not give them adequate opportunity to become familiar with the placement and be in a position to make sound decisions about its suitability. Consequently, their 1st impressions of a placement tended to be superficial and changed once the SLWMD was there.

1 "We quickly became very disappointed in the curriculum.
..it had seemed so good when we visited."
Young Person and Mother, Group 1

2 "We liked the look of the building and the course started off quite well but then things soon went downhill...I (young person) want more than a nice place."
Young Person and Mother, Group 1

3 "He (young person) had always wanted to go there (D7) and he was really looking forward to it...now he wants to get away, its nothing what we expected."
Young Person, Mother and Stepfather, Group 1

Respondents felt very ignorant about assessment procedures and the criteria used by placements. This ignorance caused anxiety and worry which increased due to the funding arrangements. The data shows that SLWMD and Carers do eventually receive the funding required but the delays encountered causes emotional problems. In the majority of cases the source of funding is from the Local Authority Social Work Department. SLWMD attending full-time education courses are awarded bursaries and funding is then provided by Local Authority Education Departments. The following 2

case-studies provide an insight into the experiences of some of the respondents: -

- 1 The Carer described the 'battle' she experienced together with her husband to secure funding of the principal placement for her daughter. Because this placement was located outwith Scotland, both the Local Social Work Department and the Education Authorities were reluctant to fund the placement. After significant persuasion and argument the money was finally agreed upon with both Departments playing a role. This process took a considerable amount of time during which the Young Person and the Carers suffered from worry and anxiety. The Carer describes how she became 'emotionally spent' and that she suffered from depression.
- 2 The Carer described how worried she felt about getting funding for a placement that both herself and the Young Person wanted. The 1st placement that the Young Person was expecting to attend did not offer a place after the assessment period. This happened 2 weeks before the Young Person left school. Therefore another placement had to be found very quickly but the machinery in the Social Work Department to process a new application for funding did not work at such a speed. As the Young Person and Carer were offered a place they had to agree upon it immediately but the Carer was extremely worried that funding might not be secured in time. She described how she felt a victim to the system and powerless to intervene. Living on her own she commented that as she had no-one to share her worries with and her health deteriorated.

3 Preparation for leaving school

The respondents (17) complained about the shortage of time (0-3 months) available to prepare for leaving school and moving on to the new placement. 3 SLWMD left school without knowing their new placement so no preparation

could be made. Although the SLWMD had been following school leaving programmes, they felt insufficiently prepared for the new placement. They then found settling in more difficult.

4.54 SLWMD and Carer Expectations for the Future

SLWMD and Carers were asked about their future expectations. They commented on how long they felt their present post-school placement arrangements would last.

12 SLWMD (5 from group 1 and 7 from group 2) saw the arrangements as being permanent even though they were not satisfied with the levels of service provision. The respondents that had 2 placements were all wanting the 2nd placement to be permanent. All of them (7) had left the 1st placement within 1 year. 5 SLWMD had expected to leave within this time span as their 1st placement package had included their school and this had only been a temporary arrangement. The other 2 SLWMD had expected their 1st placement to be permanent but it had proved unsatisfactory.

The respondents were keen to have the future clearly marked out and permanent placements secured because they did not want to experience again the traumas encountered on leaving school. They also felt very aware about the shortage of placements and the lack of choice between placements. They stated that they knew of no other possible placement.

9 knew that their placement would no longer be available between 2-5 years. 5 of these SLWMD were attending Colleges of Further Education and their courses lasted for 2 years. 3 had decided the new placement they wanted. The other Young Person wanted the type of his placement package to remain unaltered but for the principal placement to be changed because it was located approximately 250 miles from his home. He wanted to move to a placement he knew and was located near to the carers' home.

1 Young Person was undecided because she wanted an alternative placement

that had not made available to her when she left school so the present arrangement was temporary until a place was offered.

4.55 The Respondents' Perceptions of an 'Ideal' Placement

The SLWMD and Carers described their 'ideal' placement package which they saw in terms of an existing placement (5) or as one in their imagination (9). 8 did not respond to the question.

The 5 respondents, who saw their 'ideal' placement as an existing placement, saw that placement meeting their IPSD needs. For 2 respondents, this was their principal placement. The other 3 were in residential centres and they saw another residential placement as their 'ideal' because 2 had not been given a place because there were no vacant places and the other had 'failed' the assessment.

The 9 respondents who described their 'ideal' placement as an imaginary placement were able to highlight the types of provision they wanted. This included:-

- 1 placement to be located near the Carer's home
- 2 placement to encourage greater maturity and independency
- 3 placement to offer greater academic development

8 respondents felt unable to describe their 'ideal' placement. They said this was because they had never expected to be able to achieve their aspirations and they had always only considered the 1 placement they had been offered. They explained that because of the shortage of places and the lack of choice they had never thought about what might be possible. 1 Carer commented that she preferred not to compare the reality with an ideal situation for fear that there would be too great a disparity between the 2. The following quote sums up many of the respondents feelings on the matter :-

"it's no use dreaming about what would never happen".

CHAPTER FIVE
ANALYSIS AND INTERPRETATION OF THE DATA

5.1 The Major Findings

The major research findings clearly indicate that there is a radical change in emphasis in the transition from school to adult formal service provision. For most of the YPWMD studied, this proved to be a transition from support for personal and social development via a complex informal and formal network, centred on home and school in differing combinations, to an expectation that YPWMD will, with relative passivity, 'fit in' to a placement and accept an associated 'package' of services. Paradoxically, the transition is often associated with a drastic limitation of services and of personal choice. The impact upon and the consequences for the quality of life experienced by a YPWMD were substantial. To add to this problem, both YPWMD and Carers described the process as problematic and gave cause for considerable worry and anxiety.

The planning of the transition takes place through the FNA process, yet it is given a relatively low profile until the close proximity of the final school leaving date. Different parties are involved with the meetings and come with different perspectives and 'agendas' so that the focus of the meeting is removed from discussing the identification and meeting of post-school needs through appropriate service provision and delivery. Up until that time YPWMD and Carers chose to postpone the transition and opt for an extension to schooling which is viewed as a preferred option given the scarcity of post-school placements and services, especially the opportunity for continued post-school education.

Research findings showed that there were 3 types of placements available to YPWMD, broadly defined as 'day-centre', 'residential-centre' and 'Further Education centre' with YPWMD and Carers generally opting for a 'residential type' placement. They also expressed a preference for the provision and

delivery of the post-school placement package to be a long-term arrangement. For those YPWMD who chose to live at home, Carers were very critical of the lack of availability of formal support they received, especially from statutory agencies. They described how they and the YPWMD relied on informal support to cope with daily living. For the same group of YPWMD, they expressed their wish for access to community facilities, for leisure and sport. This was an area of provision that was found to be limited and poorly delivered.

Within the placement package, findings revealed the concern YPWMD and Carers have for the uncertainty of extension of school delivered therapies, in particular, physiotherapy and this concern was justified as therapies cease to be provided at the same level following the transition. There was also a similar concern voiced about the shift from paediatric to adult medical services. A significant factor responsible for limiting the quality of life for YPWMD was found to be the institutionalised life-style offered through the transition from school to adult based provision and lack of opportunity for personal and social development.

These findings can be explained by focusing on the key arguments which have emerged through the exploratory study of the research topic. Before listing and discussing these arguments, it would be helpful for analytical purposes to distinguish between 2 broad principles of provision of formal services for YPWMD. The 1st emphasises a 'user-led' approach to the structuring of formal service provision, while the 2nd is predominantly a 'service-led' approach.

The 'user-led' approach starts with the user and may involve an assessment of the extent to which informed choice can be made by the user, but the essential principle is that the design, provision and delivery of services are geared to enhancing the personal and social functioning of the user.

The 'service-led' approach starts with the design of services for categories of people with disabilities, including those with multiple disabilities, and provides a base, usually via a day or residential placement (though it can be a parental home) for the provision and delivery of support and activity programmes.

Throughout the fieldwork, it became apparent that YPWMD and Carers were concerned with the 'user-led' approach whereas the adult-based service providers participating in the planning and provision of services adopted the 'service-led' approach.

The key arguments emerging from the research relate to:-

- 1 the FNA process
- 2 the divergent 'professional' practices
- 3 the Carer participation and influence
- 4 placements and associated packages of services
and the implications for quality of life.

These arguments are inter-related and inter-dependent and have to be viewed holistically as they all play a significant role in explaining the research findings. The key arguments and secondary arguments are presented together with 12 case-studies which illustrate the conclusions reached through the research.

5.2 The FNA Process

FNA meetings have significantly different implications for the different parties involved. For educators and associated professionals FNA processes initiate a stage of 'signing off', rather than 'handing over'. A 'book' was opened with the setting up of the Record of Needs and it is closed with the decisions made in the FNA Report. For Social Work representatives, FNA processes herald additional responsibilities (for the most part with

detailed individual assessments very much a matter for the future).

For Carers, FNA processes , in which they tend to play a passive role, mean facing up to the implications of school-leaving and entry to 'adulthood' of their YPWMD but for the YPWMD experiencing the transition, the FNA process rarely allows for meaningful involvement. The process of enabling and empowering YPWMD to take control of their lives, (either independently or in conjunction with Carers), is incompatible with the type of service-led provision found in this study. Statutory requirements and guidelines appear to be directed more at ensuring that the procedural routines have been followed correctly than at highlighting the ways in which professional expertise is to be harnessed to enable YPWMD to make positive choices about ways of meeting developmental post-school needs through the design, provision and delivery of appropriate individually tailored services. Because minimum statutory regulations for FNA specify a compulsory meeting prior to the school leaving age, but the most likely outcome of such a meeting is the extension of educational provision to age 18, participation in the assessment of post-school needs in the year prior to actual school-leaving is optional for most young people, carers and professionals involved. At such meetings, held in the later stages of the school-leaving process, often shortly before the final school leaving date, the discussion is very much focused on post-school placements so that the topic of post-school needs in terms of personal and social developmental needs, is made up of service-led judgements and the assignment of placements discussed according to the broad category of disability with which a YPWMD is labelled. In earlier meetings, including the statutory meeting, educator control tends to lead to the displacement of discussion aimed at pinpointing post-school needs and the development of personalised plans matched with specific service inputs, by the sharing of information on present needs including the extension of full-time school based education.

For the participants of the meeting, these more immediate issues take precedence over discussing post-school needs which are seen to be difficult to fully comprehend at this stage and which adult service-providers believe they cannot plan for so far ahead of the actual school leaving date.

The inefficiency of the FNA process to adequately plan for the transition to adult-based services is apparent in the lack of preparation time given to YPWMD and Carers to adjust to their new lifestyles. From the user-led perspective, SLWMD and Carers find this period of time surrounding the final school leaving date a time of anxiety and worry and the lack of time to make adequate preparations exacerbates these feelings making the transition harder to cope with and with consequences for quality of life. SLWMD are unable to come to terms with their new lifestyle, to get to know the placement or placements, the staff and other service users. For many SLWMD they are going to live in another part of the country which they do not know and their feelings of being isolated from their families is exaggerated. There is limited time available for the YPWMD to make informed choices about the design, provision and delivery of the services they want and to have discussions about these choices. YPWMD are therefore being put in a position where by provision and delivery is service-led. From the service-led perspective, service providers are also unable to become familiar with the individual personal and social development needs of the SLWMD, so they cannot ensure that the appropriate services are provided and appropriately delivered. Significant gaps in provision and delivery can then develop leading to diminishing quality of life.

5.3 Divergent 'Professional' Practices

Through the transition, YPWMD and Carers pass from school-based to adult-based provision. With the former, there is a significant sense of participation because school-based and school co-ordinated provision of

services are organised on the principle assessment, recognition and matching of individual needs of a YPWMD with available resources. There is a clear intent to tailor provision of services to individual requirements. Where this principle is carried through into practice, both YPWMD and Carers experience a sense of participation (even when resources are recognised to be inadequate to meet their aspirations). This sense of participation ceases with adult-based service provision and it is a contributory cause of the dissatisfaction YPWMD and Carers feel for post-school provision.

Problems experienced by YPWMD and Carers during the transition and with the final outcome stem from the situation whereby many staff representing key Social Work/Social Services agencies at FNA meetings have no prior knowledge of the pupil at the centre of the FNA. They also lack a detailed working knowledge of the different levels of personal and social functioning associated with various forms of multiple disability, or of the potential placement settings and the services which can be mobilised in and through such settings and sometimes both. The scope for making a viable assessment of post-school options for access to services based upon individual needs is, in most cases, therefore severely limited. This tends to lead to a clear contrast in the focus of discussions concerning Social Work placements/services compared with those relating to continued educational placements and related services. The focus of discussions about social work placements/services tends to centre upon whether a YPWMD can fit into a particular placement and have a 'package' of services developed around this, with clear consequences for lack of participation, enabling and empowerment. There is then no detailed attempt made to assess post-school personal and social developmental needs in order to identify and match appropriate resources available in formal service providing agencies to such needs in order to enhance the quality of life of the

YPWMD.

A secondary issue arising from professional lack of working knowledge, is that professionals put up hidden defence mechanisms to conceal their inability to cope with the situation. On occasions this ploy was seen to lead to professional rivalries and conflict scenarios which hinder the planning process.

Educational Psychologists were found to have a far greater understanding of the personal and social development needs of the YPWMD but they limited their use of this knowledge to identifying present school-based needs and reaching decisions on applications for extensions to continued education. The approach is 'needs-led' but it is not employed in the planning of post-school needs of which the Educational Psychologist was found to play a very minor role.

5.4 Dilemmas of Carer Participation and Influence

The fact that most Carers continue to accept substantial responsibilities for the support and care of YPWMD even after school-leaving, produces divergent but not irreconcilable pressures. On the one hand, however protective the Carer, members of both informal and formal networks are likely to be, at the very least, signaling by word and action that parents have a responsibility to enable children with multiple disabilities to be less dependent than formerly, when they reach the school-leaving stage. The demands upon the Carer are much greater when the social pressures are much more overt. The school-leaving transition constitutes a period of flux and change for the YPWMD in particular, but also for those who are most closely involved with him/her in daily activities.

At the point of school-leaving, familiar forms of support and development, often with a substantial residential element, are left behind. Future patterns of support and development are, at best planned but not

experienced and may be much more uncertain. It has also to be recognised that 'enabling' is not a simple task and may involve considerable extra and different demands upon a Carer, especially when the familiar package of support and development have been substantial.

On the other hand, most Carers appear to have an interest in claiming for themselves time and energy to devote to other commitments. Therefore, the nature and range of the post-school package of formal services is likely to be of critical interest to them as well as to the YPWMD. Not only do they have an interest in being seen to be 'doing the best' by their offspring, but also a direct personal interest, insofar as the pattern of their own lives is about to change.

The crux of the argument is that the identification of a placement package, or set of individualised development plans with appropriate support inputs, which offers the prospect of an improved, or at least not inferior quality of life for a YPWMD, enabled Carers to pursue both of these sets of interests positively. By contrast, a clash between these two sets of interests is most likely to produce powerful feelings of guilt and hostility towards those who seem to promise so much but deliver so little. Those few Carers who choose to cocoon their children in the family home, are an exception, but even they cannot ultimately avoid change. It is also very much open to question how far the interests of the YPWMD are being adequately protected in such instances.

Despite their keen interest in the outcome of the school-leaving process, Carers generally played a passive and isolated role in the planning of provision and found the process to be negative, causing worry and anxiety and aggravating health problems. There was very little evidence to suggest that the Carers were treated as 'partners' who were consulted and fully involved throughout the transition process. They did however anticipate the FNA process as going to be a positive experience and they started with

high expectations. It was perceived as a 'crutch' and a means of coping with their fears for the future. These feelings of optimism were found to quickly give way to feelings of discontentment and pessimism which increased as the process got underway and no concrete decisions were ever reached.

5.5 Planning and Provision of Post-School Services

The impact of differing professional perspectives during preparations for school-leaving is marked, regardless of the ultimate quality of placement and associated packages of services.

Professional ideas vary substantially in terms of how most effectively to deliver services. The results from the fieldwork of placements and/or service 'packages' reveals differing 'philosophies' of provision/care. Three dimensions are of major analytical significance which are, the degree of independence/dependency, the degree of informality/formality in daily living arrangements and the degree of individual/group centredness. Taken together these can be used to develop two contrasting approaches. Firstly the normalisation, enabling and empowerment approach in contrast secondly with the segregated/dependency model. Placements and services may vary according to each of the dimensions, but the polar opposite types offer considerable insight into the structuring of post-school options for YPWMD. Placements and packages of services available to SLWMD were found to have significant implications for quality of life. Evidence is quite clear from the sub-population studied that the transition from school to post-school arrangements is associated with experience of a reduction in quality of life for YPWMD (from YPWMD and Carer perspectives). The fieldwork identified gaps in provision which resulted in the personal and social development needs of the YPWMD, the service-user, remaining unmet, especially in the area of development.

Adopting the 3 dimensions described above, post-school placements offered to the YPMD showed elements of dependency, formality in daily living arrangements and group centredness, in summary, the segregated/dependency model. As such, the principles of normalisation were not found to be evident in practice except to a limited extent in the Further Education type placements. Institutionalisation was particularly found in residential, further education and hospital type placements.

Looking generally at the levels of provision in the different types of setting, evidence would suggest that provision and delivery of services is most appropriate to the YPMD in the further education type setting because a greater proportion of social and personal developmental needs are met. This level of provision decreases with day type placements, followed by residential and hospital type settings which are significantly less capable of meeting the individual personal and social development of SLWMD. Good practices were found to be limited in a number of post-school placements and within placements. In only a minority of placements was there found to be a comprehensive coverage of services that would meet all areas of development needs.

In addition to the lack of adequate access and lack of appropriate aids, adaptations and resources, the research found significant problems connected with the staffing of establishments and these proved to be a key factor in whether a placement offered the YPMD the potential for quality of life. Evidence shows that there is a shortage of numbers of staff so that staff:YPMD ratios are too high and which limit the performance of service delivery. Too few staff were suitably trained and qualified for the roles they were being asked to perform and this also has serious implications for service delivery. Due to the shortage of numbers they very often were task-oriented rather than person-oriented resulting in a lack of independency, privacy and autonomy for the YPMD and the

implementation of the segregation/dependency model. The observed relationship between staff and the YPWMD was seen to limit quality of life and personal development. Staff were found to adopt the role of 'loco-parentis' with the YPWMD and this restricted the opportunities for maturation and risk taking. Other staff adopted a 'nursing' role so the YPWMD were 'cared for' instead of being enabled and supported. There was no evidence of an equal, interdependency relationship between staff and service-user, rather the latter was a passive recipient of services. This is contrary to the elements of the enabling/empowering model.

'Bench-mark standards' against which formal post-school services are likely to be judged by YPWMD and Carers are set by the individualised and personalised packages of support and care mobilised through the schools. Hence it is neither surprising to find, nor difficult to predict that, when faced with offers of placement packages which appear to offer neither the familiar range of supports nor individual tailoring, YPWMD and Carers are likely to be highly critical of the quality of services on offer. This is exacerbated by the nature of the limited choice of placement package, the most common form of which is 'to take or leave it' with pressure made to accept, rather than a genuine choice between positive and viable alternatives. YPWMD and Carers can also be channelled into considering only 1 placement despite any doubts they may feel about it. Even when there is a choice of placements offered, albeit restricted, YPWMD and Carers find it difficult to make clear and accurate judgements about the appropriateness of a placement, partly because they found evaluation difficult when visiting a placement and partly because they were uninformed. The fact that the tailoring of the package to meet individual 'needs' is most commonly deferred to some unspecified future date or presented at the point of leaving school, does nothing to boost Carer confidence. There was no evidence to suggest that the majority of YPWMD

made any informed choices about their futures. Indeed only a minority of SLWMD played an active role in the decision-making. For those who did participate in the discussions, they complained about the lack of information regarding opportunities available to them.

Current definitions of statutory responsibility, together with the increasing prevalence of the notion of scarce resources having to be managed effectively, encourage professionals to limit their potential contribution and to structure and control the options available to YPWMD and Carers to the extent that access to public/voluntary sector resources is involved. Contradictions between professional and bureaucratic decision making on the one hand and user-led enabling and empowerment philosophies on the other become all too apparent.

The image of an 'ideal' placement/service package from a Carer and YPWMD perspective tends to be that of a half-way house that is 'small', 'informal/personalised', 'homely', 'developmentally challenging for each specific individual', yet accessible and safe. In practice placements/services of this nature are rarely available. However, analytically there are strong communalities between the professionals' 'normalisation, enabling and empowerment' model, and YPWMD and Carers' ideals.

Proximity to the Carers home was a significant factor together with Carer contact with the placement. It could be argued that as the YPWMD has become, to service providers, an 'adult', then there is a case against Carers being involved with the placement unless invited to do so by the YPWMD. However, it would be fair to allow Carers a period of time in which

to readjust their relationship with the YPWMD and come to terms slowly with their new status. The same point can apply equally to the YPWMD. The 'ideal' type of placement/service package would in the view of Carers provide a level of support sufficient to encourage further personal and social development and would also reduce the degree of dependency of YPWMD on their parents and informal carers. This element of provision be delivered both within placements and within the Carers' homes. For YPWMD to experience a high quality of life, appropriate services must be delivered to the Carer which was found not to be happening in practice. Carers supporting YPWMD at home were critical of the lack of respite care, of home-based aids and adaptations and of the general lack of advice and information.

5.6 The General Findings Highlighted Through Personal Experience :

12 Case Studies

There is a major disjunction in the quality of life experienced by SLWMD. The FNA process fails to adequately plan for the transition to adult-based service provision and delivery and the provision available to SLWMD fails to address their personal and social developmental needs. These conclusions from the major research findings are illustrated in the following case-studies. 12 case-studies are included in order to fully represent different characteristics of the sub-population and to represent different features of the planning and provision of formal post-school services.

The case-studies describe the individual experiences of each Young Person of the FNA process and the post-school provision offered to them as a result of the process. They describe the problems encountered and examples of good and bad practice. Each case-study concludes by stating the quality of life experienced by the Young Person following the transition from

school. The case-studies are a result of the fieldwork carried out during the course of the research and illuminate the experiences of the YPWMD found to exist at that time. The personal situations of each of the YPWMD can have since changed. For reasons of confidentiality, the names of the YPWMD are referred to by letter and the placements are referred to by the code used in the fieldwork and in Chapters 3 and 4.

Included within the case-studies is the spread of functioning levels as described in the functional classification. 5 different home regions are also included. The post-school placements found in the studies represent the different types of settings, 'day', 'residential', 'further education' and hospital. There are examples where the Young Person has not been offered a placement and is at home on a full-time basis. The YPWMD in the studies include those who are satisfied with their quality of life and there are those who are dissatisfied. Some have had 2 post-school placement packages with different types of settings, which have either increased or decreased their quality of life. There are also examples where the placement has come as a 'shock' and that their expectations have not been fully realised.

Within the case-studies are examples of articulate YPWMD who have clearly expressed their views about the future which are either in agreement or conflict with professional and parental intent. Other YPWMD and Carers have passively agreed to decisions made, without active participation, and accepted the outcomes although there are Carers who have actively participated to the point where they have taken on the responsibility for securing formal provision themselves.

None of the case-studies were able to include examples of a 'Named Person' being present to assist and support the YPWMD and the Carers as no evidence was found in the fieldwork of this taking place. Neither is there an example of the Record of Needs being discontinued. All YPWMD keep the

Record open, mainly because this ensures them that FNA meetings will take place and many of the YPWMD have had several FNA meetings, but there are 2 examples where only 1 meeting was held. A consequence of the meetings is that either the transition is well planned or it left until the final school leaving date and the arrangements have to be rushed. Examples of both of these scenarios are included.

5.61 Case Study One

Male (S) Home Region - Lothian
Attended School B as a day pupil Low level of functioning

The young person (S) had the 1st FNA meeting at 15.2. He was given 2 extensions at school until a place was available at D7. It was generally accepted that pupils from the school would be offered a place at D7. However, S left at the beginning of the 2nd extension as it was felt he was no longer benefiting from educational provision. This decision was reached without another meeting being held. Placement D7 was no longer considered suitable and the only placement offered was a hospital placement (H1) which had been used for respite care. It was arranged that S would live at home and attend H1 daily. The Carers passively agreed to this decision as they knew of nowhere else and they were grateful something was offered. Their role at the meeting was minimal and they said that they did not really understand the procedure but that they trusted the school, 'to do their best for us'. They greatly worry about the future as they find it increasingly difficult to cope with S at home especially with the minimal support being offered, no respite care and the Carer's deteriorating health. The Carers described the placement as very institutionalised with limited opportunities for stimulation and self-development.

5.62 Case Study Two

Female (S).
Attended School A as boarder.

Home Region - Strathclyde
Medium-low level of functioning

The young person (S) had the 1st FNA meeting when she was 17.8. The focus of the meeting was on discussing post-school placements as S was due to leave school very shortly.

The 2nd meeting was held when S was 18.3 with discussion on R11, R1, R16, a day-centre/home package and the need for a high level of physical care and help with feeding. The Carers would only consider R11 as they felt the other placements could not offer the support S required. R11 had a long waiting list so S was given a further extension at school, applied and granted in 2 separate instalments.

1 month before S was due to leave school, a 3rd meeting was called. S was aged 20.8 and on her 3rd extension. The Carers refused to attend because no placements had been found for S since the 1st meeting and they feared that they would be pressurised into accepting H1 as they had been pressurised into accepting R1 after the 2nd extension had expired. The meeting was not held. S left school and returned home on a full-time basis.

The Carers, who faced financial difficulties due to redundancy, explained how they had spent a considerable amount of time and money in trying to find a suitable placement. They said that they felt they had to do this because the effort and contribution by the professionals was negligible, particularly support from the Social Work Department. Their final decision to not attend the 3rd meeting echoed their feelings of hopelessness and disillusionment with the system. They wanted S at home rather than attend an unsuitable placement and they had been told about D4 that had recently opened.

S left school and remained without any service provision other than Carer

support for 1 year when she was offered a part-time place at D4. During this time at home, the Carers had only had 1 fortnight of respite care. At the same time S's name was still on the waiting list for R11. They found it increasingly difficult to cope.

During the time S spent at home, the Carers noted how she had regressed in terms of levels of functioning and how she had become withdrawn. This slightly improved when S started at D4. However, S receives no physio and she spends the majority of her time in a 'special care unit' and the mother feels that there is insufficient stimulation and promotion of skills. S shows signs of frustration and displays of temper tantrums which arise through boredom. Another area of unmet need are social needs. As S lives at home there is very little opportunity for her to socialise and integrate with the community except through occasional church events.

5.63 Case Study Three

Male (A)
Day pupil at School B

Home Region - Fife
Medium level of functioning

The 1st FNA meeting was held at school when the Young Person (A) was 15 years. It was concluded that A would benefit from continued education. During this extension period, it was suggested that A should attend F2 to study for Standard Grade, Modern Studies. Discussion was limited to considering educational needs and looking to the short-term future. 4 months before the end of the extension another meeting was held in the Child Guidance Clinic in Fife. There was no representative from the school present. The main conclusion was for A to leave School C in the summer and attend F2 on a full time residential basis for A to gain greater independency and maturity. Very little discussion took place on long-term future arrangements despite the fact that the plans at F2 was only for a very limited period. F2 proved to be a very satisfactory placement and A

had a high quality of life.

The 2nd placement package was planned for a 2 day part-time placement at the local college of Further Education for a 1-2 year course and 3 days at D5. Unfortunately, D5 was full so A only has the college placement which has led to a decrease in quality of life. The Carer was most concerned that the provision offered could not maintain and extend the tremendous progress A had achieved in the last 2 years at F2. The Carer (a mother living alone) described the limited support she received to cope with A at home. There was no respite care and only after much 'fighting' was she given a down floor flat with appropriate aids and adaptations.

5.64 Case Study Four

Male (A)	Home Region - Strathclyde
Day pupil at School C	High-medium level of functioning

The 1st FNA meeting was held when the Young Person (A) was 14.5. It was decided that school education should continue until A is 18 and study for Standard Grade exams for entrance to F4 for 2 years prior to going to university. It was agreed that this plan of action would suit A's present and post-school needs. A participated fully in these decisions.

The 2nd meeting was held 1 year later to up-date the Record of Needs and apply for a further year's extension.

During this time at school, A was able to prepare for the transition to F4 which would involve being residential with weekend visits home. There were also visits to universities to select appropriate courses at F4. A was given a word processor by the local Education Authority on a temporary basis. However, despite the time available to ensure that the transition went smoothly for A, the place at F4 and funding was not confirmed until 4 months before the term started.

A left school as planned and moved into F4. He found settling in easy and

enjoys the academic and social life fully. A felt that all his needs were being met and that his quality of life had slightly improved because he felt that he had outgrown school.

5.65 Case Study Five

Male (D)
Day pupil at School B.

Home Region - Central
High level of functioning

The 1st FNA meeting was held when the Young Person (D) was 15.1. D was making good progress at school and could cope with examinations. It was decided school education should continue until 18. A significant amount of discussion was on present needs and the current work programmes.

The 2nd FNA meeting was held 1 year later, while D was studying for Standard Grade examinations. D had decided that he had outgrown school and he wanted to leave at 16. This caused problems for provision planning as he wanted to leave within a couple of months and because the resources available in his home area were very limited.

The package, put together by the Social Worker, involved D continuing to live at home, attend D2 with the possibility of attending courses at the local technical college, and for continued speech therapy. The Carers were satisfied with these suggestions and had visited D2 on 1 occasion with D but School Staff saw leaving school as a retrograde step in his development.

The outcome of the move from school to D2 has led to a decrease in quality of life. D has left for school for over 2 years and stated, "Ever since I left there (School B) I have gone back the way." D has experienced considerable pain, stiffness and restricted movement because of the lack of physiotherapy and only after the intervention of his G.P. can D attend a local hospital for 1 session of physiotherapy a week. In other areas of functioning D feels he has regressed considerably, especially regarding his

educational stimulation and communication skills as D is very aware that people find it increasingly difficult to understand him, including his own family and he finds this distressing. Because of these problems, he has been asked to change from a full-time course to a less demanding part-time course which he finds less stimulating leading to boredom and frustration. His contact with the Further Education college ceased when due to deteriorating mobility, D was unable to cope with travelling to college. D also felt that his social life was limited. D explained how the majority of people attending D2 were what he described as 'mentally handicapped' whereas he sees himself as 'physically handicapped' For this reason, he feels it is difficult to interact socially and make close relationships. In retrospect, both D and the Carers regret their decision on leaving school. Their 1st impressions of D2 had been mis-founded and they were resentful at the way they were given an inaccurate picture of the provision available to D. Furthermore, they admitted that they had found it extremely difficult to accurately assess the potential of D2 on 1 visit, especially when it was brand new which helped it to look inviting.

5.66 Case Study Six

Male (A)
Boarder at School C

Home Region - Strathclyde
Medium-low level of functioning

The 1st FNA Meeting was held when the Young Person (A) was 15.0. 17 people were present at this meeting but not A. There was no representative from the Social Work Department. The conclusion reached was for A to remain at school until 18 years and R11 was suggested.

The next meeting took place when A was 17.9, a few months before the final school-leaving date. Post-school placements were more fully discussed as the Carers expressed concerns about R11 and there were no vacancies. F4 was suggested as being suitable for A as it could offer the opportunity for

continued education and residential accommodation. 3 other placements were also suggested, R16, F1 and R17. The Carers were only willing to consider F1 but the Authorities were not prepared to fund it. Because of the lack of time and the problem of finding an appropriate placement the Carers went to great lengths to have A funded for a further year at school until aged 19. This was finally granted but only after a considerable struggle with the Authorities. The Carers argued that their application for a bursary was no different than if they requested a bursary for a university place. They felt that if a grant was unforthcoming A would be discriminated against. During this additional year, a further 3 meetings were held. The Carers made great efforts to find a placement. They stated how they had to "push and push and push to get a place" and explained this was because A has multiple disabilities. In the mother's own words, "I think it is all wrong that because he (A) is mentally ^{4/}right and physically all wrong there is nowhere to go".

Finally 2 months before A had to finally leave school a place became available at R11. The Carers said that by this time they had to accept R11 despite earlier misgivings.

During the trial period A expressed his satisfaction with R11. However, this was a 'honeymoon' period and he quickly realised that he was not receiving the degree of development he needed. This was leading to problems of frustration, behaviour difficulties and general signs of regression. There were also problems with A having to sleep in a dormitory with 5 other older men and the toileting arrangements prevented independency and autonomy. For communication A is dependent on computer aids yet these are not available at R11. To compensate, A has access to F5 once a week for 1 session. This has proved insufficient to provide A with the stimulation and continued education he requires and wants. He also lacks any physiotherapy which he is dependent on to prevent stiffness

and additional pain and discomfort. Since leaving school, A has a significant lower quality of life. For this reason the Carers are seriously contemplating A to be at home full-time. They themselves are feeling guilty about A's situation and worried about the future.

5.67 Case Study Seven

Male (I)
Boarder at School A

Home Region - Central
Medium level of functioning

The Young Person (I) was 15.3 at the 1st FNA meeting which concentrated on discussing present needs. It was noted that when I left school he would be wanting a residential placement. 3 placements were suggested, R11, R1 and H2. The Carer was immediately dismissive of H2 but was persuaded by the meeting to consider it. No places were available at R11 so R1 was the only possible placement. The meeting recommended a 2 year extension.

A 2nd meeting was held when I was 16.3. The same placements were discussed with R1 remaining the only possibility. Arrangements were made for the Carers to visit and an application was made for an assessment.

The 3rd FNA meeting was held when I was aged 16.10. The Carer had visited R1 and did not see it as being able to meet I's needs. She was also very upset at being told by the management staff that a place would only be available for I if she proved her commitment to fundraising over a 2-3 year period. She was however persuaded to continue considering it and she described how she felt pressurised but unable to voice her opinions more strongly without support. A further application for an extension was forwarded.

Throughout this time the mother was having serious health problems which resulted in her being hospitalised. This added to her worries for the future and her desperation at finding somewhere she was satisfied with so that if anything happened to her she felt that I would be happy and his

needs met.

The 4th FNA meeting took place when I was aged 17.5 and again R1 was stated as the only placement. I's name was put on the waiting list to take up the 1st available^a place. I was able to stay at school until the summer leaving date, but it was decided for him to accept a place if it was offered in case there was nothing in the summer. The point was also made that if a place was refused now there may not be another offer. The Carer was very unhappy about this suggestion so it was decided that I would go to R1 as soon as a place was offered but that if this was before the summer leaving date, he could attend school on a daily basis. The Carer accepted this because there was no alternative.

Shortly after the 4th meeting I was offered a place at R1 which was accepted on the understanding that he attended school until the summer. The split placement arrangement did not help I who found it very confusing to be in 2 different placements.

At R1, I showed no signs of developing in any skills area. The Carer commented that, "they (R1) seem to be kind to him (I) as he isn't showing any signs of distress". When she was asked about what I did at R1 she said that she understood that he spent a significant amount of time watching videos and television and "one of the residents feeds him." She also added that when I returned home, the clothes that had been bought for him with his own money were too small. Her final comments on R1 was that she "avoided going there (R1) because it upsets me too much seeing those poor pathetic wee souls."

5.68 Case Study Eight

Female (G)
Boarder at School A

Home Region - Strathclyde
Medium level of functioning

The 1st FNA meeting was held at school when the Young Person (G) was 15 years. The conclusion reached, after considerable discussion on present needs, was to make an application for 1 year extension, after which a residential placement that offered stimulation and education was thought to be appropriate in particular, R3 and R11. The Social Work Department was given the responsibility to follow these options.

The 2nd meeting was held when G was 16 years. The Carer wanted an application to be made for a further extension but this was delayed until 2 months before the end of the 1st extension. The Carer felt that nothing was being accomplished and time was rapidly running out.

A 3rd meeting was held, 1 month before the end of the extension period. It was confirmed at this meeting that a 2nd extension had been granted. No further progress was made concerning post-school placements although the Carers voiced their interest in a Rudolf Steiner establishment. They clearly stated that they could not meet G's needs at home. They had not found R11 satisfactory although they had always been led to believe that G would leave School A and go onto R11 and they resented wasting time visiting it as there was a significant waiting list.

Both Carers were extremely critical of the Social Work Representative that was allocated to them and that they had been told that she was unable to offer sufficient assistance because she had never had to "deal with such a case before."

After the 3rd meeting had been held the Carers decided that they would achieve more if they took over the responsibility of securing the final post-school arrangements. The Carers had G assessed with the result that a provisional place was offered in R3. Their intervention was helped by

personal 'influential' contacts. Through this contact they were also offered a choice of 6 different placements which had never been previously discussed and this the carers found very annoying and disturbing that it was through 'chance' that the young person was able to find an appropriate placement. Everything was finally confirmed 1 month before G was due to leave school so there was no time for G to make adequate preparations. R3 has proved to be a very successful placement. The carers feel that G's needs are being met and she experiences a high quality of life, making progress in various skills. The mother stated that "I am only beginning to live after eighteen years."

5.69 Case Study Nine

Male (M)
Boarder at School C

Home Region - Strathclyde
High-Medium level of functioning

The 1st FNA meeting took place when the Young Person (M) was 16.3. It was decided that M would remain at school until 18 then continue his education at F4 and be a weekly resident. A suitable course had been identified and the residential accommodation was found to be acceptable. Many visits had been made through the school by M and the Carers and everyone confirmed that it was appropriate. The meeting was therefore concerned with ensuring that M's present needs and preparation for F4. Responsibility for M after F4 passed to the Authority Careers Officer. No Social Work Department Representative was invited to attend as M was continuing in education and remained the responsibility of the Education Department. M was present at the meeting and fully participated.

Despite high expectations, F4 proved, within the 1st year, to be unable to meet all M's needs, particularly in educational development for which F4 had been selected. The course M undertook was not demanding enough and little progress was made. M has regressed and become depressed and bored. In

addition, in order not to interfere with financial benefits, M was enrolled^L_A as a part-time student studying for no more than 21 hours per week which he found insufficient. His quality of life decreased.

5.610 Case Study Ten

Female (K) Home Region - Lothian
Day Pupil at School B High-medium level of functioning

The 1st FNA meeting was held when the Young Person (K) was 15.1 and an extension to 17 was applied for. This was granted and a further extension was applied for at the 2nd FNA meeting. K was due to leave school at 18. The Carers were not present at either of these meetings.

At both meetings placement D7 (Special Care Unit) was suggested. Many pupils went to D7 and it was assumed that K would do the same because of the lack of alternative placements. All the procedure surrounding assessments and visits to D7 were carried out throughout the latter year at school. Both K and the Carers were happy with this arrangement. During the last 2 years at school K had made significant progress. She needed plenty of stimulation and continued education to maintain and develop the skills she was acquiring otherwise she became bored and frustrated causing temper tantrums.

When it was time for K to leave school she was informed that no place was available at D7. The school did not feel that the Carers could cope with K being at home full-time so it was suggested that K went to H1 which had been used for very occasional respite care. Nobody felt that this was a suitable placement so a further extension of 1 term was given to K. The Local Education Authority reluctantly agreed but pointed out that K was the responsibility of the Social Work Department who had been made aware of K's developmental needs. At the end of this K was finally given a place at D7. Throughout this period, the Carers and K had been very worried and upset.

At D7, K's quality of life decreased. She began to regress, developed severe temper tantrums and she became very withdrawn. The Carer attempted to find an alternative placement but was told she should be content that K was 'going somewhere each day'. She also tried, unsuccessfully, speaking to staff to see if K's needs could be better met. Towards the end of a year of the situation getting progressively worse, the Carer decided K should be at home full-time. By a chance meeting she spoke to a member of staff from D10 and a place was found. Since attending D10 K has begun to re-learn the skills she lost while at D7 and her quality of life has improved greatly.

5.611 Case Study Eleven

Male (S)
Boarder at School A.

Home Region - Strathclyde
High-medium level of functioning

The 1st FNA meeting was held when the Young Person was 16.4. The need for a residential placement was stated and 5 placements were discussed. Out of these, R12 was considered unsuitable, the Carers were against R1 and R9 had no vacancies. This left R11 and R18 as possibilities. An extension was applied for and granted.

The 2nd FNA meeting was held when S was 16.10. The same placements were discussed, despite the negative factors previously raised.

Following this meeting, the Local Authority Social Worker tried to encourage the Carers to visit R1 but they refused even though they were told that there were few alternatives. Placement R18, was also rejected as it was too far from his home. Placement R11 stated that no place would be available because S had Hepatitis B.

When the 3rd FNA meeting was held S was 17.10 with no chance of a further extension as the Education Department had refused to continue funding. No other placements had been suggested and the relationship between the Carers

and the Local Authority Social Worker had broken down. This had led to a series of different Social Workers being assigned to 'the case' who were unfamiliar with S's needs and past events and also unaware of other placements.

The Headteacher then suggested R4 but the details about it were unknown. Because of the pressure of time and lack of an alternative the meeting seized the chance to see this placement as the 'answer to the problem'. S left school in the summer with the intention of taking up a residential place at R4 but at the last minute it fell through and S returned home on a full-time basis.

Throughout this the Carers became very worried and frustrated. They both had major health problems and problems with their other children. The Carers felt they were pressurised into finding placements and into accepting a placement which they did not think was appropriate. At no time was there any support from a 'Named Person'.

S's quality of life decreased when he left school. He lives in the top floor flat of tenement building with his parents. His mother has found that S's speech and mobility have deteriorated.

5.612 Case Study Twelve

Male (A)
Day pupil at School B.

Home Region -Lothian
High level of functioning

The 1st FNA meeting was held when the Young Person (A) was 14.10. The Carers were not present. The meeting discussed A's present needs which were to ensure continued school-based education and behaviour modification so an application was made for 1 year extension which was granted.

At the meeting and during this time at school there was discussion about possible placements for A. These were to be day placements and both A and the Carers wanted D7 and they expected a place to be available when A left

as they saw D7 as 'an extension of (School B)'. The other possibility was for A to attend a local college on a full-time basis as he was attending on day release from school or attend D11 which was still being designed. The carers felt they were unable to make an accurate judgement about D11 so it was dismissed.

A 2nd meeting was planned for when A would be 16.10 but it was cancelled as A decided to leave school. The assessment at D7 had been unsatisfactory. No other placements were available so A returned home on a full-time basis with a low quality of life.

CHAPTER SIX
RECOMMENDATIONS BASED ON THE RESEARCH FINDINGS

6.1 Introduction

The research was an exploratory study concerned with identifying the issues and problems of planning and making provision of formal post-school services for YPWMD. Evidence highlights the inadequacies of the current system of assessing needs and securing appropriate provision which offer a high quality of life.

The final aim of the research was to develop and generate a series of recommendations which take on board the problems of planning and providing formal post-school services as identified through the fieldwork. They are presented within the context of current legislation, the Disabled Persons' (Services, Consultation and Representation) Act (1986), Section 13, and the National Health Service and Community Care Act (1990). Although these pieces of legislation were not applicable during the research period, they have important implications for the research recommendations and these are briefly discussed.

Shortly before the commencement of the research, the Disabled Persons' Act (1986) was passed which set out a way of achieving the planning and provision of services. The sections of the Act relevant to SLWMD were Sections 1, 2, 3 and 13. Section 13 was implemented in 1990 and requires the identification and assessment of need for post-school services of young people considered to be 'disabled' by Social Work Authorities. It is carried out together with the FNA and all conclusions reached are entered in the FNA report. There are new duties placed on the departments of Social Work and Education to collaborate more closely together, exchanging information and planning the transition from school into adulthood, keeping all the young people

under review. Representation by Departments of Social Work is obligatory. These features of Section 13 go some way towards covering the gaps and problems in the FNA procedure. For Section 13 to be fully effective, Sections 1, 2 and 3 should have been implemented as they are central to the objectives and intentions of the Act. However, it was decided by the Government in March 1991 that they would not be implemented.

Towards the end of the fieldwork period, the National Health Service and Community Care Act (1990) received Royal Assent. It gave effect to the proposals made in the White Papers, 'Working for Patients' (1989) and 'Caring for People' (1989). The key elements of the Act are: -

- 1 joint working of statutory agencies, and the voluntary and private sector in the main stages of work - planning, assessment, care management and service delivery
- 2 new community care arrangements should lead to an improvement in quality and effectiveness of services
- 3 the effective management of resources linked to carefully assessed individual needs
- 4 extending the range of service providers to include Local Authorities, Voluntary and Private organisations. The Local Authorities can then provide a wider range of services and greater choice.

The Act will not be fully implemented until April 1993 when Part IV of the Act, certain Part III provisions and Scheduled 9 and 10 are applicable. They are being implemented in 3 stages starting in April 1991.

The central aim of the community care policy is to help people lead full and independent lives in their own homes or in 'homely settings' through appropriate service provision that offers choice. At the same

time there should be a reduction in the reliance on residential care. Carers are offered support. Service provision is to contain flexibility, integration, independency and choice both for people with disabilities and their Carers. There should be a range of services creating a 'spectrum of care' from domiciliary support to residential care in long-stay hospitals. Provision should be organised through joint planning and 'case management' with local authorities having responsibility for delivery.

The research recommendations are divided into 2 sections. The 1st section discusses the recommendations to improve and adapt the school leaving process and the 2nd focuses on the recommendations made for the outcome of the school leaving process. All the recommendations are pragmatic, grounded in the research and starting from what was found through the fieldwork.

6.2 Recommendations for the School Leaving Process

The following recommendations focus on different aspects of the school leaving process which include:-

- 1 the FNA meeting procedure
- 2 the identification of post-school needs
- 3 the role played by Carers
- 4 informed choice of post-school provision
- 5 preparation for life after school.

6.21 The FNA Meeting Procedure

1 The timing of the formal meeting

It is recommended that official recognition is given to FNA meetings held when the YPWMD is between 16-17 years and not only to the present legally required meeting, pre-16. Fieldwork found that YPWMD choose to remain at school until 18 so post-school planning must take place post-16 but with

sufficient time for adequate preparation. Decisions should not be made only a short period of time before the final school leaving date. Planning before 16 concentrates on present needs and forwarding applications for school extensions. Recognition of later meetings will focus discussion on post-school needs and appropriate provision. It was also found that post-school service providers were reluctant to plan post-school provision until the YPWMD was reaching 17.

2 Informed professional participation

For the planning of formal post-school provision to be relevant to the YPWMD and for the provision to meet developmental needs, it is important that the professionals participating in the meetings are well informed about the YPWMD, their individual personal and social developmental needs and the different types of provision available.

Because the YPWMD will depend largely on Social Work Departments for post-school provision, it is essential that a Representative from the Department attends meetings consistently and takes on the responsibility for YPWMD. This requires the Social Worker getting to know both the YPWMD and Carers at the beginning of the school leaving process and accurately assessing post-school needs. This will allow accurate identification and securement of appropriate provision packages together with co-ordinating with other service providers.

Closer co-operation between professionals is necessary. Their participation should be inter-disciplinary and not only multi-disciplinary which only dictates that different professionals put forward their points in isolation of each other. Inter-disciplinary participation forces professionals to interact together and respond to other professional opinions.

3 The meeting agenda

It is recommended that each meeting has a set agenda and where relevant, based on the minutes of the previous meeting. This should be circulated prior to the meeting so all participants can be better prepared and organised and unnecessary repetition could be avoided. The circulation of an agenda could act as a prompt to those participants who have been remiss in carrying out some action that they were directed to do in the conclusions of the last meeting.

If the meeting is the 1st, an agenda would be helpful in setting out clearly the aims of the meeting and list of those people participating in the meeting would also be informative, especially to the YPWMD and the Carers. A list of expected participants could also prompt people into attending.

The content of the agenda must stress the identification of post-school needs and not the emphasis on post-school provision.

4 The role of the YPWMD

YPWMD must play a more prominent role in the FNA process and decisions must be made with the YPWMD and not made for them. For YPWMD to play this role, they must be well informed and well supported.

5 Abolition of crisis management

In order to allow the YPWMD time to prepare for the transition and to avoid YPWMD and Carers feeling worried, stressed and anxious, it is vital that post-school planning is not carried out just before the final school leaving date. This will also prevent YPWMD and Carers being put in the position of being pressurised into accepting a placement, even though they do not feel it to be appropriate, because of the close proximity of the final school-leaving date.

6.22 Identification of Post-School Needs

1 Checklist of IPSD

It is recommended that at every meeting a checklist of IPSD is consulted and used as a means of recording the IPSD of the individual YPWMD. A checklist would concentrate discussion on IPSD and aid identification. All participants, including the YPWMD, should have access to the checklist and discussion should be inter-disciplinary. The participants will have to 'opt out' rather than 'opting in' to a comprehensive statement of post-school needs. The consultations and use of the checklist must precede any discussion on post-school service provision to meet needs.

2 Individually-centred IPSD

The identification of IPSD must be individually-centred. The YPWMD must not be seen as a member of a group with similar disabilities. Every YPWMD is an individual and must be treated as such with their own specific needs and rights regardless of common levels of functioning.

3 Transfer of records

The transfer of documents recording IPSD should take place between schools and post-school placements. These documents should be used as a source of information for post-school service providers to ensure the continuity of provision in the transition and as supplementary information to their own assessments. This practice would prevent any needs being neglected that were addressed at school.

6.23 The Role Played by Carers

1 The briefing of Carers

It is recommended that Carers are well briefed before a meeting takes place so that they understand the process and feel informed to play a prominent and active role. They will also feel more confident in voicing their opinions.

2 The treatment of Carers by professionals

Carers must be treated as partners and fully consulted at all times.

Professionals must not patronise Carers such as using unnecessary professional jargon. If it is necessary, it must be accompanied by simple explanations. Every attempt must be made to put Carers at their ease with meetings taking place in relaxed surroundings, few people attending and ensuring that the Carers are fully acquainted with other participants.

3 The Named Person

Many Carers would find FNA meetings easier to cope with if they were supported by a Named Person as described in legislation. This person would offer pertinent advice and support. For Carers who for different reasons attend meetings on their own, the support of another person would be invaluable.

6.24 Informed Choice of Post-School Provision

For the planning of provision to be effective, it is important that all participating in decision making is informed about the choice of provision. It cannot be determined if provision will meet IPSD when the details about the provision is vague and inaccurate and non-specific to the individual YPWMD.

Information about provision and in particular, placements can be available through a prospectus which lists the placements available with accurate and up to date information on the placement and services offered. Schools could keep a 'library' of information on placements and resource provision accessible to YPWMD and Carers. Such information would have to be frequently up-dated.

Informed choice of provision would be encouraged if Carers were issued with a checklist to take with them when they visited placements. This

checklist could include questions that to provide them with the information they wanted. Before and after visiting placements, YPWMD and Carers should be provided with an information package produced by placements and which may for example include a video about their service provision and delivery.

6.25 Preparation for Leaving School

To help the transition period to be positive and successful for the YPWMD, it is important that the YPWMD has time and is well prepared to cope with leaving school and moving into adult service provision. This can start with an improved school leaving programme which encourages greater independency and maturity and it should include experiences of what will be provided after school. Closer liason between schools and post-school placements would help YPWMD, Carers and staff understand how each placement operates. Placement staff could be acquainted with a Young Person's on-going development programmes and be briefed by School Staff as to how services are delivered. Likewise, School Staff can find out what type of activities the Young Person will experience in the new placement. As part of the school leaving preparation it is important that the Young Person makes several visits including overnight stays where appropriate. This gives both the YPWMD and the placement staff the opportunity to become acquainted and for the YPWMD and the Carer to become familiar with the placement generally.

During the preparation time, it is important that YPWMD are fully involved in all decision-making and planning of services and they make informed choices at all stages.

6.3 Recommendation for the Outcomes of the School Leaving Process

The following recommendations focus on post-school service provision and in particular on:-

- 1 increasing quality of life through improvements in services
- 2 increasing the choice of post-school service provision
- 3 the organisation and administration of post-school services.

6.31 Improvements to Post-School Provision and Delivery

- 1 Greater focus on the individual at the centre of service provision and delivery to meet personal and social developmental needs. Emphasis should be on independency, enabling and empowering.
- 2 Greater emphasis on the development and maintenance of skills in all areas of functioning including more opportunities in continued education.
- 3 Greater recognition by service providers to develop the level of maturity of YPWMD, allowing risk-taking and experiential learning.
- 4 The availability of 'half-way' house type placements so that the YPWMD does not move straight from the school environment to an adult environment.
- 5 The replacement of institutionalised residential provision by small, informal group and individual living provision with appropriate levels of support available.
- 6 Greater attention to promoting community integration on a functional, social and locational level.
- 7 Greater provision of paramedical services, especially physiotherapy and speech therapy by trained and experienced therapists with access to appropriate facilities and equipment. This provision should be made available as frequently and regularly as required by YPWMD and provide continuity with the provision that had been available at school.

- 8 Increased staffing levels in post-school placements with trained, motivated staff with awareness of the Principles of Normalisation. These Principles must be integral to service delivery and the organisation and administration of post-school placements. No staff should adopt a 'nursing' type role or act in 'loco-parentis'.
- 9 All areas of service provision and delivery should be subjected to quality control through a quality assurance policy procedure recognised and implemented by the service provider and the YPWMD.
- 10 Greater provision of services in the Carers' homes to support both the YPWMD and the Carers. In particular, more opportunities for 'respite care' should be available in the form that is wanted by the YPWMD and the Carers. Other services to be available are more appropriate aids and adaptations and greater advice and information.

6.32 Increasing the Choice of Post-School Placements

It is strongly recommended that YPWMD have a greater informed and realistic range and choice of appropriate post-school placements that will meet their personal and social developmental needs. A reduction of the shortage of appropriate placements will reduce the pressure for places and allow YPWMD adequate time to plan and prepare for the transition during the school leaving period. Increasing the number of placements would also mean that YPWMD and Carers would be more likely to have the placement located within their local community which was what they wanted.

6.33 The Organisation and Administration of Post-School Services

- 1 It is recommended that post-school services are perceived as an enabling and development package with the provision and delivery being user-led. Services would be co-ordinated with the YPWMD at the centre

and inter-dependent with a variety of service providers using a variety of resources. No area of developmental need should be unmet. The setting up of the package would be through discussion and consultation between the YPWMD and the provider.

- 2 YPWMD and Carers should have easy access to a person with the responsibility of providing support, advice and counselling after the YPWMD has left school and who could oversee and monitor the provision package if necessary. This person should be independent of the service providers.
- 3 Post-school placements should ensure that the YPWMD has a 'Keyworker', a member of staff with the responsibility for overseeing the provision and delivery of services to the YPWMD and to work interdependently with the YPWMD.
- 4 Post-school services should be organised and administered to ensure continuity with school based provision.
- 5 All service provision and delivery should be regularly and frequently assessed by the YPWMD, the Carers and the providers to ensure that the IPSD of the YPWMD continues and changes are made when required.

6.4 Summary of the Recommendations

The research recommendations focus on the school leaving process and the outcomes of the school leaving process. The broad aims of the recommendations are:-

- 1 To ensure that the FNA procedure plays an effective role in identifying the post-school developmental needs of YPWMD and in planning formal post-school service provision. This requires official recognition of at least 1 meeting held when the YPWMD is post 16.6 years. At all meetings there must be effective informed

participation and YPWMD and Carers playing an active role within the structure of an interdisciplinary assessment.

- 2 To ensure that formal post-school service provision is carefully planned, adopting an individually centred and needs-led approach and which gives YPWMD adequate time to prepare for the transition.
- 3 To ensure that formal post-school services provision follows the independent/enabling/empowering model to meet the IPSD of YPWMD and offer them the potential for a high quality of life.
- 4 To ensure a greater range and choice of post-school placements with greater emphasis on the availability of 'half-way' house type placements, the opportunity for continued education, placements of small size, locally based and if residential, incorporating informal living style arrangements.
- 5 To ensure the development of individual enabling and development packages by YPWMD, Carers and service providers, and which co-ordinate a variety of user-led services from a variety of service providers, providing continuity from school-based provision.

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APPENDIX 3.1

The Profile Questionnaire

PROFILE QUESTIONNAIRE.

This profile questionnaire is designed for all pupils aged 13+ on August 1st, 1986 in order to build up a description of their abilities and disabilities. The questionnaire is divided up into sections with each section focusing on one particular area of the curriculum. Data collected will be used in the research project currently underway on the needs of disabled school leavers. It is important that wherever possible all the questions are answered. Thank you for your co-operation, time and effort.

SECTION 1

GENERAL INFORMATION.

- 1.1 Name of school. (Please tick) Corseford Stanmore Westerlea
- 1.2 Chronological age of the young person years months
- 1.3 Sex of young person (Please tick) Male Female
- 1.4 Mental age of young person years months
- 1.5 Description of the young person's condition ie. diagnosis
- 1.6 Description of the young person's associated handicaps
- 1.7 Description of the young person's prognosis
- 1.8 Father's occupation. (If presently unemployed, please give former occupation if known).
- 1.9 Mother's occupation. (If presently a house-wife, please give former occupation if known).
- 1.20 Please indicate the type of course of study the young person is currently engaged
- (a) Primary level
 - (b) Secondary level
 - (c) Non-applicable
- 1.21 Please list and comment on any inappropriate behaviour patterns exhibited by the young person
eg. self-mutilation, vomiting, rocking.

SECTION 2

MOBILITY

Please indicate the mode of mobility of the young person and tick whether it applies to inside or outside conditions.

Mode of mobility

Inside and outside

Inside only

Outside only

(a) Ambulant

(b) Independent wheelchair mobility

(c) Dependent wheelchair mobility

SECTION 3

MOTOR SKILLS

Please tick the type and quality of motor skills as exhibited by the young person.

MOTOR SKILLS

NONE

POOR

VARIABLE
QUALITY

GOOD

(a) Gross motor skills

(b) Fine motor skills

(c) Perceptual motor skills

SECTION 4

COMMUNICATION

Please indicate below the type of communication used by the young person in an 'every-day' type situation

(a) The young person uses conventional speech and can be understood

(b) The young person uses conventional speech but has difficulty in being understood

(c) The young person uses sign or symbol language, or both (eg. Makaton, Bliss)

(d) The young person uses the following types of methods for communication
hand pointing, crying, vocalisations, gestures, eye pointing etc.

(e) The young person is unable to communicate in any way

SECTION 5

INTERACTION

Please tick what degree of interaction the young person has with the following

HIGH

LOW

NON-EXISTENT

(a) Parents

(b) School staff

(c) Classmates

(d) Other children

(e) Strangers

SECTION 6**COMPREHENSION**

Please indicate the degree of comprehension and recognition the young person has in the following aspects shown below. In each case, please tick as applicable.

GOOD

BAD

NON-APPLICABLE

- (a) Basic objects i names of
 ii use of
 iii selection of

- (b) Basic colours i names of
 ii matching of
 iii selection of

- (c) Basic shapes i names of
 ii matching of
 iii selection of

- (d) Words i simple
 ii complex

- (e) Pictures i simple
 ii complex

- (f) Numbers i simple
 ii complex

- (g) Size i simple
 ii complex

SECTION 7**LIFE SKILLS**

7.1 TOILETING Please tick as appropriate

- (a) Doubly incontinent
(b) Singly incontinent
(c) Toilet trained (for the majority of the time)

7.2 FEEDING Please tick as appropriate

- (a) Complete assistance required
- (b) Some assistance required
- (c) The young person can feed self

These answers should apply to normal everyday meals and snacks

7.3 DRINKING Please tick as appropriate

- (a) Complete assistance needed
- (b) Needs cup held
- (c) Drinks un-aided

7.4 PERSONAL HYGIENE AND DRESSING

Please indicate the degree of assistance required by the young person in each of the following activities

DEGREE OF ASSISTANCE THE YOUNG PERSON REQUIRES

FULL

PARTIAL

NONE (can manage by self).

- (a) Wash hands
- (b) Wash face
- (c) Wash body
- (d) Undressing
- (e) Dressing

THANK YOU VERY MUCH FOR ALL YOUR ASSISTANCE.

APPENDIX 3.2

Coding Sheet for the Profile Questionnaire

Question	High	Medium	Low
2	1, 2, 3	4, 5, 6	7, 8, 9
3	10, 11, 12	4, 5, 6, 7, 8, 9	1, 2, 3
4	1	2, 3	4, 5
5	1, 2, 3, 4, 5,	6, 7, 8, 9, 10	11, 12, 13, 14, 15
6 a	1, 2, 3	4, 5, 6	7, 8, 9
b	1, 2, 3	4, 5, 6	7, 8, 9
c	1, 2, 3	4, 5, 6	7, 8, 9
d	1, 2	3, 4	5, 6
e	1, 2	3, 4	5, 6
f	1, 2	3, 4	5, 6
g	1, 2	3, 4	5, 6
7 a	3	2	1
b	3	2	1
c	3	2	1
d	11, 12, 13, 14, 15	6, 7, 8, 9, 10	1, 2, 3, 4, 5

APPENDIX 3.3

Strands Three and Five : Methods of Data Collection and Processing

The methods of data collection and processing were similar for both Strands Three and Five of the fieldwork strategy. They are therefore described together in Appendix 3.3.

In both sets of fieldwork, data was collected through conducting semi-structured interviews (see Appendix 3.4. and 3.5.). Both interview schedules were divided into sections so that separate areas of information could be collected and these section corresponded to the aims set down for the fieldwork. A semi-structured interview was used to ensure comprehensive data collection and allow the interviewee the freedom to express opinions and discuss experiences.

In both investigations, it was planned to record each interview but in the event of this not being possible the interviewer took detailed notes.

Interviews that had been taped were transcribed and together with notes from the non-taped interviews the information collected was recorded on a data base. This was divided into sections which matched the sections in the interview schedule. The decision was made not to use computer spread sheets because of the relatively small number of respondents involved and to ensure that information difficult to code was not excluded or misrepresented in the final results

APPENDIX 3.4

Strand Three : Carer Interview Schedule

Section One - FNA Meetings

- 1 meetings attended
- 2 comparisons between meetings
- 3 purpose of meetings
- 4 attitude to meetings

The following questions to be asked for each meeting attended: -

- 5 venue
- 6 Chairperson
- 7 people present and their participation
- 8 discussion details
- 9 Carer participation
- 10 Young person participation
- 11 decisions and conclusions reached
- 12 attitude to extension procedure

Section Two - Post-school placements

- 1 number/types/names/details of placements
- 2 knowledge of placements
- 3 visits to placements
- 4 attitude to placements
- 5 placement expectations
- 6 information on placements
- 7 placements offered/accepted
- 8 satisfaction/dissatisfaction with placements

Section Three - Post-school needs

- 1 identification of Young Person's post-school needs
- 2 aspirations for the Young Person

Section Four - Current formal service provision

- 1 details of current formal services provision
- 2 details on contact with service providers
- 3 satisfaction/dissatisfaction with provision/providers
- 4 gaps in provision
- 5 information/knowledge/advice on provision available

Section Five - Social Background

- 1 age/occupation/health of Carers
- 2 details of siblings
- 3 house tenure/size/adaptions for Young Person

APPENDIX 3.5

Strand Five : Young Person and Carer Interview Schedule

Section One - Post-school Placement

Questions repeated for each post-school placement

- 1 name/type/location of placement(s)
- 2 date placement started/age of Young Person
- 3 attendance details
- 4 description of placement(s)- physical features
staffing
services provided
activities offered
- 5 satisfaction/dissatisfaction with placement(s) and reasons
- 6 comparison with school based service provision
- 7 Young person attitude to progress/regression since leaving school
- 8 Carer contact with placement(s)
- 9 placement attention/meeting post-school needs of Young Person
- 10 where applicable - comparison between post-school placements

Section Two - Transition Period

- 1 description of experiences in components of the transition period
 - initial visits/arrangements
 - assessment procedures
 - length of time between school and placement(s)
 - trial period/settling in period
 - time period between accepting placement and taking up place
- 2 when/where placement(s) suggested
- 3 first impressions of placement(s)
- 4 choice of placements
- 5 readiness/preparation for leaving school

Section Three - Placement Expectations

- 1 placement expectations - real/imaginary
- 2 placement preferences

Section Four - Future aspirations

- 1 aspirations for the future concerning post-school placements

Section Five - Formal services provided outwith the placement(s)

- 1 description of formal services and service providers
- 2 satisfaction/dissatisfaction with services and services providers
- 3 gaps in provision

APPENDIX 3.6

Strand Four : Data Collection and Processing

1 Data Collection

Data was collected by interviewing placement staff and by making a detailed observation of the placement. 2 interview schedules were drawn up, 1 designed for a 'residential' type placement (Appendix 3.7) and the other for a 'day' type placement (Appendix 3.8). Selected parts of both schedules were used if a placement functioned as a 'residential' and a 'day' placement including Further Education placements. The schedules were semi-structured to allow for additional information to be recorded. Both schedules were divided into 5 sections.

The observation of the placements was carried out using 2 observation schedules, 1 for 'residential' type placements and the other for 'day' type placements (Appendix 3.9 and 3.10). Selected parts of both schedules were used for a placement offering both 'residential' and 'day' type provision. The schedules list the service provision/delivery under the headings of privacy, independency, autonomy and development that is required for the personal and social development and functioning of YPWMD.

2 Recording and processing the data

Whenever possible the interview was recorded and the transcription together with observational and other additional information were recorded on a data base. This was divided up into different areas of need and services required to meet those needs within a 'residential' type setting and within a 'day' type setting. Information from the data base gives an account of what needs are met, what services are offered and in what manner the services are delivered for each post-school placement. Gaps in service provision and delivery could then be identified.

APPENDIX 3.7

Post-School 'Residential' Type Placement Interview Schedule

SECTION ONE - PHYSICAL ENVIRONMENT.

- 1.-1. Is E geographically isolated from amenities/facilities (ie. need travel facilities)?
- 2. Is E on a hill?
- 3. Is E among 'ordinary' housing?
- 4. Is E in a 'poor' area?

2. Access

- Internal
- 1. is there access to all parts of the building?-if not why.
 2. list no-go areas for S.U.
 3. are there adequate facilities for re-charging w/chairs
- External
- 4. is there access to the grounds?
 5. access at all times?

- Community
- 6. what are the internal transport facilities into the comm.
 7. can it be used any-time?
 8. can people go alone?
 9. what alternatives are there?
 10. details on public transport opportunities
 11. are any areas locked so access curtailed at any time?

3. Is there an overall impression of the place being homely or institutional?

- 1. eating in small groups
- 2. no batch processing
- 3. private facilities/small group sharing
- 4. unobtrusive staff/admin facilities
- 5. no uniforms
- 6. no rules/regulations pinned up
- 7. unobtrusive notice-boards
- 8. no queueing
- 9. non-institutional external appearance
- 10. homely features-curtains, rugs, mirrors, pictures
- 11. smells
- 12. external sign
- 13. adequate heating
- 14. adequate safety provision

4. Details of sleeping/living areas

- 1. number of rooms
- 2. does S.U. have own bedroom?
- 3. own choice of furnishings
- 4. own choice of decor
- 5. lock own door
- 6. have own letter-box
- 7. have own doorbell
- 8. personal storage space
- 9. personal locks
- 10. nameplates
- 11. accessible light switches
- 12. accessible heating switches

SECTION ONE PHYSICAL ENVIRONMENT (continued).

4. Details of sleeping/living areas continued.

- 13. basic furniture - 1 armchair
 - 1 chest of drawers
 - wardrobe facilities
 - table
 - bed
- 14. is room also used as a living room or is only lounge area communal?
- 15. can certain pets be kept?
- 16. own choice of bedding
- 17. television aerial
- 18. telephone point
- 19. non-slip floor material in rooms
- 20. own possessions

5. Details of bathrooms.

- 1.- personal washing areas?
- 2. toilet areas
- 3.- doors lockable?
- 4.- alternatives- numbers/ratios
- 5. degree of privacy
- 6.- aids/adaptations
- 7.- own wash-hand basin

6. Details of lounge areas

- 1.- description of what is provided

7. Details of cooking and eating areas

- 1.- what provision is made for making meals
- 2. making snacks
- 3. eating
- 4. making drinks
- 5.- provision of appropriate equipment/utensils/eating aids

8. Details of laundry areas

- 1.- can S.U. do own laundry
- 2.- what restrictions are there?

9. Details of the grounds

- 1.- describe the recreational areas
- 2.- describe the functional areas

10. Details of specialist areas

- 1.- what provision is made to offer space for specialist activities
eg. S.U.s' hobbies.

11. Call system

- 1.- describe type
- 2.- efficiency

SECTION TWO - Staff with direct contact with S.U.

1. Total number of staff.

Specialist staff.

2. Number of specialist staff and description

3. Are any of the specialist staff unqualified?

4. How many are

-1. full-time

-2. part-time

-3. volunteers

5. What are their hours per week

6. Contact between staff and S.U.

-1. amount of contact time per S.U.

-2. frequency of contact

-3. individual/group work

Support staff.

7. -1. Number

-2. Name

8. How many are-

-1. full-time

-2. part-time

-3. volunteers

9. Ratio of support staff to S.U. -throughout day -1. am.

2. pm.

3. evening

4. night

Organisation of support staff.

10. Staff rotas and shift systems.

-1. Number of shifts.

-2. Duration.

-3. Arrangements for handover eg. meeting held?

-4. Timing of shifts.

-5. Does one support staff have responsibility for one S.U. all time or for a group or for all S.U.?

11. Uniforms -1. what is the policy on uniforms

-2. reasons for the policy

-3. who wears uniforms

-4. describe uniforms

12. Terms of address - 1. how staff address S.U.

2. how S.U. address staff

13. Are support staff familiar with different means of communication.

14. Rate of staff turnover.

SECTION THREE - SERVICE USERS.

1. Name given
2. Number in total
 - age
 - sex
3. Details of range of disabilities/levels of functioning
4. Details of medical problems
5. Catchment area of service users
6. Are the S.U. segregated - (if yes answer 1.-3.)
 - 1. by age
 - 2. by sex
 - 3. by disability
7. Maximum period of stay:
8. What procedures/committees exist for S.U. to make management decisions?
9. What ways can S.U. -1. voice opinions?
 - 2. make complaints
10. Relationships? Can sleep out? Have boy/girl friends back? Sleep with other S.U.?
11. Attitude of staff to S.U.
 - 1. how is a visitor introduced?
 - 2. does staff enter room without knocking?
 - 3. is permission asked to look/visit first?
12. - 1. who has responsibility for following - special diets/visits to G.Ps/dentists etc/medication/check ups and treatment arrangements.
 - 2. who checks up?
13. personal aids. - who organises their need/provision/maintenance and servicing

SECTION THREE - Service users. continued.

11. School leavers. (ie. 18-25)

-1. What specific problems do school-leavers present?-

- a immaturity
- b homesickness
- c inappropriate behaviour
- d resentment to authority
- e inappropriate relationships
- f unable to handle 'freedom'
- g lack of independency

-2. How deal with problems

-3. How well do young S.U. usually settle in?

12. What is provided to help with transition needs?

- a placement procedure
- b loss of friends
- c new routine
- d distance from home
- e new friends/acquaintances
- f new support staff
- g absence of structured timetable
- h new location of home base and surrounding community

13. What is provided to cope with young disabled peoples' specific adolescent needs?

- a lack of maturity
- b lack of independence
- c lack of opportunity to 'risk take'
- d lack of life/social experiences
- e mobility problems
- f unable to have had experience with opposite sex, drink etc.
- g treated child - like
- h low future aspirations or unrealistic expectations
- i great concern about personal appearance eg. if drool, speech problems
- j lack of self confidence

14. Is the young person offered - the same accommodation as other residents?

- the same support network?
- the same facilities?
- the same activities/training?

SECTION FOUR - ACTIVITIES

1. Organised activities -1. What activities are offered? (*if compulsory)
2. How organised?

- a. Recreational
- b. Academic
- c. Vocational
- d. Social

2. Training programmes -

1. who does the training
2. how is it organised
3. does the keyworker approach exist
4. are targets aimed for
5. how individual is the training programme
6. where does it take place
7. what evaluation takes place to see progress
8. how is review carried out - who

present/frequency/regularity/aims of review

9. detail the training offered to maintain/develop skills in the following areas - washing/toileting

- dressing/undressing
- feeding/food preparation
- mobility
- health care
- communication
- finance
- housekeeping

10. what reviews are there for health-care and social care?

3. Community involvement.

- 1. is it organised or is it left up to the individual
- 2. is it restricted to certain times if so why
- 3. when can S.U. visit home

4. Entertaining/visitors/socialising.

- 1. can the S.U. entertain at any time?
- 2. who?
- 3. where? (in own room)
- 4. can S.U. make own refreshments at any time?
- 5. can S.U. make own meals at any time
- 6. when can parents visit.

5. Living activities. (how organised/time-tabled/flexibility)

- 1. eating arrangements- (flexibility/choice/ind. needs/nutritious)
- 2. cooking arrangements
- 3. toileting and personal hygiene (washing/dressing)
- 4. housework
- 5. laundry
- 6. shopping
- 7. personal management eg. finance
- 8. looking after personal possessions including valuable items

6. What are the arrangements for holidays?

SECTION FOUR ACTIVITIES (continued)

7. Typical daily timetable.

Time and arrangements - 1. for getting up/washing/toileting/dressing

2. breakfasting

3. a.m. activities

4. lunch

5. p.m. activities

6. tea

7. evening activities

8. getting to bed/washing/undressing

8. What parts of the daily regime are compulsory/free?

SECTION FIVE - AIMS AND POLICIES OF THE ESTABLISHMENT.

1. What does the Manager see as the aims of the establishment? -

- 1. Is independent living promoted
- 2. Is temporary residence encouraged and move into the community
- 3. Meet individual needs or batch processing?
- 4. Freedom of choice/autonomy
- 5. promotion of self esteem/self respect/dignity
- 6. privacy
- 7. maintain physical and mental abilities and encourage development
- 8. encourage risk taking

2. What specific aims are there for the young S.U.

- 1. specific training programmes- achieve maximum potential
- 2. does daily regime differ from rest of residents?
- 3. F.E. opportunities
- 4. specific activities offered?
- 5. specific community involvement

3. Parents- (with relation to school-leavers)

- 1. encourage interaction?
- 2. when is contact made - only at times of crisis?
- 3. are 'reports' sent home to keep parents informed of progree/events
- 4. does establishment see itself in ' loco-parentis'?

4. Admissions/Assessments

- 1. is it carried out to see if S.U. suitable for that establishment or to assess needs?
- 2. how much use is made of FNM reports
- 3. are contracts drawn up with S.U.? details - rentbook/security of tenure
- 4. trial periods
- 5. who makes referral
- 6. assessment procedure
- 7. entrance requirements - levels of care offered
- 8. waiting list
- 9. priority catchment areas?
- 10. is there a brochure
- 11. prior visits
- 12. liaison with schools/parents

5. Rules and regulations

- 1. details
- 2. reasons
- 3. who draws them up/alters

6. Confidentiality of records/information/reviews

7. Funding of places - are allowances organised for residents?

8. Factors affecting service provision/delivery.

RELEVANT INFORMATION FOR THE SCHOOL-LEAVER.

PLACEMENT: _____

1. AVAILABLE INFORMATION/BROCHURE.
2. REFERAL PROCEDURE.
3. ADMISSIONS PROCEDURE/ENTRY REQUIREMENTS.
4. ASSESSMENT PROCEDURE.
5. ATTENTION TO F.N.A.
6. WAITING LIST SITUATION.
7. TRIAL PERIOD FACILITY.
8. DISTANCE FROM SCHOOL/HOME.
9. POLICY CONCERNING PARENTS.
10. POLICY TO MEET ADOLESCENT NEEDS.
11. EFFORTS TO EASE TRANSITION FOR YOUNG PERSON.

SCHOOL LEAVER INFORMATION - CONTINUED. PLACEMENT

12. FUNDING OF PLACEMENT

13. DETAILS OF THE OTHER SERVICE USERS - AGE/SEX/LEVELS OF FUNCTIONING

14. LIAISON WITH SCHOOLS AND FUTURE S. U. /PARENTS

15. SPECIAL PROVISION FOR SCHOOL LEAVER

16. LENGTH OF ATTENDANCE

17. PROCEDURE/ADVICE/SUPPORT TO LEAVE CENTRE - FUTURE PLACES

18. INVOLVEMENT WITH RESPITE CARE

APPENDIX 3.8

Post-School 'Day' Type Placement Interview Schedule

Section one Physical Environment.

1. Location

2. Site

3. External access

- Transport arrangements for S.U. to get to centre
- Transport facilities to get into community - public
 - private

4. Internal access

- S.U. can get anywhere in centre
- What areas are inaccessible - why?

5. Details of washing/toileting areas

- number of toilets
- segregation?
- accessibility of toilets
- doors lockable
- aids/adaptations
- number of accessible/adapted wash-hand basins
- facilities for overall wash - accessible/adapted
- accessible switches
- accessible taps
- w/chair access

6. Details of cooking/eating areas

- is there a separate area for eating
- amount of space
- seating arrangement
- where is food prepared
- provision available for making own snacks
 - drinks
- provision of appropriate equipment/utensils/eating aids

7. Details of quiet/rest areas

- does such an area exist?
- carpeted?
- comfy furniture

8. Details of grounds

- extent
- use made of them
- access for S.U.

9. Details of specialist areas

- adequate space
- for therapies - computer area, physio area, ADL area,
- for educational activities - flexible area
- for recreation - private area/rest area

Physical environment - continued.

10. Adequate heating provision
11. Adequate safety provision
12. Adequate lighting provision
13. Adequate ventilation
14. Adequate windows
15. Good standard of decor
16. Good standard of cleanliness
17. Posters/materials/work out on display and for use at any time.

Section two. Staff.

1. Total number of staff

Support care staff. (Describe role)

2. Name given

3. Number in total

 full-time

 part-time

4. Ratio of support staff to S. U.

5. Qualifications/specialisms

Specialist staff. (Describe role)

5. Total number

6. By specialism-

-Number

-Hours per week

-Who full-time

- part-time

- volunteers

-Any unqualified?

-Amount of contact time per S. U.

-Frequency of contact

-Organisation of contact - individual/group work?

7. Uniforms

-policy

-who wears uniforms

-description

8. Terms of address

-how staff address S. U.

-how S. U. address staff

9. Arrangements for staff to discuss

-work and progress of S. U.

-problems with S. U.

-general problems

-staff meeting discussions - arrangements, policy issues, news

10. Extra staff/volunteers/MSU - to release staff eg. for outings, meetings.

11. Training provision

12. Staff turnover - rate and subsequent problems

Section three Service users.

1. Name given
2. Number in total
sex
age
3. Description of lowest level of disability
highest
range of disabilities
medical disabilities
4. Catchment area - distance to travel to centre
5. What ways exist for S.U. to voice opinions
complaints
to take part in running of centre
6. General period of attendance
7. Future moves available
8. Relationship between S.U. and staff - equal
- teacher like
- nurse like
9. Who takes responsibility for health-care
10. Who organises personal aids - needs/provision/maintenance/servicing
11. Contact with parents - formal and informal
12. Contact/liason with other agencies connected with S.U.

Section Five Activities.

1. Skills Development activities

- areas covered/priorities for time - communication
mobility
social
self-help

2. Educational/development activities

- topics covered/priorities

3. Recreation/leisure activities

- description/number/range available

4. Details of community involvement

Support Arrangements.

1. Washing/toileting

- set times?
- support available at all times?

2. Eating/food preparation

- availability of support
- choice of menu?
- option to 'opt out'?
- who prepares food?
- snacks/drinks available during the day?
- time period for eating?

Activities continued.

Training/Development

12. Programmes/aims - S.U. makes up own programmes?
13. Individually needs centred or group centred
14. review/assessment procedures
15. record keeping
16. choice of S.U. to be involved with what activities and development programmes
17. outline typical daily timetable and weekly inputs - length of lunch-time important - S.U. participation in timetabling/regular change in activities/adequate length of day
18. organisation of activities
19. what limits activities
20. established curriculum
21. finance available to fund activities- in/out/extra-curricula
22. equipment for
 - communication aids
 - computer/software
 - physio
 - music
 - educational materials
 - art materials
 - aids for self help
 - aids for life skills
23. Quantity/quality/appropriateness of equipment
24. Finance available for equipment

Section six. Aims and policies of the establishment.

1. Aims as seen by manager
2. Rules and regulations
3. Contract arrangements with S.U. (what if broken?) - to attend centre and to participate in activities.
4. Funding of places
5. Future plans for establishment.

RELEVANT INFORMATION FOR THE SCHOOL-LEAVER.

PLACEMENT: _____

1. AVAILABLE INFORMATION/BROCHURE.
2. REFERAL PROCEDURE.
3. ADMISSIONS PROCEDURE/ENTRY REQUIREMENTS.
4. ASSESSMENT PROCEDURE.
5. ATTENTION TO F. N. A.
6. WAITING LIST SITUATION.
7. TRIAL PERIOD FACILITY.
8. DISTANCE FROM SCHOOL/HOME.
9. POLICY CONCERNING PARENTS.
10. POLICY TO MEET ADOLESCENT NEEDS.
11. EFFORTS TO EASE TRANSITION FOR YOUNG PERSON.

SCHOOL LEAVER INFORMATION - CONTINUED. PLACEMENT

12. FUNDING OF PLACEMENT

13. DETAILS OF THE OTHER SERVICE USERS - AGE/SEX/LEVELS OF FUNCTIONING

14. LIAISON WITH SCHOOLS AND FUTURE S. U. /PARENTS

15. SPECIAL PROVISION FOR SCHOOL LEAVER

16. LENGTH OF ATTENDANCE

17. PROCEDURE/ADVICE/SUPPORT TO LEAVE CENTRE - FUTURE PLACES

18. INVOLVEMENT WITH RESPITE CARE

APPENDIX 3.9

Post-School 'Residential' Type Placement Observation Schedule

Aims/Policies.

1. Independency
2. Autonomy
3. Privacy
4. Education/development for changing life in the community
5. Normalisation/integration in the community
6. Meeting individual needs
7. Service User participation in decision making/management
8. Self-development/self-determination.

Service provision for basic/personal needs.

Washing/toileting.

- Privacy - private bath
- private toilet
- private wash basin
- lockable doors
- staff preserve privacy

- Independency - support available 24 hrs.
- wheelchair access
- handrails
- hoists
- accessible taps
- accessible switches
- adapted shower/bath
- adapted toilet
- adapted wash basin

- Autonomy - wash/toilet when wish

- Development - regular/frequent advice/learning self-care skills
- aims
- monitoring
- review
- input from professional staff to development
- input from support staff

Eating/Food preparation.

- Independency - make own meals
- make own snacks
- make own drinks
- access
- suitable equipment
- sufficient length of meal-times
- special diets
- support available 24 hrs.
- suitable aids

- Autonomy- eat when wish
- drink
- choice of meals/menu
- choice of snacks
- seating arrangements
- discussion of menus

- Development - regular/frequent advice/learning self-care skills
- aims
- monitoring
- review
- input from professional staff to development
- input from support staff

Dressing/undressing.

- Privacy - private bedroom
- private storage areas
 - lockable door
 - lockable storage space
 - staff preserve privacy

- Independency - support available 24 hrs.
- accessible storage

- Autonomy - dress/undress when want
- choice of dress

- Development - regular/frequent advice/learning self-care skills
- aims
 - monitoring
 - review
 - input from professional staff to development
 - input from support staff

Mobility.

- Independency - complete access
- access to public transport
 - access to private transport
 - electric wheelchair recharging facilities
 - appropriate site/location
 - support available 24 hrs.

- Autonomy - no prohibited areas
- no locked areas unless by agreement
 - exercise choice at all times

- Development - regular/frequent advice/learning mobility skills
- aims
 - monitoring
 - review
 - input from professional staff to development
 - input from support staff

Health requirements.

- Privacy - health details private
- disability details confidential

- Independency - G. P.
- Dentist
 - Optician
 - administers medication

- Autonomy - responsibility/choice medication
- arrangement of treatment/care

- Development - regular/frequent advice/learning self-care/communication skills
- aims
 - monitoring
 - review
 - input from professional staff to development
 - input from support staff

Communication.

- Independency - staff familiar with communication method(s)

- Autonomy - choice of method(s)

- Development - regular/frequent advice/learning communication skills
- aims
 - monitoring

- review
- input from professional staff to development
- input from support staff

Finance.

Privacy - affairs confidential

Independency - responsible for finance/valuables
 - organisation for finances

Autonomy - choice
 - control over allowances/benefits

Development - regular/frequent advice/learning life skills
 - aims
 - monitoring
 - review
 - input from professional staff to development
 - input from support staff

Sleeping.

Privacy - own sleeping area
 - lockable door
 - staff preserve privacy

Independency - support available 24 hrs.

Autonomy - sleep whenever choose
 - choice of bedding
 - choice of clothing
 - choice of habits

Home-Base.

Privacy - private living area/personal possessions
 - private furniture
 - lockable door
 - staff knock
 - own doorbell
 - own nameplate
 - own letterbox
 - own telephone point
 - own television point

Independency - rentbook/contract arrangements
 - responsible for living space
 - support available 24 hrs
 - 24 hr call system
 - accessible switches
 - appropriate/accessible laundry facilities
 - appropriate/accessible cleaning equipment
 - non-slip flooring

Autonomy - choice of movement
 - decoration/furnishings
 - pets
 - organise housekeeping

Development - regular/frequent advice/learning life skills
 - aims
 - monitoring
 - review
 - input from professional staff to development
 - input from support staff

Service provision for social/personal needs.

Privacy - entertain visitors privately

- lock doors
- privacy respected

Independency - support available 24 hrs.

- access within placement
- access outwith placement
- access home

Autonomy - socialise when choose

- socialise with whoever choose
- socialise where choose
- entertain
- community involvement
- lifestyle/sexual relations
- choose staff for personal support

Development - regular/frequent advice/learning social/community skills

- aims
- monitoring
- review
- input from professional staff to development
- input from support staff

Service provision for stimulation/personal needs.

Privacy - private activities

- private space

Independency - individual activities

- appropriate access
- appropriate equipment/facilities
- access into community
- support available 24hrs.

Autonomy - wide choice of activities

- personal choice
- engage in group activities
- engage in community activities
- engage in individual activities

Development - regular/frequent advice/learning appropriate skills

- aims
- monitoring
- review
- input from professional staff to development
- input from support staff

Indicators of 'homeliness'.

eating in individual/small groups

no batch processing

private living/sleeping/washing/toileting/ facilities

small group sharing of cooking/cleaning/eating/facilities

unobtrusive staff/admin facilities

unobtrusive notice-boards

no notices/rules/regulations

no queueing

informal terms of address

non-isolated site

non-institutional exterior appearance

homely internal/external features

small number of residents

no external signs

adequate heating/safety/cleanliness

APPENDIX 3.10

Post-School 'Day' Type Placement Observation Schedule

Aims/Policies.

1. Independency
2. Autonomy
3. Privacy
4. Education/development for changing life in the community
5. Normalisation/integration in the community
6. Meeting individual needs
7. Service User participation in decision making/management
8. Self-development/self-determination.

Development opportunities.

1. Facilities - location within community
 - short travelling distances
2. Space - for activities
 - separate quiet area
 - separate private area
 - separate computer area
 - separate physio area
 - separate ADL unit
 - separate flexible area
 - separate area for eating - adequate access
 - outside area attached to centre/access
3. Infrastructure - heating
 - lighting
 - ventilation
 - windows
 - good standard of decor
 - good standard of cleanliness
 - safety
4. Equipment - communication
 - computers/W. P.
 - software
 - physio
 - music
 - educational materials
 - self-help skill aids
 - life-skill aids
 - art materials
 - sufficient quantity
 - quantity
 - suitability
 - available finance
 - transport

Staffing.

1. Non-specialist staff - ratio for 1:1 development work
 - training/specialisms
2. Specialist staff - permanent/full-time/regular individual contact
 - physiotherapist
 - speech therapist
 - occupational therapist
 - educational support
 - instructors
3. Extra staff - use of volunteers
4. Training - regular/specific/monitored

5. General - 'caring' title not given
 - uniforms not worn
 - titles not used
 - minimum rules/regulations
 - complaints/suggestions procedure
 - liason with outside agencies
 - staff turn-over low
 - time for staff discussions
 - regular meetings service users/staff

Organisation of activities/development experiences.

1. Curriculum - includes components - mobility skills
communication skills
life skills
social skills
recreation
education
extra-curricular
community involvement/integration
2. Structured daily timetable - choice
 - regular changes
 - service user decides timetable
 - 'opt-out' arrangements
3. Individual development programmes - aims established
 - service user/staff determine it
 - assessments/monitoring
 - reviews
 - detailed record keeping
4. Individual activities within and outwith placement
5. Group activities within and outwith placement
6. Attendance by contract
7. Regular contact with carers
8. Available finance for activities

Support services.

1. Washing/toileting

Privacy - lockable door
 - staff preserve privacy
 - private shower area
 - segregated

Independency - accessible taps
 - accessible toilet
 - accessible wash-hand basin
 - accessible switches
 - accessible shower area
 - adapted toilet
 - adapted wash-hand area
 - adapted shower area
 - handrails
 - access
 - available support staff

Autonomy - choice exercised at all times

2. Eating.

Independency - aids
- time
- support available
- attention to special diets
- make own snacks/drinks
- food preparation

Autonomy - choice on menu
- sit anywhere
- choose snack/drink

3. Mobility.

Independency - access total in placement
- support always available
- transport available
- access into community
- transport into community

Autonomy - no restricted areas
- choice to come/go into community

4. Communication.

Privacy - quiet/private area

Independency - use own method/staff knowledge/familiarity

Autonomy - choice of communication

APPENDIX 4.1

Individual Profiles

Profile 1

Age when survey conducted : 15.9 Sex : Male
Home region : Lothian School : Day pupil at School B.
Functional classification : High

A is ambulant both indoors and outside and enjoys being independent. He copes well with motor skills when using his left side but his skills are poorer when using his right. Communication is by conventional speech and when not too excited he can be well understood. He very much enjoys helping to do odd jobs especially around the garden and with cars. Basic comprehension is good. School records show an I.Q. in the mid 50s and a mental age of 3.0 years. He interacts well with all school staff, peers and other adults. A is continent and only requires very little assistance doing up fastenings when dressing/undressing. A can exhibit some unpredictable and inappropriate behaviour when frustrated.

Profile 2

Age when survey was conducted : 17.3 Sex : Female
Home region : Lothian School : Day pupil at School B.
Functional classification category : High/Medium

A is ambulant both inside and outside. She is continent and requires very little assistance with daily living skills. Some help is needed to cut up food, for dressing/undressing and for washing. She can sometimes show inappropriate behaviour by rocking though it is not clear when this happens and why. Communication is by conventional speech though it can be indistinct and affected by excessive drooling. School reports show a mental age of 4.6 years and comprehension is variable being better with naming and understanding the use of basic objects and colours. A has visual difficulties which hinders her comprehension. She interacts well with family and school staff but her degree of interaction is lower with peers and strangers. Motor skills are of variable quality.

Profile 3

Age when survey conducted : 18.6 Sex : Male
Home region : Strathclyde School : Residential pupil at School A
Functional classification category : High/Medium

S is ambulant both inside and outside. He has variable quality gross motor skills and no fine or perceptual motor skills. Comprehension is very poor with a higher degree of comprehension about the names and uses of very basic objects. S communicates using conventional speech but his speech is very repetitive and sometimes meaningless. He interacts well with familiar adults but tends not to wish to interact with strangers or peers. S is continent and he requires very little assistance with daily living skills although he needs to be supervised. At present he is on anti-convulsant medication.

Profile 4

Age when survey conducted : 15.2 Sex : Male
Home region : Strathclyde School : Residential pupil at School A
Functional classification category : Medium

The young person comes from a very insecure home background and is presently under the guardianship of his older sister. The family do not give S all the attention he requires and he is left short of necessary items of clothing and material possessions. However, despite these problems, S is a very sociable, outgoing and happy character, communicating

through the use of a lightwriter and Bliss as he has no other form of communication except eye-pointing and gesturing. S has dependent wheelchair mobility outside but can be more independent inside. Interaction tends to be less with classmates but good with everyone else including strangers. Motor skills are of variable quality and comprehension is good with S taking a great interest in all around him. He is continent and requires full assistance for all basic personal needs. School records show a mental age of 9.0 years.

Profile 5

Age when survey conducted : 19.3 Sex : Female
Home region : Strathclyde School : Residential pupil at School A
Functional classification category : Medium

S is non-ambulant but is mobile in a self-propelling wheelchair requiring supervision at most times. She can 'bunny-hop' around small indoor areas. Fits have been controlled since infancy with medication. Communication is non-verbal in the conventional sense as S vocalises and points. Motor skills are poor and fine motor skills are non-existent. She interacts well with parents and school staff but less so with peers and strangers. S's comprehension is limited to the names and uses of basic objects. Her mental age is reported to be 2.8 years. She is continent and requires some assistance with daily living skills.

Profile 6

Age when survey conducted : 15.10 Sex : Female
Home region : Lothian School : Residential pupil at School A
Functional classification category : Medium/Low

L has dependent wheelchair mobility both indoors and outdoors and she exhibits no fine motor skills or perceptual motor skills. Her gross motor skills are of variable quality. L has no conventional form of communication and can make herself understood by eye-pointing and occasionally with Bliss. Comprehension is described as good in all areas apart from more complex words and numbers. School records show a mental age of 5.0 years. The degree of interaction is dependent on the person, good if parents and school staff but low with peers and strangers. L is doubly incontinent and requires complete assistance for all living skills. She tends to keep in poor health and has recurring chest complaints which become more acute during the winter months.

Profile 7

Age when survey conducted : 13.7 Sex : Female
Home region : Fife School : Day pupil at School B
Functional classification category : Medium to Low

The young person (C) is non-ambulant and fully dependent on a wheelchair indoors and outdoors, requiring assistance at all times. C has poorly developed motor skills and uses her right hand more than her left. Communication is through vocalisation, especially squealing and she has inappropriate use of a very limited number of phrases. Comprehension is restricted to a very limited inconsistent knowledge of the names and uses of basic objects. School records show that C has a mental age of 2.6 years with an assessed I. Q. of below 40. Interaction is good with her parents but not with peers. C is doubly incontinent and requires assistance with feeding, washing and dressing/undressing. At times C exhibits inappropriate behaviour by grabbing and chewing random objects. Care must be taken at all times in case of epileptic fits.

APPENDIX 4.2

Three Case Studies Describing Individual Experiences of the FNA Process

Case Study One

Young Person: - (L), Female, Boarder at School A, Low-Medium level of functioning.

FNA Meeting One

This meeting was the 2nd FNA for L. She was 15.10 and due to leave school in Summer 1988. At the 1st FNA meeting, held in School B prior to the commencement of the fieldwork period, the decision had been reached that L would benefit from moving to School A for 1 year and then spending a further year at School A as an extension. L had become a boarder when moving to School A.

Present at the meeting were: -

- | | | | |
|---|----------------------|---|--|
| 1 | Headteacher | 4 | Teacher |
| 2 | School Social Worker | 5 | Carer |
| 3 | School Nurse | 6 | Local Authority Educational Psychologist |

The Local Authority Social Worker had been invited, agreed to attend but then failed to appear. The Careers Officer did not attend because L would not be seeking employment after leaving school. The Community Doctor was at a funeral.

The Headteacher chaired and minuted the meeting which was divided into discussing how well L was settling into School A and discussing post-school placements.

The discussion on the 1st part passed over quickly as L had settled well into school and was adjusting well to boarding.

The 2nd part began with the Carer being asked if she wanted a residential placement. The question was asked because L had moved to School A as there had been management problems at home. However the Carer made it clear that she was very doubtful about a residential placement. She admitted to feeling very worried and anxious and that this was affecting her health and personal circumstances. She said that she felt particularly concerned about whether L could cope with an adult type environment. She admitted that L was 'babyed' and also L was expected to leave when still only 17 years.

The meeting then turned to discussion on actual placements. The 1st was a hospital placement located very near the Carer's home. The School Social Worker explained that she did not know the placement but thought that there was an adolescent unit attached to the hospital and that this would help with the problem about L moving into an adult environment. The only needs expressed in relation to the placement was that L required a 'high staff ratio' and physiotherapy but after this was stated there was no information as to whether this placement could offer such a provision.

This was the only possible placement to be mentioned which upset the Carer who was angry that such a situation was ridiculous and that her child was leaving school in a short period of time with nowhere to go to. She stated that she wanted a placement that resembled School A but geared to adults and that there was a great need for such a placement especially as Carers get older and can no longer cope with offering the degree of support required. Other members of the meeting agreed with her comments but reminded the Carer that she had been 'spoilt' with the provision available at school and that she could not expect to find the same quality of provision in an adult placement.

The conclusions reached at the end of the meeting included: -

- 1 The Headteacher suggested a 'Caresearch'
- 2 Headteacher requested a further extension due to the lack of available placements at present and give more time to find somewhere.
- 3 The meeting agreed that at the next meeting the Local Authority Social Work department had to be represented
- 4 Next meeting in 9 months

FNA Meeting Two

This was the 3rd meeting. The members present included the following: -

- | | | | |
|---|--------------|---|-------------------------------|
| 1 | Headteacher | 4 | School Social Worker |
| 2 | School Nurse | 5 | Carer |
| 3 | Teacher | 6 | Local Authority Social Worker |
| | | 7 | Community Doctor |

Absent were the:- Local Authority Educational Psychologist and the Local Authority Careers Officer.

The meeting was chaired and minuted by the Headteacher.

The meeting was held in 2 parts with the 1st being concerned with L's present school progress. Reports were read out and commented on. It was stressed that L had very individual means of communicating and eating and therefore at any future placement it would be important for support staff to be well informed. Concern was expressed as to L being unsettled in recent months. The carer made no comments throughout these discussions.

The meeting then moved to post-school placements. The extension had been granted and that L would now leave school in Summer 1989. The Carer was very pleased and this was the 1st time she had heard the news. Between the meetings, the Carer had visited the hospital placement and agreed that she liked what she had seen although this had been limited. The Community Doctor stated that a long term placement was unlikely as it was against current policy. Therefore, although this placement had been the only 1 discussed at the last meeting it was not likely to be a possibility.

The meeting then turned to the Social Work Representative to make placement suggestions. She stated that she understood that a residential placement was required because the carer's home was not fully equipped to deal with L's needs but that there would be no money available for the provision of any aids or adaptations. She could only suggest 1 placement but she did not know anything about it. The Headteacher knew it would not be suitable because she had visited it. When pressed to make suggestions, the Social Worker explained that she could only make tentative suggestions and she would need to make more detailed enquiries later. To make the situation more stressful, the Representative informed the meeting that a Field Social Worker could not be allocated until 6 months before the school leaving date. The meeting concluded with the following lines of action:-

- 1 Arrangements to be made for time to be spent by L at the placement
- 2 Respite arrangements to be set up
- 3 A Field Social Worker to be allocated as it was vital there was someone who could identify possible placements.
- 4 The next meeting was arranged for four months time.

FNA Meeting Three

This was the 4th meeting. Members present included:-

- | | | | |
|---|----------------------|---|----------------------------|
| 1 | Headteacher | 5 | Carer |
| 2 | School Nurse | 6 | L. A. Field Social Worker |
| 3 | School Social Worker | 7 | L. A. Divisional Assistant |
| 4 | Teacher | 8 | Community Doctor |

Apologies were given by the Local Authority Educational Psychologist. The Headteacher chaired and minuted the meeting.

The meeting began with a review of current progress. It was stressed that a larger wheelchair would help L with her communication systems. The Headteacher stressed that this meeting had been held so soon after the last because of the lack of Social Work involvement.

The meeting then moved onto the post-school needs section. The Field Social Worker explained that he had not yet met L and the Carer. It was stressed that a residential placement was wanted but he could make no suggestions. When the Headteacher asked about new placements planned for Lothian, she was told that no finance was available and that residential

placement provision was already overstretched due to community care policies being implemented. Plans to let L go to the hospital placement had not taken place and she was still waiting to hear a confirmation from the hospital placement as to whether a long term place could be offered.

There then followed a controversy over when to hold the next meeting. The school and Carer wanted another meeting in 7 months whereas the Social Work Representatives wanted to leave it for a year. The former was decided. The meeting closed with the following conclusions:-

- 1 Community Doctor to contact the hospital placement to chase up a decision
- 2 Carer and Field Social Work to arrange L to stay in the hospital placement for respite and visit other placements.
- 3 Field Social Worker to become acquainted with the needs of L the carer.
- 4 Next meeting set for 7 months time.

Postscript

The 5th meeting did not take place at the date set and in fact took place outwith the fieldwork period 3 months before L was due to leave school. The researcher was informed that at this meeting no further progress was made in identifying and securing a residential placement for L. The meeting concluded that a further extension should be applied for up to L's 19th birthday. The alternative is that L would have to return home but the Carer's house is not suitable. A following meeting was set for the time L was due to leave school.

Case Study Two

Young Person: - (S), Female, Boarder at School A, Medium level of functioning

FNA Meeting One

This was the 1st FNA meeting. S was 16.4.

Members of the meeting included:-

- | | | | |
|---|--------------|---|-------------------------------|
| 1 | Headteacher | 4 | School Social Worker |
| 2 | School Nurse | 5 | L.A. Educational Psychologist |
| 3 | Teacher | 6 | Carers |

Apologies were received from the Careers Officer and the Special Needs Co-ordinator. There was no Local Authority Social Work Representative although an invitation had been sent. It was decided therefore that the minutes of the meeting should be sent to the Area Organiser in S's home district (Fife Region).

Meeting was chaired by the Local Authority Educational Psychologist and minuted by the Headteacher.

Discussion began with a review of S's current progress at school including a significant time spent on discussing S's progress in the area of communication and physiotherapy. Certain concern was expressed over S's health situation and contact has to be made to a Medical Officer as no-one was present. It was concluded that S should remain at school until 18 so an extension was to be applied for. This section had taken up the majority of the meeting's time.

In the 2nd part the discussion centred on identifying and assessing possible placements. It was stated that the Carers wanted a residential placement. 5 different placements were put forward by the Headteacher and the School Social Worker. The Carers immediately dismissed the suggestion of a hospital placement. 2 residential placements were suggested. 1 of these was dismissed by the School Social Worker because their policy was not to take on school leavers. The Carers were unsure of the other because of the significant distance from their home but it was decided that they would visit the placement, a further education/residential placement which was thought to be suitable. The 5th placement was also dismissed because it was a day placement. The father works at sea and is away from home for considerable periods of time and the mother felt unable to cope with supporting S on her own with 3 small children to look after.

Throughout these discussions on placements the father expressed his displeasure at the absence of the Local Authority Social Work Representative and at the fact that there had been no Social Work involvement for at least 18 months.

There then followed some discussion on holiday and respite arrangements with the School Social Worker taking charge. Again the absence of a Local Authority Social Worker was significant as that department has to secure funding and a decision had to be made.

The meeting concluded the following:-

- 1 an extension was to be applied for
- 2 Social Work representative to be present at next meeting
- 3 holiday/ respite arrangements to be concluded
- 4 Carers to make visits of placements
- 5 the date of the next meeting was determined to fit in with the father's leave programme.

FNA Meeting Two

This meeting was held 9 months after the 1st because of the lack of Social Work representation which hampered progress in securing post-school provision. Members of the meeting included:-

- | | | | |
|---|----------------------|----|--------------------------------|
| 1 | Headteacher | 6 | L. A. Educational Psychologist |
| 2 | School Nurse | 7 | Careers Officer |
| 3 | School Social Worker | 8 | L. A. Senior Social Worker |
| 4 | Teacher | 9 | L. A. Homemaker |
| 5 | Carer (Father) | 10 | Special Needs Co-ordinator |

Local Authority Educational Psychologist chaired the meeting and the Headteacher minuted.

The meeting began with the Educational Psychologist giving the background to S as there were some present who did not know S. He then summarised the points made at the last meeting. It was explained that S would be leaving school in 12 months time it was the purpose of this meeting to determine a placement. Current progress at school was discussed. The father frequently intervened and questioned any points made. Turning to social needs outwith school, the Social Worker explained that arrangements had been made for holiday and respite periods.

The 2nd part of the meeting on placements predominated the whole meeting. It began with the father emphasising the need for a residential placement. The Senior Social Worker was asked to give details of provision in Fife. She began by saying that although they could offer support in the home they could not provide this on a 24 hour basis, thus establishing that S did not have the opportunity to live at home if she wanted. The Social Worker was then unable to make any positive suggestions except to suggest a house that was unstaffed overnight, a centre for people with mental disabilities and a centre belonging to the Cheshire Home Foundation and aimed at nursing terminally ill people. All these suggestions were immediately dismissed. It was explained that it was the policy of Fife to provide, for people with physical disabilities, small, group home placements and not larger staffed group homes. Therefore as far as social work were concerned there really was no placement suitable for S.

Discussion then turned to the placements that had been suggested primarily by the School Social Worker at the last meeting. The Carers had visited these placements and in particular the Further Education/residential placement was felt to be the most attractive proposition and an assessment was to be arranged. At this point the Special Needs Co-ordinator intervened and questioned the funding situation and if the placement would go ahead with an assessment if the funding had not been determined. It was suggested by the Senior Social Worker that as there was nowhere within the region, provided either by Education or Social Work Departments that would suit S then it would seem that joint funding by both Education and Social Work Departments should be made available.

The father strongly stated that as time was running out it was vital for decisions to be made at the meeting and that so far all that had been discussed were simply ideas and these should have been put forward at the last meeting so that visits could have been made. He became angry that suggestions were being made by people who did not know S or who had even met her. He also stated that it was very wrong that after 2 years discussing the future no real progress had been made and discussions still amounted to possible ideas.

The meeting concluded with the decision that the further education/residential placement was to be explored seriously with both education and social work departments funding the placement and that a

decision about funding had to be reached within 2 months when there should be another meeting to take arrangements further.

FNA Meeting Three

This meeting was held 2 months after the 2nd in the Area Social Work Offices. The people present included:-

- | | | | |
|---|-------------------------------|---|------------------------------|
| 1 | Assistant Headteacher | 6 | Area Organiser (Social Work) |
| 2 | Carers | 7 | Senior Social Worker |
| 3 | L.A. Educational Psychologist | 8 | L.A. Homemaker |
| 4 | Careers Officer | 9 | L.A. Social Worker |

Meeting was chaired by the Area Organiser and minuted by her secretary.

The meeting started with the Homemaker summarising the situation as far as Social Work Department involvement was concerned. She concluded that it had been decided that the further education/residential placement was the most appropriate placement. This was to be a 2 year placement. Funding was then discussed. It was confirmed that the Director of Social Work had allowed a joint funding package with the Department of Education to go ahead because there was no other appropriate provision available within Fife region. The conclusion was reached that once S had fully recovered from her recent operation she would go for an assessment to the placement.

Discussion then turned to how the Social Work Department could provide support at home. The Carers were told to 'just say what you want'. The mother was caught unawares and was unable to state exactly what she needed so the decision was made for homehelp support to be provided and the Homemaker to look into arrangements.

The Carers later said after the meeting that for once there were pleased with the outcome and that at last positive, concrete decisions had been reached. The father did question as to why this could not have happened sooner so as to have saved S and the family from so much worry and anxiety.

Case Study Three

Young Person:- (L), Male, Boarder at School C, High-medium level of functioning.

FNA Meeting One

This was the 1st FNA meeting, held when L was 14.9 at school in his dormitory. People present:-

- | | |
|--------------------------|---------------------------------|
| 1 Headteacher | 6 Teachers |
| 2 School Physiotherapist | 7 Carers |
| 3 School Nurse | 8 Young Person |
| 4 Houseparent | 9 L.A. Educational Psychologist |

There was no representative from the Social Work Department.

Headteacher chaired and minuted the meeting.

Headteacher opened the meeting by stating to all present that L would be able to leave school in Summer 1988 when he would be 16. Having already spoken to L about his plans he had expressed the wish to leave school at 16 at attend a College of Further Education, located near his home, to do computing modules. Present needs were then discussed which had to be met to prepare him for the transition. This then formed the bulk of the meeting's discussion.

The meeting concluded on a note of discord. From the contributions made it seemed by the majority of the meeting, including the Carers but excluding L, that the most appropriate programme for transition was L continue at school until 1989, attend College weekly, sit General papers in the Standard Grade exams then go to college. However, L with some support from the Local Authority Educational Psychologist wanted to leave in Summer 1988. To resolve this problem, it was decided that it was important for L, the school and the Carers to find out further information about the college, the facilities and the courses. It was also vital for the family to decide which course of action they wanted. A further meeting was proposed for 5 months time.

FNA Meeting Two

This meeting was held 4 months after the 1st, again in school, in the physiotherapy room. People present included:-

- | | |
|----------------|---------------------------------|
| 1 Headteacher | 6 Houseparent |
| 2 Carers | 7 College Representative |
| 3 Young person | 8 L.A. Educational Psychologist |
| 4 Teacher | 9 Community Doctor |

There was no representative from the Social Work Department.

The Headteacher chaired and minuted the meeting.

The meeting began with the members being informed that the family had made the decision that L would remain at school for a further 2 years and leave in Summer 1989. The Headteacher suggested that therefore it was the purpose of this meeting to make decisions about this 2 year period at school. The Carers were pleased with the decisions made and these were confirmed by the Local Authority Educational Psychologist who would make an application for a further years extension at school. It was stated that there would not be any problem about this as L was continuing his education and taking external examinations for preparation to college. The meeting concluded with the next meeting being set for 15 months time when arrangements would be made for leaving school.

(This 3rd meeting was held outside the fieldwork period. It is known that no significant problems occurred with the plans set and everything went ahead with starting college as arranged).

APPENDIX 4.3

**Results of Service Provision/Delivery in 'Residential' and
'Residential/Day' Type Post-School Placements**

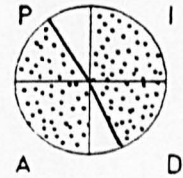
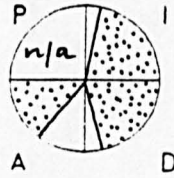
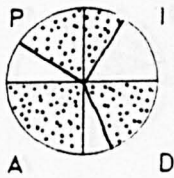
Residential Placement R2

Services for basic/personal needs

Washing and toileting

Eating and food preparation

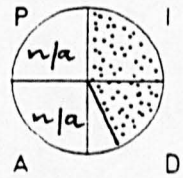
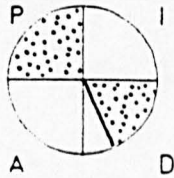
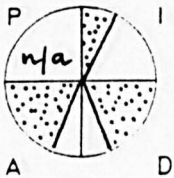
Dressing/undressing



Mobility

Health care

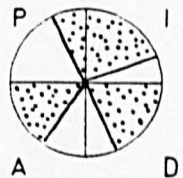
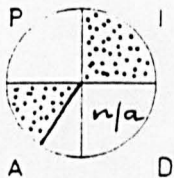
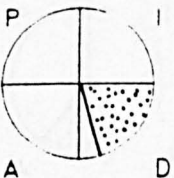
Communication



Finance

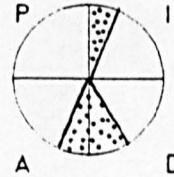
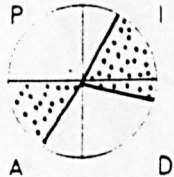
Sleeping

Home-base

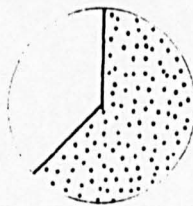


Services for : social/personal needs

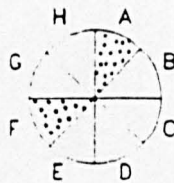
stimulation/personal needs



Provision of a "homely" atmosphere



Aims of the placement



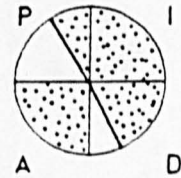
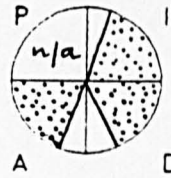
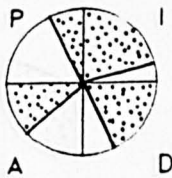
Residential Placement R6

Services for basic/personal needs

Washing and toileting

Eating and food preparation

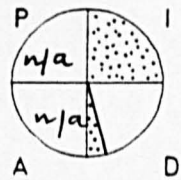
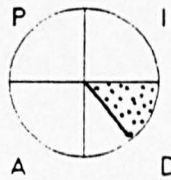
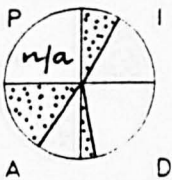
Dressing/undressing



Mobility

Health care

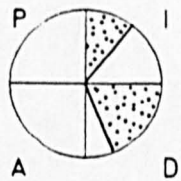
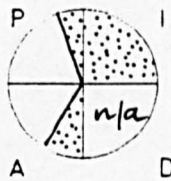
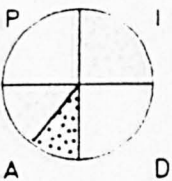
Communication



Finance

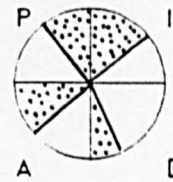
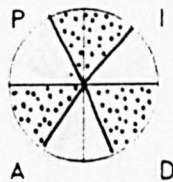
Sleeping

Home-base

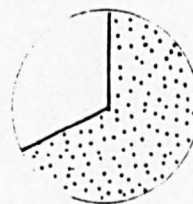


Services for : social/personal needs

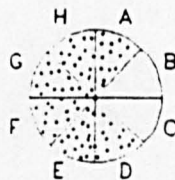
stimulation/personal needs



Provision of a "homely" atmosphere



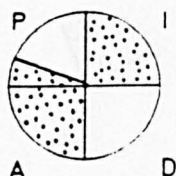
Aims of the placement



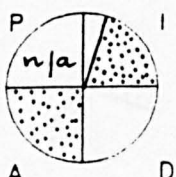
Residential Placement R13

Services for basic/personal needs

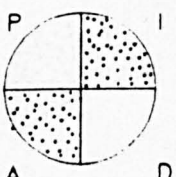
Washing and toileting



Mobility



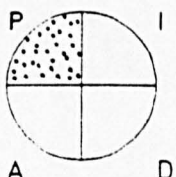
Finance



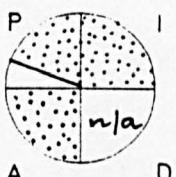
Eating and food preparation



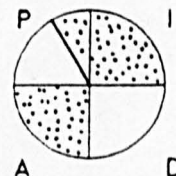
Health care



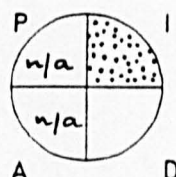
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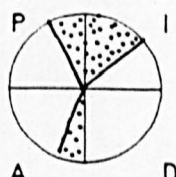
Dressing/undressing



Communication

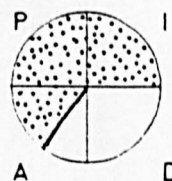
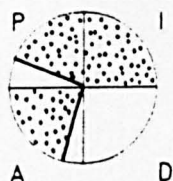


Home-base

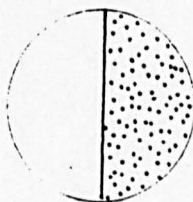


Services for : social/personal needs

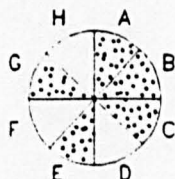
stimulation/personal needs



Provision of a "homely" atmosphere



Aims of the placement



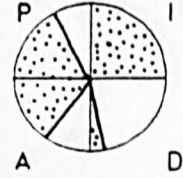
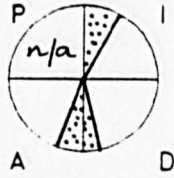
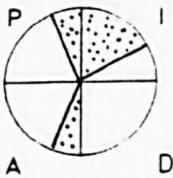
Residential Placement R14

Services for basic/personal needs

Washing and toileting

Eating and food preparation

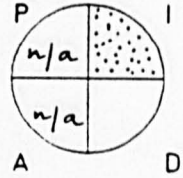
Dressing/undressing



Mobility

Health care

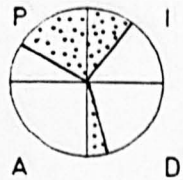
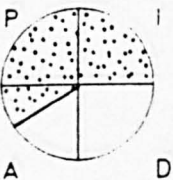
Communication



Finance

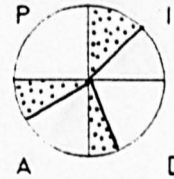
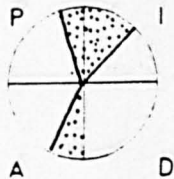
Sleeping

Home-base

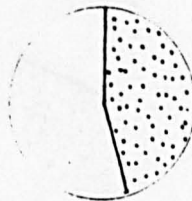


Services for : social/personal needs

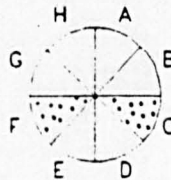
stimulation/personal needs



Provision of a "homely" atmosphere



Aims of the placement



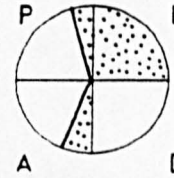
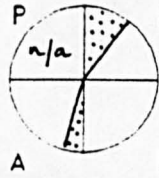
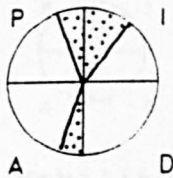
Residential Placement R15

Services for basic/personal needs

Washing and toileting

Eating and food preparation

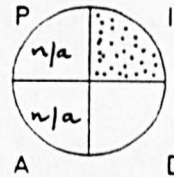
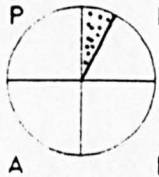
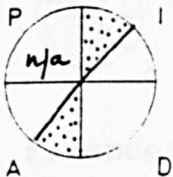
Dressing/undressing



Mobility

Health care

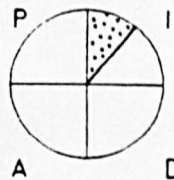
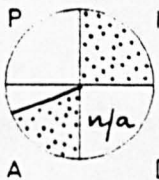
Communication



Finance

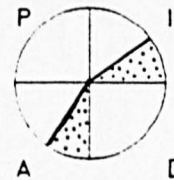
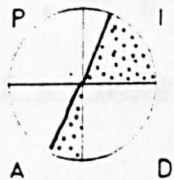
Sleeping

Home-base

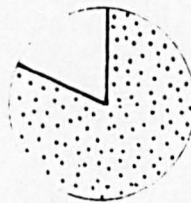


Services for : social/personal needs

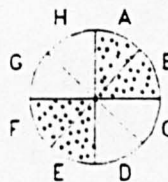
stimulation/personal needs



Provision of a "homely" atmosphere



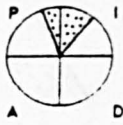
Aims of the placement



Residential Placement R1

Services for basic/personal needs

Washing and toileting



Eating and food preparation



Dressing/undressing



Mobility



Health care



Communication



Finance



Sleeping



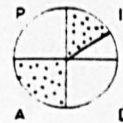
Home-base



Services for : social/personal needs



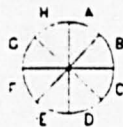
stimulation/personal needs



Provision of a "homely" atmosphere



Aims of the placement



Services for development needs

Facilities



Staff



Equipment



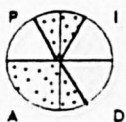
Organisation of activities



Residential Placement R3

Services for basic/personal needs

Washing and toileting



Eating and food preparation



Dressing/undressing



Mobility



Health care



Communication



Finance



Sleeping



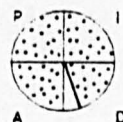
Home-base



Services for : social/personal needs



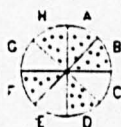
stimulation/personal needs



Provision of a "homely" atmosphere



Aims of the placement



Services for development needs

Facilities



Equipment



Staff



Organisation of activities



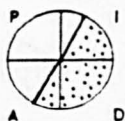
Residential Placement R5

Services for basic/personal needs

Washing and toileting

Eating and food preparation

Dressing/undressing



Mobility

Health care

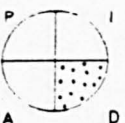
Communication



Finance

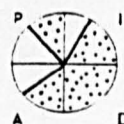
Sleeping

Home-base



Services for : social/personal needs

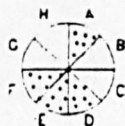
stimulation/personal needs



Provision of a "homely" atmosphere



Aims of the placement



Services for development needs

Facilities

Equipment



Staff

Organisation of activities



Residential Placement R8

Services for basic/personal needs

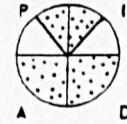
Washing and toileting



Eating and food preparation



Dressing/undressing



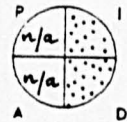
Mobility



Health care



Communication



Finance



Sleeping

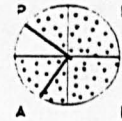


Home-base



Services for : social/personal needs

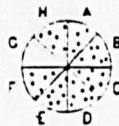
stimulation/personal needs



Provision of a "homely" atmosphere



Aims of the placement



Services for development needs

Facilities



Staff



Equipment



Organisation of activities



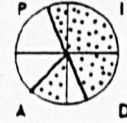
Residential Placement R9

Services for basic/personal needs

Washing and toileting

Eating and food preparation

Dressing/undressing



Mobility

Health care

Communication



Finance

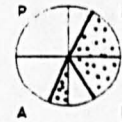
Sleeping

Home-base



Services for : social/personal needs

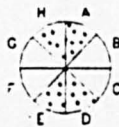
stimulation/personal needs



Provision of a "homely" atmosphere



Aims of the placement



Services for development needs

Facilities

Equipment



Staff

Organisation of activities



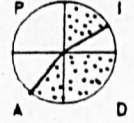
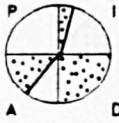
Residential Placement R10

Services for basic/personal needs

Washing and toileting

Eating and food preparation

Dressing/undressing



Mobility

Health care

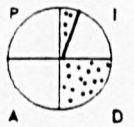
Communication



Finance

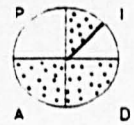
Sleeping

Home-base



Services for : social/personal needs

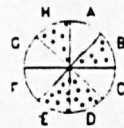
stimulation/personal needs



Provision of a "homely" atmosphere



Aims of the placement



Services for development needs

Facilities

Equipment



Staff

Organisation of activities



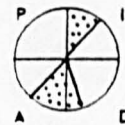
Residential Placement R11

Services for basic/personal needs

Washing and toileting

Eating and food preparation

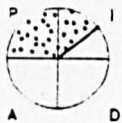
Dressing/undressing



Mobility

Health care

Communication



Finance

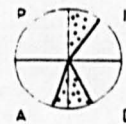
Sleeping

Home-base



Services for : social/personal needs

stimulation/personal needs



Provision of a "homely" atmosphere



Aims of the placement



Services for development needs

Facilities

Equipment



Staff



Organisation of activities



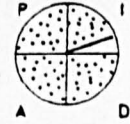
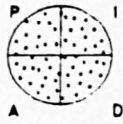
Residential Placement R12

Services for basic/personal needs

Washing and toileting

Eating and food preparation

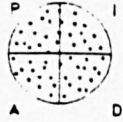
Dressing/undressing



Mobility

Health care

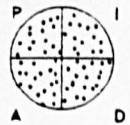
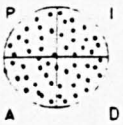
Communication



Finance

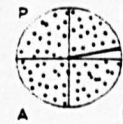
Sleeping

Home-base



Services for : social/personal needs

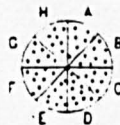
stimulation/personal needs



Provision of a "homely" atmosphere



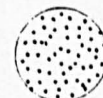
Aims of the placement



Services for development needs

Facilities

Equipment



Staff

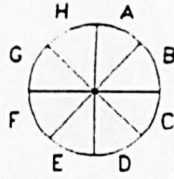
Organisation of activities



APPENDIX 4.4

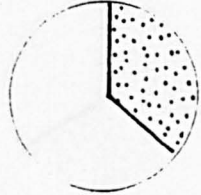
Results of Service Provision/Delivery in 'Day' Type Post-School Placements

Day Placement D1
Aims of the placement

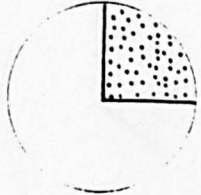


Services for development needs

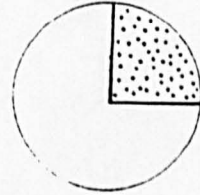
Facilities



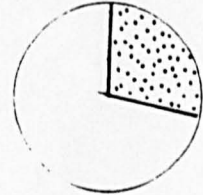
Staff



Equipment

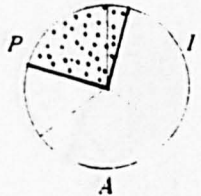


Organisation of activities

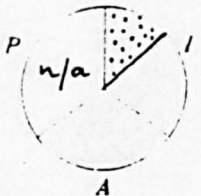


Services for basic/personal needs

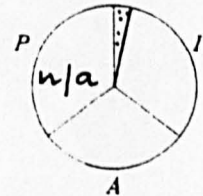
Washing and toileting



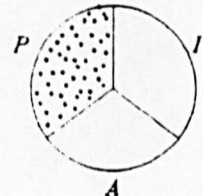
Mobility



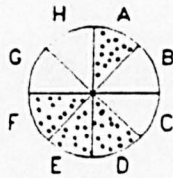
Eating and food preparation



Communication

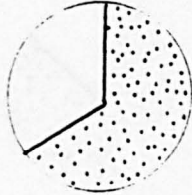


Day Placement D2
Aims of the placement

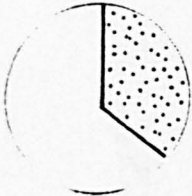


Services for development needs

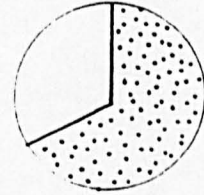
Facilities



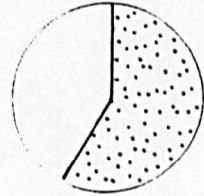
Staff



Equipment

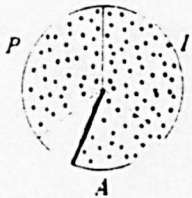


Organisation of activities

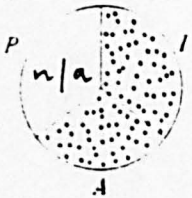


Services for basic/personal needs

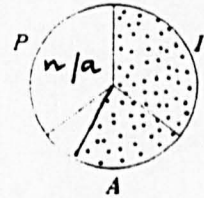
Washing and toileting



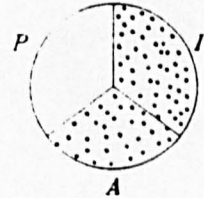
Mobility



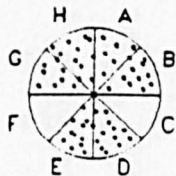
Eating and food preparation



Communication

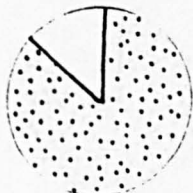


Day Placement D3
Aims of the placement

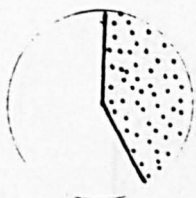


Services for development needs

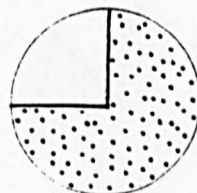
Facilities



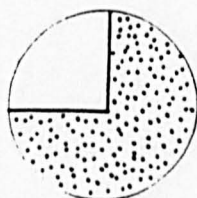
Staff



Equipment

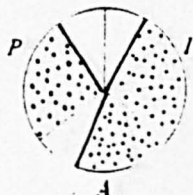


Organisation of activities

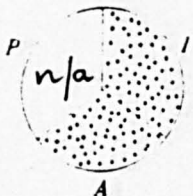


Services for basic/personal needs

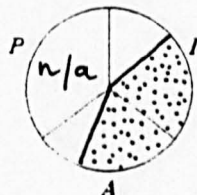
Washing and toileting



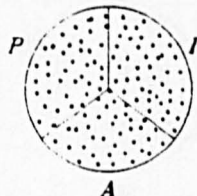
Mobility



Eating and food preparation

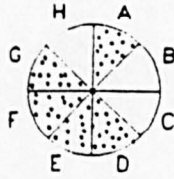


Communication



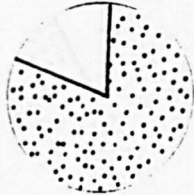
Day Placement D4

Aims of the placement

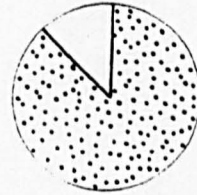


Services for development needs

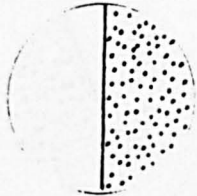
Facilities



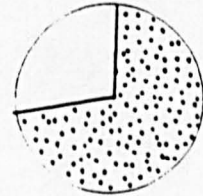
Equipment



Staff

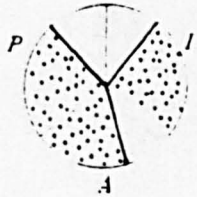


Organisation of activities

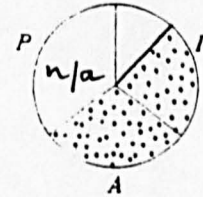


Services for basic/personal needs

Washing and toileting



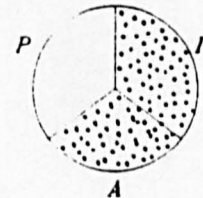
Eating and food preparation



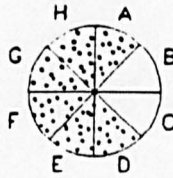
Mobility



Communication

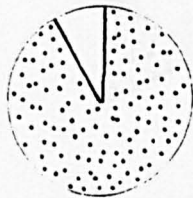


Day Placement D5
Aims of the placement

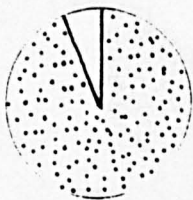


Services for development needs

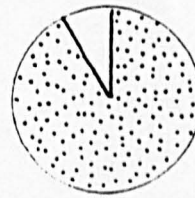
Facilities



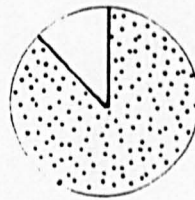
Staff



Equipment

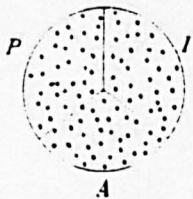


Organisation of activities

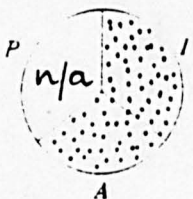


Services for basic/personal needs

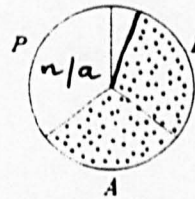
Washing and toileting



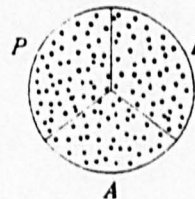
Mobility



Eating and food preparation

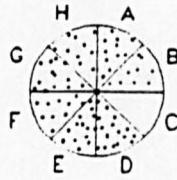


Communication



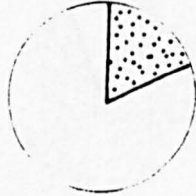
Day Placement D6

Aims of the placement

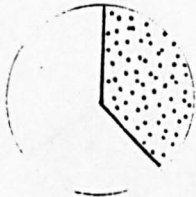


Services for development needs

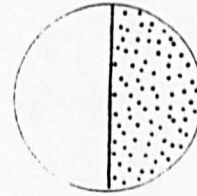
Facilities



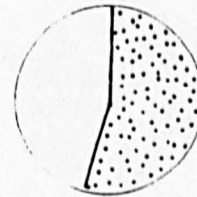
Staff



Equipment

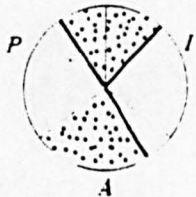


Organisation of activities

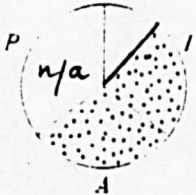


Services for basic/personal needs

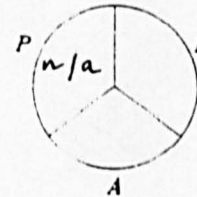
Washing and toileting



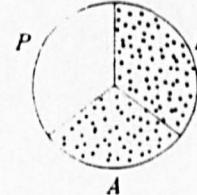
Mobility



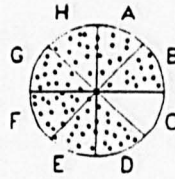
Eating and food preparation



Communication

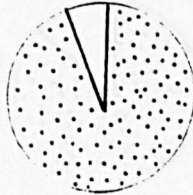


Day Placement D8
Aims of the placement

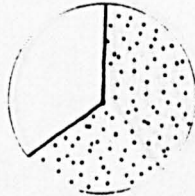


Services for development needs

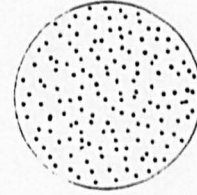
Facilities



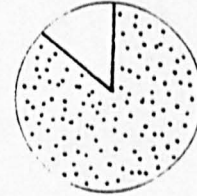
Staff



Equipment

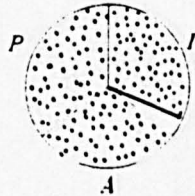


Organisation of activities

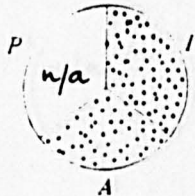


Services for basic/personal needs

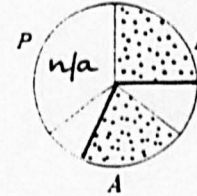
Washing and toileting



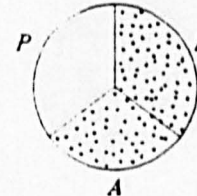
Mobility



Eating and food preparation

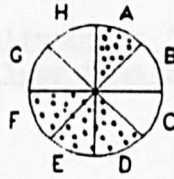


Communication



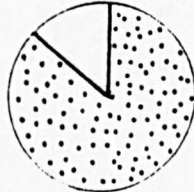
Day Placement D9

Aims of the placement

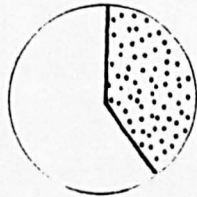


Services for development needs

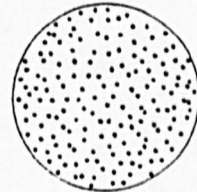
Facilities



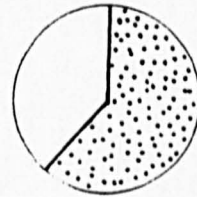
Staff



Equipment

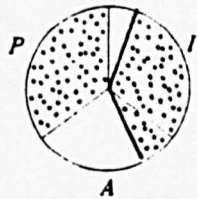


Organisation of activities

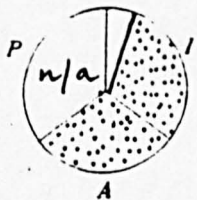


Services for basic/personal needs

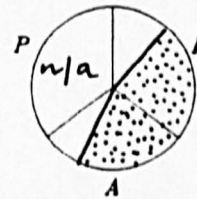
Washing and toileting



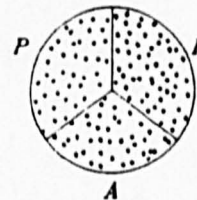
Mobility



Eating and food preparation



Communication



APPENDIX 4.5

**Results of Service Provision/Delivery in 'Further Education/Day' and
'Further Education/Residential Type Post-School Placements**

Further Education placement with residential facilities. F2.

Services for development needs

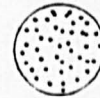
Facilities



Staff



Equipment



Organisation of activities



Services for basic/personal needs

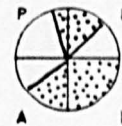
Washing and toileting



Eating and food preparation



Dressing/undressing



Mobility



Health care



Communication



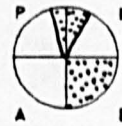
Finance



Sleeping



Home-base



Services for : social/personal needs



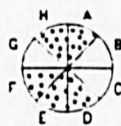
stimulation/personal needs



Provision of a "homely" atmosphere



Aims of the placement



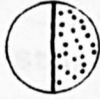
Further Education placement with residential facilities. F4

Services for development needs

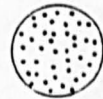
Facilities



Staff



Equipment



Organisation of activities



Services for basic/personal needs

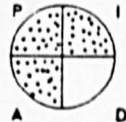
Washing and toileting



Eating and food preparation



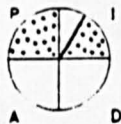
Dressing/undressing



Mobility



Health care



Communication



Finance



Sleeping



Home-base



Services for : social/personal needs

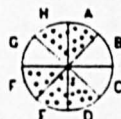
stimulation/personal needs



Provision of a "homely" atmosphere



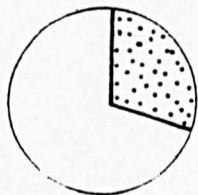
Aims of the placement



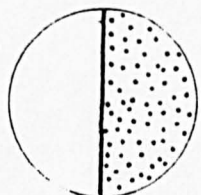
Further Education placement without residential facilities. FS

Services for development needs

Facilities

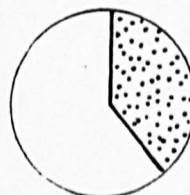


Staff

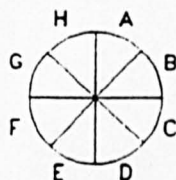
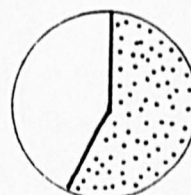


Aims of the placement

Equipment

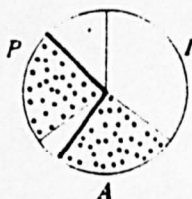


Organisation of activities

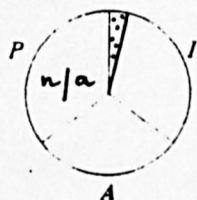


Services for basic/personal needs

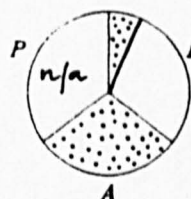
Washing and toileting



Mobility



Eating and food preparation



Communication

