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ISSUES IN THE PRESCRIBING OF PSYCHOTROPIC AND PSYCHOACTIVE MEDICATION FOR PERSONS WITH LEARNING DISABILITY: QUANTITATIVE AND QUALITATIVE PERSPECTIVES.

Thesis presented to fulfill requirements for PhD degree by

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June 2001

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GLOSSARY OF TERMS

GLOSSARY OF TERMS

Psychotropic medication	Any agent prescribed for the purpose of bringing about behavioural, cognitive or emotional changes.
Psychoactive medication	Any agent that has psychotropic effects regardless of the intent when prescribing the drug.
Mental retardation	Mental retardation refers to substantial limitations in present functioning. It is manifested as significantly sub-average intellectual functioning, existing concurrently with related disabilities in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics and work. Mental retardation begins before age 18.
Learning disability	The preferred term for mental retardation used in the republic of Ireland. Definition as above.
Normalization	The process of bringing or restoring to the normal standard. In the case of persons with learning disability, normalisation refers to the process of integrating them into the community so as to lead as normal a life as possible.
Deinstitutionalisation	The practice of caring for individuals in the community, rather than in an institutional environment with resultant effects on the individual, the individual's family, the community, and the health care system.
Front line staff	Staff working directly with persons with learning disability. Such staff include nursing staff, childcare staff, teachers, workshop supervisors and unqualified staff.
Differential diagnosis	The determination of which two or more diseases (or disorders) with similar symptoms is the one from which a patient is suffering from based on an analysis of the clinical data.
Challenging behaviour	Culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.

Stereotypy	Motor behaviour that is repetitive, often seemingly driven, and non-functional. This behaviour markedly interferes with normal activities or results in severe bodily self -injury. The behaviour is not due to the direct physiological effects of a substance or a general medical condition.
Tardive Dyskinesia	A syndrome of potentially irreversible, involuntary, dyskinetic movements that may develop in patients who have been treated with antipsychotic medications (for example phenothiazines) longer-term. Other drugs known to cause tardive dyskinesia include: tricyclic antidepressants, selegiline, clozapine, levamisole and metoclopramide.
Anticholinergic medication	An agent that blocks the parasympathetic nerves. An agent commonly prescribed to counter the extrapyramidal side effects (shaking, orofacial movements etc) of many of the antipsychotic medications
Stimulant medication	A class of medication which includes amphetamine and dexamphetamine. Amphetamines act by releasing noradrenaline stored in nerve endings in both the CNS and the periphery. Typically stimulant medication or psychostimulants are used in the treatment of attention deficit disorder (with and without hyperactivity) and in some cases for appetite control.
Anxiolytic medication	Agents that alleviate anxiety, tension, and neurotic symptoms, promote sedation, and have a calming effect without affecting clarity of consciousness or neurological conditions. Some are also effective as anticonvulsants, muscle relaxants, or anaesthesia adjuvants. Adrenergic beta-antagonists are commonly used in the symptomatic treatment of anxiety but are not included here. Substances with a benzodiazepine ring structure widely used to treat anxiety and neuroses. Drugs in this class also generally have sedative or weak hypnotic properties and may be effective as muscle relaxants, anticonvulsants, and anaesthesia adjuvants.
Hypnotic medication	A class of medications used to induce sleep. Hypnotics in full doses can disrupt the normal sleep pattern. Hypnotics do not induce natural sleep.
Polypharmacy	The administration of two or more medications from one class of medication.

Co-pharmacy	The administration of two or more medications from different classes of medications.
Monopharmacy	The administration of one medication only from one class of medication.
Diagnostic over-shadowing	Where diagnosticians tend to attribute abnormal behaviour to the presence of a learning disability and overlook coexisting psychopathology.
PRN medication	Medication prescribed on an "as required" basis.
Antidepressant medication	An agent that stimulates the mood of a depressed patient, including tricyclic antidepressants and monoamine oxidase inhibitors.
Antipsychotic medication	Antipsychotic drugs (also called neuroleptic drugs and major tranquillisers) are a chemically diverse (including phenothiazines, thioxanthenes, butyrophenones, dibenzoxazepines, dibenzodiazepines and diphenylbutylpiperidines) but pharmacologically similar class of drugs used to treat schizophrenic, paranoid, schizoaffective and other psychotic disorders, acute delirium and dementia and manic episodes (during induction of lithium therapy), to control the movement disorders associated with Huntington disease, Gilles de la Tourette's syndrome and ballismus and to treat intractable hiccups and severe nausea and vomiting. Antipsychotic agents bind to dopamine, histamine, muscarinic cholinergic, a adrenergic and seratonin receptors. Blockade of dopaminergic transmission in various areas is thought to be responsible for their major effects: antipsychotic action by blockade in the mesolimbic and mesocortical areas, extrapyramidal side effects (dystonia, akathisia, parkinsonism and tardive Dyskinesia) by blockade in the basal ganglia and antiemetic effects by blockade in the chemoreceptor trigger zone of the medulla.

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ABSTRACT

The administration of psychotropic and psychoactive medication for persons with learning disability and accompanying mental illness and/or challenging behaviour has undergone much critical review over the past two decades. Assessment and diagnosis of mental illness in this population continues to be extremely problematic. Some of the common problems of psychopharmacological treatment include polypharmacy, irrational prescription procedures and frequent over-prescription. It is clear that all forms of treatment including non-pharmacological interventions need to be driven by accurate and appropriate diagnoses. Where a psychiatric diagnosis has been identified, it greatly aides the selection of appropriate medication, although a specific medication for each diagnosis, as was once hoped, is simply no longer a reality in practice. Part one of the present thesis seeks to address many of the current issues in mental health problems and pharmacological treatment to date. The author undertook a drug prevalence study within both residential and community facilities for persons with learning disability within the Mid-West region of Ireland in order to ascertain the current level of prescribing of psychotropic and psychoactive medications for this population.

While many attempts have been made to account for the variation in prescribing, little systematic and empirical research has been undertaken to investigate the factors thought to influence such prescribing. While studies investigating the prescribing behaviours of General Practitioners (GP's) have illustrated the complex nature of the decision making process in the context of general practice, no similar efforts have yet been directed at examining the prescribing behaviours of Consultant Psychiatrists. Using The Critical Incident Technique, the author interviewed Consultant Psychiatrists in the Republic of Ireland to gather information relating not only to their patterns of prescribing for learning disabled populations, but also to examine reasons influencing their prescribing in addition to several related factors. Part two of this thesis presents the findings from this study and a number of issues are raised, not only in relation to attempting to account for the findings from part one of the thesis, but also with respect to implications for improved management and clinical practice.

CHAPTER ONE

INTRODUCTION TO LEARNING DISABILITY

1.1 Chapter Introduction

In recent years significant advances have been made in the field of Learning disability/mental handicap. There is now a greater understanding of the condition of learning disability per se in addition to the many complex secondary handicaps associated with it (epilepsy, challenging behaviour etc.). In few other professions can the concept of the inter-disciplinary process be seen to be as effective as it has been and continues to be within learning disability. Perhaps the most significant of these changes has been the shift from "institutional" or hospital settings to community integration and living. This has been particularly evident in Great Britain (and also in Ireland) where the number of hospital beds for people with learning disability has been greatly reduced and many of these hospitals have been closed down. This has invariably led to an increase in the number of community facilities required. Such changes have been very beneficial in many respects, especially for the individuals in question, but such policy changes do create anxiety amongst the families and carers of these clients. Much of this anxiety rests with the fact that many families feel their family member will not be able to cope and integrate into community living and on this basis, a service will not be available. If anything, this emphasises the need for continuing residential care for many clients and the importance of the support that is required for client and family alike.

1.2 Aims of the Chapter

The aims of this chapter are several-fold. Firstly one will examine some of the historical perspectives in terms of the study of learning disability. Terminology and labelling will be examined in some detail before moving on to a definition of learning disability and the many problems associated with the varying definitions and classification systems used. Epidemiology, prevalence and causes of learning disability will be discussed before moving on to look at the social aspects of learning

disability and their relevance. Many other associated topics will be discussed in conjunction with the main sections throughout the course of the chapter.

1.3 Terminology and Labelling

For the last number of years there has been a growing debate as to the terminology used within the field of what is presently termed learning disability. For years, especially in Ireland, the term mental handicap was used and to date some centres still adhere to this term. If one looks to the general public, there is still a great deal of confusion regarding the differences between mental handicap and mental illness. The majority of this confusion tends to stem from the historical perspectives of mental handicap where these individuals were segregated from society and placed in psychiatric institutions alongside patients with mental illness. In this respect there is still a sense of stigmatisation associated specifically with the term "mental handicap", perhaps far more than any other term used to date. From the perspective of the individual, one has to search for a term, which will both describe and place an emphasis on their real difficulties, while also and perhaps more importantly have no negative connotations for the individual, which may deter community integration. Those who bear the term "mental handicap" find it stigmatising and offensive while the parents of these individuals are often hurt and shocked when such terminology is used.

Fraser and Green (1991) note that definitions and classification systems will always be a problem area and the field of learning disability is by no means an exception. No matter what terms and definitions one uses, there will always be connotations involved - be they positive or negative. To date there is still no one globally accepted term for or definition of learning disability/mental handicap, and there is far more involved than just using a term or understanding a definition. "Mental handicap is in some respects a confusing and unsatisfactory term used to describe a

condition of lifelong intellectual impairment and accompanying disabilities in social functioning. It is not simply a clinical diagnosis: it is a social process of changing expectations, labelling and families coming to some understanding of what handicap means" (Fraser and Green, 1991, p.1; Booth, 1978).

Although several varying terms have been used over the past century (in every twenty five years, there has been a new term used and adapted), the question must be asked as to whether there is the need to constantly develop new definitions and incorporate new terminology. On the one hand there is clearly the need to constantly develop new ideas and terminology as a stigma will always be attached to terms over the years (negative or otherwise). In addition and on the other hand, simply changing a label will not change public perception, nor will it decrease the many problems that these individuals have. As the report of the second PSI Mental Handicap Group (working party on client terminology) has stated "it will be meaningful and important to find a new, more appropriate terminology that would create in the public mind, a truer picture of people's difficulties and remove the unnecessary additional hurt caused them by the current terms" (1992, p.2).

No matter what terminology is to be used, the issue of labelling will always be a pertinent one. Whether or not to label has been an issue for workers in the field for some years, and if one were to label, which labels should be used (Hastings, 1994). Specific to the field of learning disability, research has been undertaken which has supported both the positive and the negative effects of labelling. On the basis of the research to date on labelling in the field of learning disability, there are still no clear answers available and this has "led to a 'not proven' verdict on the damaging effects of labelling" (Hastings, 1994, p.363; Franco, 1982; MacMillan et al., 1974). As has been mentioned above, a change in terminology will not necessarily mean a change in labelling but it may necessitate more positive connotations toward the individual. As Baroff

(1991) has stated "labels cannot erase biologically determined differences, but the connotations that they evoke can affect the means through which those differences can be diminished" (p.100).

More recent research by Hastings and colleagues (Hastings and Remington, 1993; Hastings et al., 1993) on the effects of labelling, indicated that although the newer terms such as "Learning disability" and "Learning Difficulty" have more positive connotations than do the older terms such as "mental sub normality" or "mental handicap", all labels used were negatively evaluated by subjects. The only term to receive a positive rating was the use of the term "exceptional", although whether after a period of time of usage, this term would still be used in a positive sense, remains to be seen.

In Ireland and Britain up until recently, the term mental handicap was most in favour - at least in terms of those who were undertaking research and working in the field. With the development of concepts such as normalisation and advocacy in particular, the field of learning disability continued its work in trying to find de-stigmatising terminology. Individuals (with learning disability) who were involved in self-advocacy groups who were verbal and could express their views reacted strongly to the use of terminology such as "mental handicap". Although at the time this term fitted in well with the notion of physical disability, clients themselves felt the term was highly stigmatising and incorporated the notion that "mental" referred to mental illness - terminology that the field was striving to get away from for many years and the notion that "handicap" referred to a from of physical disability. These clients were more in favour of terms such as learning disability or learning difficulty.

One is now into a situation similar to the States where learning disability or difficulty refers more to problems of education. In the United Kingdom in 1991, the then Minister for Health stated that the term learning disability was to be the official term used. Although service provision

was quite similar in Ireland, there was no official stance on the matter, and the term learning disability gradually became used more frequently. Interestingly parents of children with learning disability have reacted negatively to the use of this term as many of them feel that there is too much emphasis placed on the notion of learning, thus education and thus intellectual level and it does little for those who have sensory and physical handicaps or disabilities. The term developmental disability was a term that was introduced in order to cover the entire range of handicapping conditions in the mid 1970's and in a sense it was a definition that placed an emphasis on the fact that individuals who had handicapping conditions outside of learning disability also required service provision. The term developmental disability was defined as "a severe, chronic disability, which is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before age 22; is likely to continue indefinitely; and results in substantial functional limitations in three or more areas of major life activity" (Grossman, 1983, p.168). No matter what terminology one wishes to use, there will always be the effect of labelling although this can sometimes have a positive outcome as has been emphasised by Zigler and Burack (1989) when they stated "labels can often have positive consequences, particularly since they are often a necessary precondition to the receipt of services" (cited in Reid, 1997,p.1).

More recently the term intellectual disability is being used with increased frequency, although it begs the question are we now going back to our system of classification on an intellectual basis and placing less emphasis on adaptive behaviour and social factors - factors which should have a greater emphasis placed on them in any future definition of learning disability. As is stated by Reid (1997) "terminology in this field has a short shelf life, however, and intellectual disability will probably go downhill before long also" (p.1).

1.4 Historical Perspectives

In terms of a history of the study of learning disability, this particular field has had a very difficult start. It has by no means been straightforward with the development of accurate and reflective definitions, terminology and classification systems - on the other hand it has progressed very slowly and gradually with new definitions and terminology being introduced every number of years. Previous to the twentieth century, the concept of learning disability (which will be used throughout this chapter to denote mental handicap/mental retardation/intellectual impairment etc.) was defined largely in terms of social and vocation competence. In many communities this was an accepted value and the majority of communities cared and looked after those who needed providing for.

1.5 "De-institutionalisation" and Community Integration.

Throughout the 1980's in Ireland we have seen a marked shift away from this residential care system towards care in the community (McConkey and Conliffe, 1989) - a term commonly known as de-institutionalisation. The philosophy of de-institutionalisation represents a return to community orientation, especially for those with severe and profound levels of learning disability, which was in evidence prior to the setting-up of residential facilities (institutions) in the late 1800's. Government Policy in both the Republic of Ireland and Northern Ireland have reflected the above aims and although the two services both North and South have very different styles, their objectives are very similar in nature. The Minster for Health and Social Welfare in 1985 in their green paper on services for clients with a disability stated:

> *"there is no disagreement about the philosophy which should underpin the development of policies and programmes for disabled people. The ultimate objective is to equip disabled people to realise their full potential and to participate to the greatest degree possible in the life of the community. The*

Government fully accepts that this should be the aim of public policy".

In a similar fashion, in Northern Ireland, the Dept. of Health in their Regional Strategy for Health and Social Services stated:

"the core of the Department's policy for the mentally handicapped is to help them to lead their lives as normally as possible and to keep to an absolute minimum the need for long-term hospital care, especially for children ... Concerted action to improve community services will also form an essential component of the policy".

Apart from major advances such as de-institutionalisation, psychological activities have had a specific impact in the field of learning disability. Whereas psychology started out in the field purely in terms of intellectual assessment, it soon branched into areas such as treatment, research, and evaluation and was involved in the principles of normalisation and advocacy. With the move to community living, there is now an even greater need for psychological input and specialist services to be delivered. The concept of normalisation is certainly one of the new buzzwords in the field of learning disability in recent years. Although the term has been around for some years now (Wolfensberger, 1972), and in a sense tackles the issue of labelling, it is only relatively recently that it has come of age. Normalisation refers to "provision of services and supports to people with disabilities in the ways that they are most normally provided in society for people without disabilities. It has provided a touchstone for the context and structure of service delivery and doctrines of least restrictiveness in treatment" (Jacobson and Mulick, 1996, p.3).

1.6 Establishment and Development of The American Association on Mental Deficiency (AAMR).

One of the most fundamental points in terms of a history of the study of learning disability was the establishment of a manual for classification and it was not until the late 1950's that this manual was published by the

AAMD (American Association on Mental Deficiency). This manual drew heavily on the side of those in favour of intelligence as a system of classification and thus the IQ definition of learning disability was incorporated. Although level of learning disability was defined in terms of deviation in measured intelligence, there was note taken of adaptive behaviour - especially in a later edition published two years later. Still at this time the only scientific measure of social adequacy was the Vineland Social Maturity Scales, which were developed by Doll (1936). On this basis alone, there was not enough evidence or instruments available in order to change the classification system of the time. Nihira (1969) in the United States in the late sixties was the first to develop a truly scientific approach to the assessment of adaptive behaviour and in 1969 the first edition of the Adaptive Behaviour Scale was published.

1.7 Definitions of Learning disability – AAMR and WHO Definitions

Defining learning disability is by no means an easy task and there is still much debate in the field as to how intelligence should be defined. Some theorists such as Guilford (1979) define intelligence in terms of a theoretical cognitive capacity. Others such as Sternberg (Sternberg and Salter, 1982) define intelligence as "goal directed adaptive behaviour" while Kimble et al. (1984) see intelligence in terms of the ability to solve real life tasks. Either ways, both approaches (intelligence V's adaptation) can have a contribution to the definition of learning disability - each with their advantages and disadvantages. Perhaps the greatest advantage in terms of intellectual capacity as the criterion is that intelligence quotient measures have been developed methodically over the years on large samples of individuals, they have explicit strengths and weaknesses and they do not prejudge adaptability. If one used social adaptation as the criterion, this generally fails to distinguish individuals of normal intelligence - "who have a psychiatric disorder, a specific learning disability, or who are socially impaired for some other reason. It harks back to the days when many such people were placed in institutions for

the retarded" (Scott, 1994, p.617). Both the WHO (World Health Organisation - ICD-10) and the APA (American Psychiatric Association - DSM-IV) use both these criterion in their definitions of learning disability.

The American Association on Mental Retardation's (AAMR) latest definition of Learning disability places further emphasis on the notion of adaptive behaviour. Their definition of mental retardation (learning disability) published in 1992 is as follows:

> *"Mental retardation refers to substantial limitations in present functioning. It is manifested as significantly sub-average intellectual functioning, existing concurrently with related disabilities in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics and work. Mental retardation begins before age 18". (AAMR, 1992).*

In a similar fashion the World Health Organisation (WHO) in its ICD-10 classification system takes into account both intellectual functioning and adaptive behaviours when it states:

> *"Mental retardation is a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities ... Adaptive behaviour is always impaired ... the assessment of intellectual level should be based on whatever information is available, including clinical findings, adaptive behaviour and psychometric performance". (WHO,1992).*

No matter what definition one wishes to choose when referring to those with learning disability, in a sense all definitions only tell one so much and as can be seen from the above, the major influence is still in terms of intellectual capacity with only slight reference to adaptive functioning. However, over the decades, substantial changes have taken place in terms of the terminology that is used to describe individuals with learning disability. At the start of this decade, terms such as idiots, morons and

feeble-minded were very much in vogue and in part it was due to the use of such terminology that the distinctions between learning disability and mental illness were so unclear.

1.8 Degrees/Levels of Learning disability.

The degree or level of learning disability is again within the framework of a classification system based largely on intellectual assessment and performance. Learning disability is divided into four distinct levels or strata - mild, moderate, severe and profound. Severity of learning disability is based or determined by concurrent presence of IQ scores in addition to adaptive limitations within the above four ranges. Table 1.1 below indicates the four levels of learning disability, as determined by intellectual level and adaptive limitations.

Table 1.1: A table depicting the four levels of learning disability, their IQ range and extent of adaptive limitations.

Level/degree of learning disability	IQ range	Extent of concurrent adaptive limitations
Mild	55-70	2 or more domains
Moderate	35-54	2 or more domains
Severe	20-34	all domains
Profound	Below 20	all domains

As the level or degree of learning disability becomes more severe, the prognosis and outcome of the individual becomes more restrictive.

Mild level of learning disability can be viewed largely in terms of academic achievement and cognitive performance. Very often mild learning disability is not picked up on straight away in terms of schooling and it may not be until a problem arises (i.e. academic failure or problem

behaviour) that the possibility of learning disability is looked into. This again emphasises the society is which we live in - which places so much emphasis on academic performance and achievement purely in terms of schooling and one's ability to perform in this respect. Language development is generally quite good in those within the mild range and they have a good ability to put together a complex sentence. Schooling will generally follow the normal routine and movement in the adult role will also develop normally. However in terms of "fitting in" to this adult role, many complications may arise especially in terms of involvement in adult services and participation.

Those with a moderate level of learning disability will generally be recognised earlier as having some form of learning disability because of the evident delays in their developmental milestones. Language in particular is affected and on entry to school, these children will generally communicate in one to two word utterances and gestures. Academic performance as predicted is delayed when one compares them to those with mild levels of learning disability. Supervision is required in respect to vocational activities and very often self-care supervision may also be needed.

Similar to individuals with a moderate degree of learning disability, those within the severe range are identified quite early in life. Not only are there substantial deficits in developmental milestones but milestones such as standing, walking and toilet training may also be delayed significantly. As noted by Jacobson and Mulick (1996), these children are also at greater risk of developing conditions such as epilepsy and cerebral palsy. These children need much supervision in the areas of self-care, toileting and feeding. Generally language development is poor with only some children using two or three word utterances later in years. Close supervision and assistance is needed with vocational skills and attention span on tasks can be quite poor. In the past, residential care

was perhaps the only option for many but this process is gradually beginning to change over time and especially in the last two decades. Clients with a profound level of learning disability are identified very early in infancy, largely due to severe limitations in development. Mortality rates are generally far higher in these clients than in those with severe or other levels of learning disability. Mobility can very often be quite poor due to physical handicaps, motor or sensory difficulties and by the age of ten only some of these children will have developed the skills to walk unaided. Self-care skills are quite poor and require much supervision, as do their skills in general. The communication process is developed by means of gesture rather than language although one-word utterances or vocalisations are quite common. Basic skills that these individuals have can be worked with by means of individual input, structured stimulation and interaction with others. Full time care is generally required, and this has been provided by residential care settings up until now - the process of de-institutionalisation is far more difficult with these clients compared to others due to many of them being in a fragile medical condition or the lack of adaptive skills or the basic coping strategies required for a move to the community.

1.9 Differential Diagnosis and Classification.

Differential diagnosis of learning disability should always be undertaken before a prognosis is established, as there can be discrepancies between functioning in terms of intelligence and adaptation. For example if one scores quite low on an intelligence test and ones adaptive functioning is above the norms for that particular level, then by taking a less severe degree than is depicted solely on the basis of the individuals intellectual score alone. In this sense one can see that a classification system based purely on intellectual criterion can be fundamentally flawed and if one classifies an individual purely on the basis of scores on an intelligence test, then one may be doing the individual a great injustice in terms of over-representing the problem - classifying the individual as

more severe than they actually are, or on the other hand under-representing the problem and classifying the individual at a level higher than they are actually functioning.

As has been mentioned in the opening pages of this chapter, there are specific problems with regard to the classification system used in determining level or degree of learning disability. Apart from the intellectual versus social criterion approaches to classification of learning disability, additional problems have emerged with regard to assessment of intelligence, and some of these problems are specific to individuals with mild learning disability. Concern has been expressed with regard to identification of those with a mild learning disability in early childhood as the identification process can be culturally biased or even linguistically biased and this has been strongly supported by research to date (Mercer, 1973). In this sense many feel that the classification system and means of identification of learning disability is inappropriate for many individuals. Again this problem has arisen largely due to a strong reliance on the use of intellectual assessment as the fundamental means of determining ones functional level.

As is noted by Zucker and Polloway (1987) "many students who are reasonably successful in relatively unstructured social or recreational activities have significant difficulty in the school setting in academic achievement, social skill development, and coping abilities" (p. 75). One can bring in the idea here of conceptual intelligence (IQ) and social intelligence (practical ability and the process of being able to adapt to ones environment). Research, which has focused on intellectual versus adaptive functioning, has shown significant differences in terms of assessment by means of intelligence and assessment by means of adaptive behaviour. The study of Popoff-Walker (1982) has shown that 40% of EMR individuals (educable individuals) did not show evidence of adaptive behaviour performance, which fell within the category of educable "mental retardation".

Another major problem with classification has been the notion of socio-economic status. As is well known in the literature there are strong links between intelligence and status (Reschly, 1981) and from research to date the links between poorer children being at greater risk of having some form of learning disability are well established. What is not so well established is how socio-economic status interacts with the many cultural factors in the classification of learning disability. Although while research is saying that those individuals who are of lower socio-economic status are at increased risk of having a learning disability especially mild learning disability, there is at the same time a significant number within these circumstances who are not classified as being within the mild range. This particular problem raises several questions with regard to research to date in addition to cultural and status factors.

On the basis of these many criticisms regarding classification, the question then arises, how does one overcome these problems and what strategies should be developed in trying to alleviate them. The answer to this question still falls within the realm of compensating for problems in intellectual assessment. For example in order to compensate for cultural or linguistic bias (apart from the obvious), it has been suggested that a scheme should be developed in order to get over the problem of such biases - initial results of this development process have essentially led to the universal "declassification" of children in many services such as EMR (education able mentally retarded individuals). A second strategy which has been discussed is to develop more stringent cut-off scores on intelligence tests - although it would alleviate the process somewhat, it would really only lead to more consistency in clinical practice. A third suggestion which has been made is to rely less on intellectual performance and to develop criteria which are sensitive to both intelligence and adaptive behaviours - a suggestion which is gaining momentum at present.

1.10 Service Provision for clients with Learning disability in Ireland.

Clients with a learning disability have long being classified as a unique population. Such classification has had both its positive and negative connotations, perhaps the majority being negative in terms of labelling individuals with learning disability. Part of this uniqueness has been an inability to cope with the society in which they are living in and a difficulty to adapt to an ever-changing society. In the early 1800's, in a time when the industrial revolution took over society, there was little room for those who were not productive and who were not capable of working. It was due to the industrial revolution that the process of segregation was introduced and has stayed with us in various forms (i.e. institutionalisation) since this time. The negative implications of the process of segregation still exist and the field of learning disability has being trying to break the links which existed between it and the field of mental illness for some years now. In 1992 for example, the figure quoted for individuals with learning disability whose service consisted of, and was based in psychiatric hospitals in Ireland was one thousand despite the fact that these clients did not have any form of mental illness (McGinley, 1992). It is surprising in this day and age that such a system still operates in this country despite the many specialist services which exist solely for those with learning disability.

Although there are extensive specialist services for clients with learning disability throughout Ireland at the present time it is only relatively recently that this group were identified as needing such a service. Up until the Irish state was founded in 1922, Ireland was under the rule of Britain and any law passed in Britain was incorporated into Irish society. Workhouses were the usual places that those with a learning disability were placed in Ireland and they were also admitted and cared for in asylums which were based throughout the country under the Lunacy Laws of the 19th century (McLoone, 1988). It was not until 1869, that the

first service provision was developed specifically for those with learning disability in Ireland and this was based in the Stewart Institute for Education, Training and Maintenance of Idiotic and Imbecile children in Dublin. As can be seen from its title, the terminology used was identical to that used in the United Kingdom at the time - largely due to it being initially established in Britain. However it was a starting point and it was not until this point that the distinctions between learning disability and mental illness were being made - it would take some time longer for the distinctions to be clarified however.

1.11 Service Provision: Planning for the Future.

Still despite the many developments over the years, the fact still remains that service provision is still not capable of dealing with the entire learning disabled population in Ireland. Those who have lost out in particular are families who have kept their children at home, especially when regional services were just being developed. Residential services are particularly difficult to obtain as although the move is from residential to community living, no new residential services are being developed and the existing services have long waiting lists and such waiting lists have continued to develop over the years. In 1987, it was estimated that approximately three hundred clients were in need of urgent residential placement (McConkey, 1987), whereas by the year 2000, this figure will have risen to one thousand. Since the early 1980's, due to many cutbacks, funding is quite scarce and this continues to be the picture at present, unlike Britain where an estimated £29 million pounds is given each year to learning disability services and mental health work. McConkey and Conliffe (1989) note in relation to planning for future services "effective planning involves more than counting heads or beds. Peoples needs, wishes and aspirations have to be taken into account. There are three major stakeholders involved. First the people with a mental handicap; secondly their families and third the professional staff involved in service delivery""(p.4).

Throughout the 1990's, a good deal of work has been undertaken by the Government in terms of the planning of services for those with learning disability. Two publications, which have been published in the 1990's have gone to some lengths to set about planning for the future are:

1] Needs and Abilities: A Policy for the Intellectually Disabled (July 1991) and

2] Shaping a Healthier Future: A Strategy for Effective Healthcare in the 1990's (1994).

The first of these publications is the report from the review group on mental handicap services which was initially developed and set-up in 1986 after discussions with the Dept. of Health and major Organisations catering for those with learning disabilities. In all there were approximately sixty-one major recommendations from the findings of the review committee and these recommendations ranged from a changing of the term mental handicap (a formal debate to be initiated into the terminology to be accepted) to the detailed cost analysis of alternative levels of care (1990).

1.12 Chapter Conclusions.

To conclude, the present chapter has focused on some of the points central to an understanding of learning disability. Despite the many achievements and developments to date, there is still much work to be undertaken in this highly specialised field, not only in terms of theory but also in terms of practice. In a sense the field of learning disability has had quite a unstable foundation as there is much disagreement on the definitions and terminology used to describe this most unique and individualistic population. There is no doubt but the debate regarding which terminology is most appropriate will continue for some time and

whether a consensus will be formed remains to be seen. What will be of interest in Irish terms is whether formal debate will commence regarding terminology to be used - a recommendation from the review group on mental handicap services (1990). Assessment and treatment procedures will continue to be refined as new and more effective techniques are implemented. The role of research in determining their effectiveness cannot be over-emphasised and many services are gradually beginning to commence research projects - many of which were long overdue. In addition with the development of concepts such as advocacy, normalisation and empowerment, individual clients are having their say as to how the future of services should be developed and what they would like to be incorporated in these services. The multi-disciplinary team will continue to be of the utmost importance in service delivery of any kind and the results of this can speak for themselves. To conclude, Scott (1994) states, "the skills of many disciplines are required, so over emphasis on one approach is detrimental. Traditionally this area has often been characterised by a lack of services, reflecting a feeling that little can be done ... there are now many opportunities to develop services and apply our knowledge, offering the prospect for the children and their carers to lead more rewarding lives" (p.640).

CHAPTER TWO

PSYCHOPATHOLOGY AND LEARNING DISABILITY

2.1 Chapter Introduction.

The provision of mental health services for persons with learning disability has received increased interest in recent years. One of the main reasons for such increased interest has been the move from older institutional-type settings to community-based services – a process known as de-institutionalisation or community integration (Wolfensberger, 1972). With the advent of de-institutionalisation, there has been a greater need for recognition that those with varying forms of learning disability are subject to the full range of mental health problems, and thus should be in receipt of the full range of mental health services (Simpson, 1997). A second reason for such interest in the mental health needs of those with learning disability is related to the first point outlined above. Now that these Service Users are moving from large institutions/residential settings to the community, there is a far greater emphasis on the principles of normalisation (Wolfensberger, 1972) for those in community care.

Before moving on, central to this discussion is the issue of mental health and more importantly mental health *problems*. As with the general population, mental health problems (of whatever form or level of severity) in persons with learning disability, can have serious implications for the individual themselves, their families, those caring for them and for public policy (Fletcher, 1988; Szymanski, 1994 and Caine & Hatton, 1998). As is noted by Simpson (1997) it is far easier to recognise *health problems* than it is to recognise *health* itself and there is a huge "subjective element" to this process (Moss, 1999) which will be discussed later in the chapter. If one turns for a moment to look for a definition of "mental health", it is by no means an easy process for anyone, and when such a definition is applied to the learning disabled population, more questions are asked than answers forthcoming. Simpson (1997) suggests a possible definition of mental health, bearing in mind the difficulties surrounding this area. He suggests a possible definition as follows:

"persons who have good mental health are able to respond to their social situation and environment in a way that is expected for their level of development, and have no significant alteration of mental functioning associated with distress or disability. It is easier to recognise health problems than to recognise health" (p.35). As will be seen later on, the above definition is largely based around the current DSM definition of Mental Disorder (DSM-IV, APA, 1994) which is the most current definition utilised at present.

2.2 Diagnosis of Mental Disorders.

Diagnosis of any form of mental disorder is based around the issue of abnormal behaviour and how this "abnormal" behaviour can be examined and identified (Davison & Neale, 1994). Essentially there are six components or methods for examining abnormal behaviour: Statistical infrequency, Deviation from social norms, Maladaptiveness of behaviour, Personal Distress, Disability or dysfunction and finally Unexpectedness (Davidson & Neale, 1994).

If one examines the diagnosis of mental disorders from a historical perspective, much of the earlier work (5th century B.C. onwards) was based around the writings of philosophers, theologians and physicians, which examined mental disorders in terms of "demonology", "somatogenesis" and "psychogenesis" (Davidson and Neale, 1994, pp.10-11). The basic premise of much of this work was that an evil spirit was said to have taken over the body of the person and this was the reason for their mental illness. On the basis of such ideas, persons who were said to be "possessed" (mentally ill) were either treated with ridicule and scorn (and put to death – witches being burned at the stake for example) or with compassion, depending on the era (Nezu, 1994). As a result of such beliefs and practices, segregation of those who were in any way "different" or "deviant" became common practice regardless of whether the person in question was deemed to have a mental illness or

have a learning disability. This had the overall effect of drawing little distinction between those with a mental disorder/illness and those with a learning disability (Nezu, 1994), a belief still held by many to the present day.

If one looks to the term "diagnosis", Szymanski et al. (1998) state that the term diagnosis "is an application of a standardised name to a certain problem, and in general medicine, a recognition and naming of a disease" (p.3). If a clinician wishes to make a diagnosis of a mental disorder either in the general population or in the learning disabled population, they refer to DSM (Diagnostic and Statistical Manual of Mental Disorders) which is now in its fourth edition, DSM-IV (APA, 1994). According to DSM-IV, a mental disorder may defined as "a clinically significant behavioural or psychological syndrome or pattern that occurs in an individual and that is associated with present distress (e.g. a painful symptom) or disability (i.e. impairment in one or more important areas of functioning) or with a significantly increased risk of suffering death, pain, disability, or an important loss of freedom" (APA, 1994, P.xxi).

Diagnosis of a disorder (of whatever type) may take many levels according to Szymanski et al. (1998). Diagnoses may be either 1} "*pathoetiologic*" (describing the specific cause of the disorder – this type of diagnosis is most accurate), or 2} "*syndromic*" (the clustering of symptoms and signs – not as accurate because of multiple agents causing a syndrome). Single symptom ("monosymptomatic") diagnosis is far less accurate in comparison to the other levels of diagnosis above. Most mental disorders are diagnosed using a "syndromic" diagnosis (meeting at least 6 of the 12 criteria for example) or "monosymptomatic" diagnosis (stereotypic disorder with self-injurious behaviour (Szymanski et al., 1998, p.3).

Since the introduction of DSM by the American Psychiatric Association in 1952 (DSM-I), there have been numerous changes. The most notable of

these changes has been that DSM has transformed from being a largely psychodynamic and psychobiological model to being an objective research-based neuroscientific model. Resulting from these changes, and especially with the introduction of DSM-III (APA, 1980) DSM now incorporates a "multi-axial" model, with five main axes incorporating several categories of mental disorders.

Despite the many changes to DSM criteria over the years, it still remains a classification system for the general population for the diagnosis of mental disorders. This issue in itself poses significant problems for the field of learning disability as one fundamental question arises concerning the extent to which a classification system derived for the general population can be valid, and used effectively and accurately with a population as diverse and complex as learning disability.

Before moving on however, it is necessary to review the historical perspectives on the issue of psychopathology and learning disability and how they have had impacted on the field, to the present day.

2.3 Psychopathology and Learning Disability: Historical Perspectives.

The notion that learning disability was a deficit of intellectual functioning only became truly established in the earlier part of the nineteenth century. Prior to this little distinction was made between the concepts of learning disability and mental illness. Nezu (1994) notes that "during the past 2 centuries, clinical observations and systematic research addressing these two constructs have developed along separate lines" (p.4). Early theorists tended to view the two constructs as being similar and such beliefs had major implications for both fields in terms of their theoretical understanding, research and experimentation, treatment and public policy concerns (Reiss, 1994, p.67). With the advent of a more objective approach to the study of both learning disability and mental illness, conceptual lines were drawn between the two, with intellectual

deficits been viewed as the primary deficit of learning disability, and emotional impairment been viewed as the primary deficit of mental illness. Although the drawing of "conceptual lines" between the two proved to be useful, it also served as a disadvantage which will be outlined below.

Because of the distinction now drawn between the two, many professionals in both fields felt that that those with a learning disability were in some way "immune" to psychiatric disorders (Nezu, 1994). Fletcher (1988) outlines one of the commonly held attitudes and beliefs of many professionals at the time. He notes "the mildly retarded have been characterised as worry-free and thus mentally healthy. The severely retarded have been considered to express no feelings and therefore do not experience emotional stress" (p.255). Borthwick-Duffy (1994) elaborates on this point, stating that "historically, one perspective held by many professionals has been that individuals with mental retardation were incapable of developing emotional disorders that could be characterised as mental illness (i.e. they were thought to be incapable of acquiring the same disorders as people without mental retardation). Behaviour disturbances were attributed to the impaired development that characterised mental retardation" (p.17; also Schroeder et al., 1979). Another commonly held view at the time was that if those with learning disability did develop some form of psychiatric disorder, it was qualitatively different to that of the general population. "People with mental retardation were indeed vulnerable to mental disorders but their emotional problems were of a different quality and were usually of biologic origin (Borthwick-Duffy, 1994, p.17; Szymanski & Grossman, 1984).

It was largely due to the above beliefs that the concept of "diagnostic overshadowing" was developed by Reiss, Levitan and Szyszko (1982). Diagnostic overshadowing refers to when the learning disability itself "overshadows" any additional impairments, specifically mental illness

(Reiss et al., 1982). This concept has had important implications, especially in terms of initial diagnosis and later treatment. This has been supported by the research of (Reiss et al., 1982) during which case studies were presented to two groups of psychologists. The groups differed in that one was told the client had an IQ of 60 and the other group was told the clients had an IQ of 102. Both groups were asked to diagnose the fear and plan out a treatment strategy. Findings from the study indicated that in the person with an IQ of 60, the fear was diagnosed to a far lesser degree and less likely to be referred for appropriate treatment in comparison to the other person of IQ 102 (Reiss, 1982a, 1982b). Such findings attest to the powerful nature of diagnostic overshadowing. In the above examples, Reiss (1994) states "the presence of mental retardation overshadowed the accompanying presence of abnormal behaviour usually considered indicative of psychopathology" (p.69).

Menolascino and McCann (1983) characterised the period of the early 20th century as being a "tragic interlude", in that the gap between the fields of learning disability and mental illness continued to diversify independent of each other (Nezu et al., 1992). Pollock (1944) at a joint meeting of the APA (American Psychiatric Association) and AAMD (American Association on Mental Deficiency) stated "ordinarily we regard the mentally ill and the mentally defective as separate and distinct groups ... comparatively little thought is given to the mental hygiene needs of mental defectives" (pp.261-363). Over thirty years later, Gualtieri (1979) notes that very little has changed: "Psychiatry needs to reconsider its stance towards retarded people, because a terrible barrier has grown up between the fields of mental health and mental retardation" (p.26).

Distinguishing between "primary" and "secondary" handicaps has proven useful, to a point. This debate has continued for some time - does the person primarily have a learning disability or a mental illness ? (Reiss,

1994). Asking such a question may be useful in terms of administration, planning for the future and very importantly funding, but it has immense implications for treatment. If the person is deemed to have primarily learning disability, then the mental illness is "diagnostically overshadowed". Essentially this has lead to inadequate mental health services being developed for persons with learning disability (Reiss, Levitan and McNally, 1982). "A practical consequence of labelling psychiatric disorders as 'secondary' in importance is that the needed mental health services are less likely to be funded" (Reiss, 1994, p.67).

Another factor which has led to inadequate mental health services for persons with learning disability is the shortage of qualified professionals trained specifically in the mental health needs of those with learning disability (Nezu et al., 1992). From a purely historical perspective, Gualtieri (1979) reviewed the four main Psychiatric Journals of the time. Of the 612 articles published by these journals in 1977, only 20 were devoted to "mental retardation". From the perspective of training, Phelps and Hammer (1989) surveyed Clinical and Counselling Psychology trainees, in terms of their training in learning disability. Findings indicated that 75% of clinical psychology and 67% of counselling psychology trainees did not receive training in learning disability. Finally on this point, Nezu (1994) reviewed articles from the Journal of Consulting and Clinical Psychology from 1972 to 1992 and found that of the 3,431 published articles, only 11 articles were published on the topic of learning disability (mental retardation) (p.4).

By undertaking an examination of the historical perspectives that surround the fields of learning disability and mental illness, one may now begin to understand the many difficulties that the field of learning disability is facing in the present day. With little or no real interest in the two concepts emerging until quite recently, the "gap" between the two fields is still quite distant. In addition many professionals are still of the opinion that those with learning disability are still "immune" to mental

illness, and in those persons who are dually diagnosed, their disorders are in some way "different" than others - without the presence of learning disability.

2.4 Issues in the Assessment and Diagnosis of Mental Illness in Persons with Learning Disability.

"The accurate assessment and effective treatment of mental health problems in people with intellectual disabilities is an essential component of any service aiming to improve the quality of life of its users" (Caine & Hatton, 1998, p.210). In beginning any discussion on assessment and diagnosis of mental illness in the learning disabled population, one is immediately struck by the vast amount of problems that the field is faced with. From the historical perspectives outlined above, one can see how the two fields diverged in their own ways and how this has had such a huge impact, to the present day.

As we are aware, up until recently the mental health needs of those with learning disability have been greatly neglected and this has had the effect of an under-diagnosis of mental health problems in this population (Caine & Hatton, 1998; Charlot et al., 1993; Patel et al., 1993). In turn, the "knock-on" effect of under-diagnosis, has been the inadequacy of specialist mental health services for these people (Day, 1994; Patel et al., 1993). The reasons for inadequate mental health services may be classified as follows:

⇒ Separation of mental health and learning disability services (based on historical perspectives - divergence of the two fields). This has led to the two fields operating independently of each other, and to date an integrated approach has not been developed and utilised (Campbell & Malone, 1991; Day, 1994, Caine & Hatton, 1998).

⇒ Difficulty in regard to the assessment protocol used for those with learning disability. Many assessment tools are available, specifically

for those with learning disability but many clients are non-verbal and/or unable to talk about how they feel and about their mental health status. Assessment of those within the severe and profound ranges of learning disability is frought with difficulties (Moss, 1999).

⇒ The classification systems used presently are either DSM-IV (APA, 1994) or ICD-10 (WHO, 1992). These classification systems have been developed from the general population and there is currently much disagreement about how such classification systems can be used and adapted with the learning disabled population (Moss, 1999, Szymanski et al., 1998).

⇒ Diagnostic-overshadowing (Reiss et al., 1982; Spengler et al., 1990): this occurs when the learning disability "overshadows" the presence of a psychiatric illness. As a result of this, many of the common mental illnesses have not been diagnosed in persons with learning disability which has had an impact of prevalence and epidemiology.

⇒ Differential diagnosis. This has been a particular issue with regard to diagnosis of mental illness. Is the person suffering from a mental illness, or do they have challenging behaviour ?? Many of the common mental disorders display themselves by means of aggressive episodes and challenging behaviour. How to distinguish between the two is particularly difficult, especially those who have poor verbal skills or are non-verbal, and in those who are low functioning (below IQ 50) (Moss, 1995).

⇒ Absence of adequate referral systems (Caine & Hatton, 1998). As was mentioned in the opening paragraph of this chapter, now that there is a greater emphasis on community integration and the rights of those with learning disability to mental health services, a greater emphasis must be placed on mental health service provision. This is being achieved to a certain degree with those living in the community -

as when they have problems fulfilling their "social roles", attention may be drawn to their mental health (Caine & Hatton, 1998, p.211). For those in residential care, provision of mental health services needs to be addressed, due to there not being the same emphasis on "social roles" as there is in the community, by virtue of their placement in a residential setting.

However, despite these problems being encountered, there is now a far greater understanding amongst professionals in the field of learning disability that there is a necessity for quality mental health services (Bouras, 1994, Bouras et al., 1995) and much work is being undertaken in order to resolve many of the issues at hand.

2.5 Further Issues in the assessment and diagnosis of mental illness in persons with learning disability.

Just as learning disability is a social construct, so too is mental illness (Caine & Hatton, 1998, p.211), and both are subject to much variation across time and across cultures (Littlewood & Lipsedge, 1989; Porter, 1990; Scull, 1993). If one takes the construct of learning disability, it has been subject to much change over the past number of decades. The latest definition of "mental retardation" as outlined by the AAMR (Luckasson et al., 1992) is radically different from any definition of MR in the past, as it places much emphasis on the concept of adaptive functioning, in addition to intellectual functioning, as part of its definition. This is just one example to hand, of the importance of time, a shift in thinking, importance of new knowledge, and cultural influences on one such construct. In a similar fashion with the advent of DSM (whose first edition was published in 1952 - DSM-I, APA, 1952), there have been many changes witnessed throughout the history of The Diagnostic and Statistical Manual of Mental Disorders, leading up to the recent version published in 1994 - DSM-IV (APA, 1994). As new knowledge has been gained and gathered since first published in 1952, significant changes have occurred in its Axes, categories and sub-categories. Perhaps the

most notable change (& a change which affected all versions of DSM from 1980 onwards) between DSM II (APA, 1968) and DSM-III (APA, 1980) was the change from psychobiological and psychodynamic underpinnings to a more descriptive model of reference (Szymanski et al., 1998). This again shows us the importance of the gathering of new knowledge and a change in thinking over time.

Although the DSM is a means of classification and an aid to diagnosis, historically and to a large degree, diagnosis of psychiatric disorders has been made by a psychiatrist. However as the research of Ash (1949), Sandifer et al. (1970) and Termelin (1968) has shown, very often the "clinical judgement" of a psychiatrist may be called into question and may be unreliable. As is noted by Moss (1995) when the psychiatrist undertaking or attempting a diagnosis is untrained or inexperienced in the field of learning disability, this has further repercussions for the validity of the clinical judgement.

However, as will be seen below, although the introduction of DSM (and the categorisation of psychiatric disorders) has greatly improved the reliability and validity of diagnoses, there are many problems inherent in the diagnosis of mental disorders in persons with learning disability using "standardised" criteria (DSM-IV or ICD-10).

2.6 The "Pathway" to Mental Health Services for Persons with learning Disability.

In discussing diagnosis and assessment of mental health in any population, one must make reference to *how* a person goes about any diagnosis or any assessment. In the general population, if a person feels ill (in any way), they may tell a friend, phone a doctor or pay a visit to the doctor themselves. The person's ability to *recognise* that they may feel unwell is paramount - once the person recognises that they are feeling unwell, they may be referred or they may then visit the doctor themselves and report the symptoms they are feeling (stomach ache, back pain etc.).

It is this "ability to report" the symptoms of their illness which is so very important.

Essentially, "case recognition" is the first part of any assessment process (Moss, 1999). "Cases which are not detected and referred cannot be assessed and treated" (Moss, 1999, p 2). It is in this very first phase of assessment that those with a learning disability are at a significant disadvantage. Because of the nature of the person's learning disability, they may have difficulty in verbalising how they are feeling or on the other hand, they may be non-verbal and have no means of communicating their feelings or their needs. As a result of poor communication skills, cases may not be referred and thus cannot be treated by mental health services.

The persons' ability to recognise that they are not *"feeling well"* is an essential part in the referral and assessment process. As the research of Patel et al. (1993) has shown, many persons with learning disability may have an accompanying mental illness, but many of these are simply not detected. Due to the hugely "subjective" element to this process, those with a learning disability, are again at a disadvantage due to the verbal skills necessary to identify how they are feeling. An issue which was mentioned in the earlier pages of this chapter is of relevance to the present discussion on case detection. This is the issue of staff training and the importance of staff identifying a possible problem. When the person is non-verbal or has poor communication skills, the importance of staff training in mental health cannot be over-emphasised. A number of important factors are outlined below:

⇒ Obviously when a client is non-verbal, information obtained about the person must be sought from a third-party (i.e. a person familiar with the client and interacting with them for a considerable length of time). It is necessary for that person to be in a position to provide useful and

relevant information about the client's behaviour over a period of time.

⇒ Observed and recorded *changes* in behaviour are the most useful pieces of information in addition to patterns of behaviour displayed by the client (Caine & Hatton, 1998). Invariably, most mental illnesses have a predictable time course and are recognised by a combination of behaviour patterns. If a mental illness has gone unrecognised for some time however, this makes the assessment process even more difficult as it is harder to ascertain what the pattern of behaviour has been prior to onset. Particular difficulties occur in the diagnosis of dementia in persons with learning disability as levels of cognitive functioning before and after onset may be difficult to assess (Aylward et al., 1995).

⇒ One must make allowances for individual differences in the way that disorders or the symptoms of disorders may be displayed. "The level of intellectual disability is likely to have a substantial impact on how symptoms of distress are expressed, with people with more severe disabilities expressing distress in more behavioural rather than verbal ways" (Caine & Hatton, 1998, p.215). This raises many issues in relation to challenging behaviour and its relationship to mental illness. This issue will be discussed later in the chapter.

⇒ Staff should reflect and consider alternatives for unusual behaviour displayed by the person. The particular behaviour or patterns of behaviour may not be indicative of a mental illness. For a person who is non-verbal, aggressive behaviour may be a result of physical pain or illness which has gone unnoticed. In a similar fashion, differential diagnosis may show that the behaviours displayed may be a result of the side effects of neuroleptic (or other) medication (Aman et al., 1988; Caine & Hatton, 1998).

⇒ Finally, some mental illnesses are notoriously difficult to diagnose and it may take some time to accurately diagnose a particular condition. For those persons in the severe and profound ranges of learning disability, it may be virtually impossible to assess their mental health needs due to insufficient evidence.

Whether the person in question is verbal or non-verbal, the assessment process will always involve the staff who interacts with the client, as a means of providing information. Staff perceptions of what constitutes a mental illness is another factor to be considered. How do we actually define and identify a mental illness ?? Although we broadly define "mental disorders" – see above definition - through the use of DSM-IV (APA, 1994), there are still many issues around terminology and definitions used to the present day.

As far back as 1980, Szymanski noted the problems of terminology and how they had an impact on epidemiology and prevalence. Szymanski notes "professionals in the fields of retardation and mental health often use a variety of terms such as mental illness, mental disorders, psychiatric disorder (problem, condition), emotional disorder, behavioural disorder. These 'labels' often reflect the psychological theoretical background of the person rather than a specific category, and in fact these terms are usually used interchangeably" (1980, p.63).

Even when the key informant gives information on the presenting symptoms, they may not necessarily be an accurate reflection on the behaviours, and may differ from what the client themselves feels and reports (Moss, 1999). By the very nature of third-party or key-informant reports, validity may be called into question and the information received may be influenced by a variety of factors, the most notable of these being:

⇒ *The nature of the relationship between the client and the key informant.* This can have a major bearing on the information received as obviously familiarity with the client is essential. Familiarity over time is also essential as otherwise it may not be possible to gain an accurate picture of the persons behaviour before and after onset of the symptoms.

⇒ *The existence of a prior label – such as "challenging behaviour".* The relationship between mental illness and challenging behaviour is as yet poorly understood. When a person with learning disability displays challenging behaviour, the presence of this label can have profound effects on assessment and diagnosis of mental illness. Very often, when the person presents with challenging behaviour, the possibility of an accompanying mental illness may be overlooked. It may be felt that the problem at hand is challenging behaviour-related, rather than being due to the presence of a mental illness.

⇒ *Diagnostic overshadowing.* When the presence of the person's learning disability "overshadows" the person's mental illness and thus the accompanying mental illness is not detected.

The above three factors contribute significantly to the information received from third-party or key-informant responses (Levitan & Reiss, 1983; Moss, 1999, p.12) and should be taken into consideration when examining the validity of information obtained.

All of the above points combined are of relevance to the next section on epidemiology and prevalence. Although there are a number of problems inherent in any discussion on epidemiology and prevalence, it is necessary to examine the overall findings in relation to the research undertaken to date. Such a discussion offers us a unique profile of the type of prevalence research undertaken, the methodological problems encountered, while also offering us some possible explanations and

alternatives to examining psychopathology in the learning disabled population.

2.7 Epidemiology and Prevalence of Psychopathology in the Learning Disabled Population.

Upon discussing some of the issues surrounding assessment and diagnosis of mental illness in the learning disabled population, it is not surprising a wide range of rates have been reported in the literature to date (Borthwick-Duffy, 1994; Caine & Hatton, 1998; Campbell & Malone, 1991; Reiss, 1990; Simpson, 1997; Iverson & Fox, 1989; Bernal & Hollins, 1995; Collacott et al., 1992; Crews et al., 1994; Borthwick-Duffy & Eyman, 1990; Gilberg et al., 1986; Jacobson, 1990; Linaker & Nitter, 1990 and Szymanski, 1994).

Although to a large extent, much of the problem has rested with the fact that few studies can be compared, as they used very different methodologies and modes of assessment (Caine & Hatton, 1998), there are a host of contributing factors.

Borthwick-Duffy (1994) examines these factors and notes that: "several factors have been identified as being responsible for the wide range of reported prevalence rates of psychiatric disorders among people with mental retardation and have been discussed in the recent literature ... these factors fall into two general categories including (a) definitional and identification issues and (b) sampling issues. Prevalence rates should be interpreted in the context of these factors, which may explain discrepancies and limit generalisation of findings" (p.17).

Resulting from the above statement, and as further stated by Szymanski (1994) "there are few reliable data" (p.26; also Szymanski, 1980; Szymanski & Crocker, 1989 and Russell, 1988).

2.7.1 Definitional and Identification Issues.

By means of "definitional and identification issues", Borthwick-Duffy (1994) refers to the difficulty in defining and classifying both *learning disability* (mental retardation) and *mental illness.* As was discussed earlier, the concept of learning disability has undergone radical changes over the past number of decades (Luckasson et al., 1992). Depending on the research undertaken, various researchers have used a variety of definitions and classification systems for classifying learning disability (Lowitzer et al., 1987). In terms of mental illness and how it is defined and classified, a variety of terms have been used from "mental disorder" to "behaviour disorder" (Szymanski, 1980, p.63). Depending on what definitions, terminology and classification system is used, research has varied considerably and has led to considerable differences in empirical findings.

In terms of disorders chosen to be studied from a research perspective, Costello (1982) notes that "one problem is that personality disorder, or what might more loosely be termed difficult behaviour associated with a severe functional handicap, is not always easy to distinguish from classic psychiatric disorder, and it is a moot point whether this distinction should be made" (p.39).

2.7.2 Sampling Issues.

Many of the studies to date have focussed on "selected" populations – that is populations either referred to clinics or clients in institutional settings (Szymanski, 1994). Selection of the "target" population is vital in any piece of research and it can have serious implications in terms of empirical findings (Borthwick-Duffy, 1994; Borthwick-Duffy & Eyman, 1990; Reiss et al., 1982; Schroder et al., 1979).

From the prevalence studies undertaken to date, figures obtained have ranged from 10% to 80% (Jacobson, 1990) depending on the target population selected, the definitions used and the mode of assessment incorporated (Campbell & Malone, 1991; Borthwick-Duffy, 1994; Caine & Hatton, 1998).

If one looks to figures obtained from studies in the general population, the rates reported are approximately 20% (Caine & Hatton, 1998). The research of Meltzer, Gill and Petticrew (1995) found that approximately 14% of adults between the ages of 16 and 64 years had some form of mental health problem, with 10% of the population studies having a diagnosable disorder (Simpson, 1997). Jacobson (1990) notes that conditions such as affective and anxiety disorders occur more frequently than schizophrenic disorders in the general population, as do personality disorders (Mezzich et al., 1984). Antisocial and substance abuse disorders are more frequent for males than females, while major depressive disorders, simple phobias and agrophobia are more common in females (Jacobson, 1990; Myers et al., 1984; Robins et al., 1984).

In contrast studies undertaken in the learning disabled population have given us a very different picture. The findings of Benson (1985), Forness & Polloway (1987), Fraser et al. (1986), Menolascino et al. (1986), Myers (1987), Philips & Williams (1975) and Reiss (1982) have shown that anxiety disorders, affective disorders and personality disorders occur at lower rates in comparison to schizophrenic disorders.

Studies specific to the learning disabled population have shown us that when the target population is from a "referred" sample (i.e. referred for psychiatric evaluation) figures are generally elevated (Bouras & Drummond, 1992; Pary, 1993) and if *behaviour disturbance* is included as a psychiatric disorder, then prevalence figures tend to be over 40%. The lower prevalence rates – i.e. those below 15% tend to be based on

research which examined case files as a means of identifying psychiatric disorders.

2.8 Studies on Selected/Referred Populations.

On those studies undertaken on selected populations, some of which are now quite dated, the main findings are as follows. Menolascino (1965) in a study examining the prevalence of psychopathology in children with learning disability, found an overall prevalence rate of 24.5% in this population. Webster (1970) evaluated 159 children and found in all cases there was some form of emotional disorder, and in 18%, psychosis (not specified) was diagnosed. The study of Philips & Williams (1975) examined a population of 100 children referred to a psychiatric clinic for evaluation. Of these 100 children, 87% were given a diagnosis, with the most common disorders being - psychosis (38%), behaviour disorders (26%), personality disorders (16%) and neurosis (5%). In terms of symptomatology, the author's notes that the symptoms observed in these children were similar to symptoms observed in children without learning disability (Philips & Williams, 1975).

In a survey of 132 children referred to a learning disability clinic, Szymanski (1977) found a rate of mental disorder in conjunction with learning disability in 54% of this population. In a large-scale study of 1507 residential service users, Wright (1982) found a rate of "serious mental disorders" in just 7.3% of the population studied. When these figures are broken down into the various disorders, findings show that schizophrenia occurred in 1.8%, affective disorder was diagnosed in 2.8% and early childhood psychosis in 2.7%.

In an unpublished piece of work (Szymanski - cited in Szymanski, 1994) utilised diagnostic criteria from DSM III (APA, 1980) examining a total of 123 adults and 277 children with mild and moderate levels of learning disability. According to the DSM III criteria, a diagnosis of Axis I mental

disorders occurred in 74% of the adults studied and 70% of children. The breakdown of adult diagnoses were as follows: adjustment disorder (15%), affective disorder (15%), psychotic disorder (13%), and pervasive developmental disorder (11%). In the children studied, the most frequently occurring disorders were: pervasive developmental disorder (22%), affective disorder (12%) and adjustment disorder (10%). What was interesting to note from this study was that results obtained were from children and adults with mild and moderate levels of learning disability. As was noted earlier, this begs the question as to how applicable diagnoses are when clients are below the moderate level of learning disability?

The study of Linaker & Nitter (1990) examined rates of psychopathology in an "institutionalised" population of 168 clients. In terms of the assessment method incorporated, the authors used both the PIMRA (Psychopathology Instrument for Mentally Retarded Adults) - a third party rating scale completed by staff, and case note review. Results from the study found that in terms of DSM III Axis I disorders, 146 of the 168 adults studied satisfied the criteria for same, while 153 satisfied the criteria for at least one disorder on either Axis I or Axis II. The authors also found that multiple diagnoses were common and that "level of functioning was not found to predispose to any particular diagnosis" (Linaker & Nitter, 1990, p.522). In terms of individual disorders, schizophrenia was diagnosed in 48 cases, anxiety disorder in 94 and personality disorder in 85 cases. Interestingly no diagnosis of affective disorder was identified, despite the PIMRA being significantly correlated with the Hamilton Rating Scale for Depression and the Beck Depression Inventory (Kazdin et al., 1983).

More recently the study of Crews et al. (1994) examined rates of dual diagnosis in a large state residential facility in Virginia. Although the study examined prevalence in a sample of referred service users, it utilised DSM-III-R (APA, 1987) criteria in terms of diagnoses. The

population studied were 1,273 children and adults between the ages of 10 and 80 years with levels of learning disability ranging from mild to profound. Findings showed that the overall prevalence rate for dual diagnosis was 15.55%. Although the rate achieved is quite low in comparison to other studies, the authors note that "the relatively low rate of dual diagnoses may also indicate a diagnostic overshadowing phenomenon ... abnormal behaviour in some individuals with mental retardation may be solely attributed to their mental retardation as opposed to the actual psychopathology that it reflects. Because psychopathology is overlooked, the true prevalence is underestimated" (p.729).

2.9 Studies on Unselected/Random Populations.

In one of the most widely documented studies in the literature, Rutter, Graham and Yule (1976) examined the prevalence of psychopathology in the entire population of children between the ages of 9 and 11 years on the Isle of Wight. The methodology incorporated was multi-modal as it incorporated parent and teacher questionnaires and direct interviews. Level of learning disability was ascertained by means of IQ score only. On the basis of this methodology, psychiatric disorder was diagnosed in 7% of the population studied. However, in children with an IQ of under 70, psychiatric diagnosis was deemed to be in the range of between 30 and 42% (Rutter et al., 1970).

A longitudinal study undertaken by Koller et al. (1983) followed-up on a cohort of persons with learning disability over the period of 5 years. Retrospectively in terms of those disorders diagnosed in childhood, 61% of those studied were deemed to have a behavioural disorder. The study of Lund (1985) used a random sample of 302 adults with learning disability and found that in using modified DSM III criteria, the rate of psychiatric disorders was 28%. Although "behaviour disorder" is not a formal DSM III diagnostic criteria, it was the most frequent diagnosis at

11%. The next most frequently diagnosed condition was psychosis (uncertain type) at 5%, dementia and autism (3.6% respectively), neurosis (2%), affective disorder (1.7%) and finally schizophrenia (1.3%).

Gostasson (1985) studied a random sample of adults with learning disability and found that in those with severe learning disability, mental illness was diagnosed in 55% of cases, while for those in the mild range of learning disability, the corresponding figure was 17%. For control subjects (with no learning disability) the rate of mental illness was 8%.

The study of Gillberg et al. (1986) although it did not incorporate DSM III criteria, reported on the results of 149 adolescents between the ages of 13 and 17 years of age. These children were assessed by child psychiatrists and findings indicated that 64% of those with severe learning disability and 57% of those with mild learning disability were deemed to have a diagnosis of some form of "handicapping psychiatric condition" (Szymanski, 1994, p.29). Fourteen per cent of mild and 50% of those with severe learning disability had psychotic behaviour (including schizophrenia, autism and social impairment).

Iverson and Fox (1989) used a similar methodology to Linaker and Nitter (1990) (PIMRA rating scale), but their findings were based on a random, stratified sample of 165 adults with learning disability. Results from their study showed that 35.9% of the sample had "at least one significant psychopathological disorder" (p.77). In addition, those with mild learning disability were found to have higher rates of psychopathology than those in the moderate to profound ranges. Although methodological considerations may be a factor for such a finding in the present study (an under-representation of those with mild learning disability in comparison to other levels of LD), an alternative explanation may lie in terms of the assessment method used. The PIMRA (Matson, 1989) although based on DSM III criteria, it has limitations in its use for those with learning disability who are unable to verbalise (for a discussion on assessment

tools, see next chapter). Such a factor could account for the findings achieved in the study of Iverson & Fox (1989).

In a large-scale study of 78,603 clients with learning disability, Borthwick-Duffy & Eyman (1990) conducted a study examining prevalence of dual diagnosis. The sample under study were selected from those receiving services from the Californian Department of Developmental Services and were included in the State Database. Ages ranged from 0 years to 86 years and included those service users living in state-run residential facilities, community homes, health care facilities, with parents or family members or in alternative accommodation such as psychiatric clinics or living independently. The instrument used to obtain data on dual diagnosis was the Client Development Evaluation Report (CDER, California Department, 1978; Borthwick-Duffy & Eyman, 1990). Findings indicated that approximately 10% of the clients under study were likely to be given a psychiatric diagnosis, with those in the mild range of learning disability more likely to receive a diagnosis than those in the severe range. Specific psychiatric disorders were not discussed in this paper as a specific assessment protocol was not administered and results were based on recorded information (CDER - computerised system).

The study of Reiss (1990) was unique in that he selected a population attending a community-based day programme. The methodology incorporated was a "two-step" methodology, which was stringent in terms of operationalisation. It firstly involved a random sample of 205 clients with learning disability in which a dual diagnosis-screening test was administered. Step two involved 59 clients being assessed blindly (i.e. unaware of the results of stage 1) by a clinical psychologist. The instruments used were the Reiss Screen for Maladaptive Behaviour (Reiss, 1988), case note information regarding diagnosis and finally psychological evaluations. Overall results indicated that when diagnosis was undertaken by means of a screening instrument approximately 39% of the population studied were deemed as having a dual diagnosis. When the diagnosis was based on case note information and case files,

the figure obtained was 11.7%. Thus the two contrasting figures which emerged in this study show that "these findings support the view that surveys of case files obtain relatively low rates because the mental health problems of mentally retarded people have been under-diagnosed" (Reiss, 1990, p.584).

2.10 More Recent Findings on Prevalence.

With the development of a novel assessment tool in the UK, the PAS-ADD - *Psychiatric Assessment Schedule for Adults with a Developmental Disability* (Moss et al., 1993), new impetus has been placed on the effectiveness of this assessment for persons with learning disability. An increasing volume of data is being published outlining its effectiveness as an assessment tool, be it in its checklist form, expanded rating scale form or semi-structured interview format (Moss & Patel, 1995; Moss, Prosser & Goldberg, 1996; Moss et al., 1993). It has been used frequently in the UK over the past five years, particularly on surveys of psychiatric disorders in older people with learning disability examining dementia.

As those with learning disability increasingly survive into old age (Caine & Hatton, 1998) and with a substantial volume of literature being published on ageing and learning disability, so too has there been increased interest into psychiatric disorders of old age, namely dementia (Patel et al., 1993; Zigman et al., 1995). From the research to date, the rates of dementia in persons with learning disability far outweighs those found in the general population (Patel et al., 1993; Turner and Moss, 1996).

Moss and Patel (1995) examined psychiatric symptoms associated with dementia in older persons with learning disability. They found that in those over 50 years of age who had definite dementia, they also has higher levels of sleep difficulty, hypersomnia, irritability, loss of interest and inefficient thought. Similar to studies from the general population, Moss and Patel (1995) found that cognitive and non-cognitive features

are "weakly related" and "psychiatric symptom information may be useful in screening for dementia in people with learning disability" (p.663).

Research on dementia and its association with Down's syndrome is another area growing interest for the field of learning disability. Findings to date have shown that those with Down's syndrome are "at particular risk of developing dementia" (Caine & Hatton, 1998 p.213; Zigman et al., 1995) and many over 40 years of age can develop the neuropathological signs of Alzheimer's disease (Wisniewski, Rabe & Wisniewski, 1987).

2.11 Conclusions and Recommendations.

Over the past two decades there has been a significant increase in the research undertaken in the study of persons with learning disability and accompanying psychopathology. Although many issues have been addressed, there still remain many questions to be answered. Research on identification, epidemiology and prevalence has proved useful in that it has provided us with evidence that: a} the full range of mental disorders that occur in the general population also exist in those with learning disability and b} generally, there has been an under-reporting of psychiatric conditions in this population, largely due to diagnostic overshadowing.

Researchers and clinicians alike, call for continuing epidemiological type research, as it forms the basis for definitions, causes, the planning of treatment strategies and public policy concerns. As Scott (1988) states "valid epidemiological research requires that sound, unbiased, descriptive data be collected as the cornerstone of research on the definition, causes, treatment, and basic understanding of mental retardation" (p.25).

Issues surrounding DSM criteria and classification systems still remain quite problematic. Although not discussed in any great detail in the present chapter (see chapter three on assessment issues), the question still arises regarding the applicability of any classification system based around the general population and how it may be used for persons with

learning disability (Moss, 1999; Szymanski et al., 1998). From the studies on prevalence outlined in the present chapter, it can be seen that very different figures emerge when DSM criteria are used and when the DSM criteria are adapted to suit better the needs of those being assessed. There is no doubt but future research will have to address this issue further, placing the emphasis on either adapting DSM (or ICD) to the requirement of persons with learning disability or developing a novel classification system based on the learning disabled rather than the general population.

In relation to the above point on classification systems and diagnostic criteria, how can one develop adequate and accurate assessment tools if many of the underlying theoretical issues still have to be resolved. Great advances have been made over the past fifteen to twenty years on assessment tools, but there are still major limitations. The development of the Reiss Screen for Maladaptive Behaviour (Reiss et al., 1988), The PIMRA (Psychopathology Instrument for Mentally Retarded Adults) as developed by Matson (1989) and more recently the PAS-ADD (Psychiatric Assessment Schedule for Adults with a Developmental Disability) (Moss et al., 1993) have yielded interesting results in terms of overall prevalence, and also in terms of what type of disorders are occurring most frequently in this population. Much work has yet to be done on assessment and the key to future research on this area lies in developing or adapting existing classification systems.

Developing a framework around assessment issues in those who have either poor verbal skills are or non-verbal requires careful consideration. Invariably what the findings to date have shown us are that it is particularly difficult to assess and diagnose those with an IQ of under 50 and frequently it is an impossible task. Even if the client is verbal to some degree, they may not be able to verbalise how they are feeling – thus the subjective element which is so important in assessment (and referral) is absent. One is then reliant on basing one's assessment on a third party report, which has implications in terms of reliability and

validity. This issue is where current assessment instruments very often meet their downfall and fail to assess objectively, reliably and with questionable reliability.

In conclusion, it is hoped that over the course of the next decade, similar advances will be made to those of the past ten years. There is no doubting that the next decade will offer substantial opportunities for research which will enhance our understanding and practice of assessment, caring for, and treating those with learning disability and psychopathology. However, not only is quality research necessary, but the research undertaken must be effectively translated into practice.

Finally, as Kiernan (1994) has pointed out "there appears to be a growing antiintellectualism in services and in political thinking which may, in part, be a result of the failure to translate enlightenment research, e.g. on cognitive disabilities, into 'tangible deliverables'. Antiintellectualism is a dangerous trend which needs to be countered by more effective demonstrations of the value of academic research" (p. 63).

CHAPTER THREE

ISSUES IN THE ASSESSMENT, CLASSIFICATION AND DIAGNOSIS OF MENTAL HEALTH PROBLEMS IN PERSONS WITH LEARNING DISABILITY

3.1 Chapter Introduction.

In the previous chapter the author discussed some of the principle issues arising in the field of learning disability and psychopathology. These issues included the increased demand for appropriate mental health services for persons with learning disability, historical perspectives and how these have impinged on present day services for those with a dual diagnosis, the importance of accurate and detailed assessment and diagnosis and the significance of case detection and how this proves difficult, especially in those who have poor communication skills, or those who are non-verbal. An underlying theme in all of the above issues is the issue of classification, and the classification systems used to assess and diagnose psychiatric problems. At the outset, there are many problems evident with the current classification systems used in the present day – DSM-IV (APA, 1994) and ICD-10 (WHO, 1992). One view that many professionals hold is that "psychiatric diagnosis are the creations of committees" (Sturmey, 1999, p.3), while others see psychiatric classification systems as an unnecessary "medicalisation" of many everyday problems.

The present chapter seeks to address some of the existing and current arguments surrounding psychiatric classification systems in general, and also issues pertaining to these systems when they are applied to a population such as those with learning disability. Several arguments surround applying a classification system such as DSM-IV (APA, 1994) to the learning disabled population, and how accurate and reliable assessment and diagnosis can occur on the basis of the application of such systems. This chapter will examine in detail some of the relevant issues in classification systems in the general population, and in turn see how these apply to the learning disabled population.

In addition, the present chapter will address some of the conceptual issues in terms of the interaction of different diagnostic categories and how linguistic competency is so vital for diagnosis if one uses these

standard diagnostic categories. Sturmey (1995) discusses the "potential mismatch between psychopathology in people with mental retardation and the DSM-III-R nosology" (p.357) - such issues will be paramount to the present chapter.

3.2 Common Problems in the Classification and Identification of Psychopathology in Persons with Learning Disability.

Historical perspectives have indicated to us that there has always been interest in the presence of psychiatric disorders in persons with learning disability (Nezu, 1994; Borthwick-Duffy, 1994; Sturmey, 1995). Recently however (over the past two to three decades), there has been increased interest in the concept of dual diagnosis and diagnostic overshadowing (Reiss et al., 1982) in persons with learning disability (Rutter, 1971; Matson & Barrett, 1982; Reid, 1982, Stark et al., 1988, Bouras, 1994 and Moss, 1999). Perhaps one of the major "breakthroughs" in the field of dual diagnosis is that there is now the realisation that persons with learning disability do exhibit the full range of psychiatric disorders that are present in the general population (Sturmey et al., 1991). From the reviews of Rutter et al. (1976), Reid, (1982) and Iverson & Fox (1989), it is reported that the presence of psychiatric disorders are more frequently reported in the learning disabled population when compared to the general population. Despite this fact however, Sturmey et al. (1991) state, "the precise magnitude of this effect is not clear" (p.143).

Although the previous chapter (Chapter six) examined some of the current issues in the field of psychopathology and learning disability, the author did not examine in detail issues pertaining to classification and its impact on assessment and diagnosis. To review the problematic areas in the study of psychiatric disorders in persons with learning disability, one can see seven major problems arising (some of these being discussed in the previous chapter). The first of these problems relates to the under-reporting of the reliability of classification and diagnosis. Second, major problems exist in transferring a classification system

(developed with the general population) to the learning disabled population, without any form of modification or empirical validation. Third, persons with learning disability who have poor communication skills or linguistic abilities find it difficult to report what they are feeling (internal states, emotions and experiences) (Sturmey et al., 1991; Marcell & Jett, 1985; Moss, 1999) - standard classification systems rely heavily on verbal reports. Fourth, third-part reports are frequently used in the assessment and diagnosis of psychiatric disorders in this population. Fifth, many clients are unable to maintain records of their behaviours and/or emotions. Sixth, differential diagnosis: - major difficulties exist in differentiating psychiatric symptoms from symptoms of inappropriate or challenging behaviour. Challenging behaviour may be related to the presence of a psychiatric disorder, but it may not necessarily be a symptom of it. Lastly, there is a poor relationship between diagnosis of a psychiatric disorder and treatment of it. It was once thought that specific drugs would be used in the treatment of specific disorders, but this is no longer a reality in practice.

3.3 General Issues in Diagnosis and Classification Systems.

Any diagnostic system or classification framework provides a set of "templates" in which the clinician can classify conditions and "compare information relating to the condition of a particular client" (Frude, 1998, p.9). As is noted by Sturmey (1999) classification has been the source of much controversy over the years. The issue of labelling has been seen in a very negative light, especially in the field of learning disability due to it being "dehumanising" (Sturmey, 1999).

3.4 Rational and Empirical Classification Systems.

Essentially there have been two approaches employed in the development of any classification system: rational and empirical. According to Frances et al. (1990) the rational approach is typified in the

transition from DSM-III-R to DSM-IV. DSM-III-R evolved into DSM-IV by means of a three-stage process. It incorporated extensive literature reviews (Widiger et al. (1990), analysis of unpublished data sets and field trials (Kline et al., 1993). Hence, committees were set-up to co-ordinate each of the various activities, for each of the above areas. Perhaps the main criticism of the development of such committees was that the process was open to "non-scientific influences such as socio-political pressure to make DSM compatible with ICD" (Sturmey, 1999, p.7; Malt, 1987; Frances et al., 1989 and Thompson & Pincus, 1989), along with dominant committee members and poor empirical decision making process (Zimmermann, 1988).

The second approach to classification of psychiatric disorders has been the empirical one. Empirical approaches to classification assess conditions in terms of the presenting symptoms and subject them to statistical analysis to determine if groupings of behaviours exist. The research of Farmer et al. (1994) typifies the empirical based approach to classification in which the author assessed 862 people on variables such as physical and sensory disabilities, adaptive and maladaptive behaviours. Upon statistical analysis, three factors emerged "physical" (physical abilities), "lack of skills" (general adaptive behaviours) and "behaviour" (behaviour disorders). Cluster analysis then took place, which was validated with staffing levels and residential placement. Results from statistical analysis showed the clusters where behaviour problems were prevalent and high staffing ratios were needed and where skills were in abundance and lower staffing ratios were required.

If anything, empirical based approaches to classification try to avoid "presupposed" ideas of classification based around DSM and ICD. In addition, by its very nature, empirical classification is "data driven" and uses the data formulated as a method of problem solving, which is effective in comparison to committee consensus. In terms of disadvantages, there are a number clearly evident. Firstly, due to

empirical classification being data and hypothesis driven, it is quite time-consuming and does require large sets of data, in addition to independent replications. Due to the empirical approach being based around statistical analysis, it may be limited by the pool of items placed in the data set to be analysed. A final criticism as outlined by Sturmey (1999) is that empirical classification does not always rely on theory. The development of many instruments tends to rely on theoretical assumptions, which are also an important part of clinical practice.

3.4.1 DSM and ICD Classification Systems.

The Diagnostic and Statistic Manual of Mental Disorders (DSM) was first published by the American Psychiatric Association (APA) in 1952. Revised and updated versions have been published in 1968 (DSM-II), 1980 (DSM-III), 1987 (DSM-III-R) and in 1994, the most recent version - DSM-IV was published. The World Health Organisation has followed a similar pattern over the years, and its classification system termed The International Classification of Disease (ICD) is now in its tenth edition (ICD-10). ICD-10 (WHO, 1992) is European based, while DSM-IV originated and is developed in America. Despite differences in origin, the two classification systems in their latest versions are quite similar and their categories may be used in conjunction with each other (Frude, 1998).

According to Parker et al. (1995), one of the main failings of classification systems such as DSM and ICD is "adequately to represent the diversity of human experiences of distress and the role of these category systems in practices which intensify the distress of certain groups in society" (p.37). These classification systems tend to individualise the presenting conditions, rather than considering the wider social factors, which include gender and race. Other general criticisms of DSM and ICD are that they are the creations of committees (Sturmey, 1999), categorisation and labelling are dehumanising (Frude, 1998) and fitting people into these

categories is inappropriate "medicalisation" of life's problems. In addition, Wilson (1993) has noted that power disputes are a common feature of DSM categories as many diagnostic categories serve a wide variety of interests including research, treatment, administrative and legal (Parker et al., 1995, p.38). Kirk and Kutchins (1992) note in their critique of classification systems that much of the time classification systems are driven by commercial interests, Tomm (1990) notes that classification systems are very individualistic; Gaines (1992) view is that they are "dominant conceptions of the Western self" (cited in Parker et al., 1995, p.38), while McNamee & Gergen (1992) feel they are social constructions, and are empirically invalid (Boyle, 1990).

Further criticisms relate to both the inclusion and exclusion of particular disorders. From observing both DSM and ICD one can see the number and variety of categories included in both manuals. Those clinicians who may agree and accept the value of classification and categorisation, disagree on the types of some of the categories included. Conditions such as "nicotine dependence" and "partner relational problems" may be only part of, or contribute to a wider psychiatric disorder. In relation to the exclusion of various conditions - DSM-III no longer used such terminology, as "hysteria and neurosis" which many clinicians felt were useful terms.

> As Sturmey (1999) states *"when DSM-IV expanded its codes to include 'other conditions that may be a focus of clinical attention', it encompassed a broad array of problems including relationship problems, abuse and neglect, non-compliance with treatment, academic achievement, occupational, identity, religious, acculturation and phase of life problems. Some view expansion of the scope of DSM-IV as a legitimate reflection of psychiatry, whilst others view it as the expansion of billable experiences to include almost all of life's problems"* (p.3).

Problems of categorisation are another criticism of both the DSM and ICD classification system. Psychiatric disorders are classified according to "categories". Cases are assigned to categories (depending on the number and variation of presenting conditions or behaviours) and there is very little emphasis placed on the severity or degree of the condition (Frude, 1998).

3.5 Specific Difficulties in Applying Standard Taxonomies to the Learning Disabled Population.

As mentioned in the opening pages of this chapter, there is now the realisation that persons with learning disability are subject to the full range of psychiatric disorders that are present in the general population. Although this can be viewed in a positive light, as previously those with learning disability within the mild or moderate range were seen as "worry-free", while those within the more severe ranges were seen as not being capable of a range of emotions such as depression and anxiety (Szymanski, 1980), it also brought with it the implication that a standard classification would be suitable for both the general population and the learning disabled population. As Einfeld & Aman (1995) have stated "the notion that the psychiatric problems of mentally retarded persons are similar to the rest of the population implies that the standard classifications of psychopathology are applicable to mentally retarded persons" (p.147). Two other authors who are in support of such a view are Russell (1988) and Matson (1988) and they believe that DSM-III-R criteria can be used in an essentially unmodified state to assess the psychiatric problems of persons with learning disability. The PIMRA (Psychopathology Instrument for Mentally Retarded Adults) assessment developed by Matson (1988) follows closely DSM-III-R criteria.

An opposing view held by authors such as Sovner (1986), Corbett (1979), Szymanski (1988), Aman (1991) and Moss (1995) is that the psychiatric status of persons with learning disability are fundamentally different to those seen in the general population. Moss (1995) notes that

"research on the psychiatric status of people with learning disability suggest that there are important differences from the general population in terms of the prevalence of various mental disorders" (p.9).

The research of Sovner (1986) suggests that problems such as "concrete thinking", "bizarre behaviour" and "impaired communication" limit the use of DSM-III-R criteria in assessing people with learning disability for psychopathology. The earlier study of Corbett (1979), which attempted to utilise ICD-9 criteria in an epidemiological study, also found many problems. These included a difficulty in diagnosing autism in persons with severe learning disability (in the absence of language deviance), and a difficulty in assessing the severity of stereotypic behaviours (without severity criteria). The study of Reid (1983) found that with such an emphasis placed on linguistic competency in the assessment process, it was not possible to diagnose schizophrenia in persons with learning disability with an IQ of under 40.

Aman (1991) urges caution in terms of the applicability of DSM criteria in persons with learning disability. Aman notes that the application of DSM criteria becomes more suspect as the persons level of learning disability increases. Such caution is emphasised in conjunction with the DSM-III-R's caution of "mechanical use" of criteria in persons from different cultures without assurance of cultural validity.

> APA (1987, p. xxvi) state "*when the DSM-III-R classification and diagnostic criteria are used to evaluate a person from an ethnic or cultural group different from that of the clinicians, ... caution should be exercised in the application of DSM-III-R diagnostic criteria to assure that their use is culturally valid. It is important that the clinician not employ DSM-III-R in a mechanical fashion, insensitive to differences in language, values, behavioural norms, and idiomatic expression of distress*".

This said however, Aman (1991) states, "the presence of a substantial intellectual handicap may be functionally equivalent to and probably even more profound than the cultural barriers alluded to in the DSM-III-R caveat" (p.13).

On reporting the conclusions of the Presidents Committee on Mental Retardation, MacLean (1991) states, "psychiatric diagnoses based on existing nosological schemes such as DSM-III ... may be appropriate for persons with mild mental retardation, but such schemes are inadequate for describing the disturbances of severely retarded persons". Although many researchers have used standard classification systems such as DSM and ICD to classify disorders in the learning disabled population, these classification systems do nothing to "validate" the use of such a classification system. As Einfeld & Aman (1995) emphasise "validity is conferred by a more extensive process such as examination of long-term outcome, response to treatment, etiology and relation of different diagnoses within the system to outside variables" (p.148).

Finally on this issue, there does seem to be some agreement in relation to when the level of IQ increases, the presence of psychiatric disorders seem to resemble more closely those seen in the general population (Bruinninks et al., 1988, Russell, 1985, Stark et al., 1988). The problem with this lies with the uncertainty of where this "cut-off" IQ occurs. Many researchers feel that the psychopathology of moderate learning disability should be grouped with those of the mild range, whereas others feel that those with moderate LD should be grouped with the more severe levels of LD (Russell, 1988).

3.6 Requirements of an "ideal" Assessment Instrument.

1. Ask patients about presenting symptoms, their duration and historical development.
2. Examine mental state.

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3. Use informant data to corroborate history and additional information.
4. Use historical information from case notes and other relevant medical records.
5. Be standardised and repeatable.
6. Allow standardised research diagnoses using ICD-10 and/or DSM IV.
7. Be of the simplest possible linguistic structure commensurate with an appropriate degree of sensitivity to, and discrimination between symptoms.

(Taken from Moss, 1995, p.13).

Traditionally, two principle areas of information which are used for making a diagnosis are firstly a history of the particular complaint and secondly, information gained from assessment of current mental state (Moss, 1995). One may ask the question - why such disagreement among clinicians regarding diagnosis. The answer to this question lies in the fact that clinicians do not collect information in a standardised way - collection of information is based on the clinician being:

> *"armed with a variable amount of background information like the patients age and occupation and source of referral, holds a free-ranging discussion interview with the patient, lasting anything from twenty minutes to an hour or more. In this interview he seeks to establish a diagnosis by asking the patient first about his current symptoms and difficulties and then about an ever-widening circle of other experiences and events, past and present"*
>
> (Kendell, 1975, cited in Moss, 1995, p.11).

Diagnosis in persons with learning disability has traditionally been based on clinical judgement rather than on standardised collection of information per se. In this respect the criteria for making a diagnosis was not specified and hence was difficult to determine the reliability and validity of a diagnosis. Certainly in the case of the client whose verbal skills were poor (or non-verbal), the interviewing technique as a means of

collecting information was not longer of use and this called the validity of the diagnosis into question even further. Two issues of relevance here are the issue of the small number of expert professionals in the field capable of making an accurate diagnosis when the client is unable to be interviewed and secondly, major discrepancies exist between professionals regarding the conditions or symptoms necessary for a specific diagnosis to be made.

As with the general population, applying a more structured methodology to assessment and diagnosis will invariably lead to a more reliable diagnosis. The question here for professionals working in the field of learning disability is whether applying a classification system such as DSM-IV or ICD-10 will produce diagnoses of sufficient validity and reliability and whether using these classification systems will produce a valid diagnosis from a third party report, where the client in question is unable to be interviewed due to poor linguistic abilities.

Determining whether ICD-10 and DSM-IV are valid for the learning disabled population will largely depend on studies conducted which will examine the manifestations of symptoms across all levels of learning disability, and which will include the clusters of symptoms which occur in individuals. On the basis of the results achieved from such studies, novel classification systems may be constructed which may be more "adaptable" so as to take into account the variety of mental illness found in all levels of learning disability. Verhoeven & Tuinier (1999) have made great strides towards describing specific psychiatric illnesses occurring in individuals with specific syndromes - such as Praeder-Willi syndrome. These authors believe that existing classification systems do not take into account specific psychiatric illness which occurs only in specific syndromal conditions, and which are presently "unclassifiable" with existing classification systems. Such avenues of research seem to yield exciting and novel results which point to the existence of a novel means of classifying "difficult to diagnose" disorders.

3.7 Empirical Studies reviewing the use of ICD and DSM Diagnostic Criteria.

Empirical studies to date which have examined the use of ICD and DSM in the learning disabled population have progressed along three major avenues: 1] the use of clinical interviews, 2] the use of case note reviews and 3] behavioural checklists. Each of these three areas has developed somewhat independently from each other, but are still used interchangeably and in conjunction with one another. Essentially the use of clinical interviews and case note diagnosis and used jointly, whereas psychometric measures such as checklists are used independently, although as Sturmey (1993) notes "both address essentially similar issues" (p.38).

3.7.1 Clinical Interviews & Case Note Reviews: Studies incorporating ICD.

In terms of ICD based research, a number of studies have been undertaken using ICD-9. Wing (1977) and Corbett (1977, 1979 & 1985) undertook a study using the Camberwell register, reported on the prevalence of disorders as assessed by ICD in both children and adults. Corbett (1977) reports on a community sample of 140 children in which 47% met the ICD criteria for diagnosis. The three principle diagnoses were: childhood type psychosis (17%), severe stereotypes and pica (10%). In a later study Corbett (1985), both affective illness and behaviour/personality disorders began to emerge when the population was aged between 9-24 years.

In a study reported by Lund (1985) using a Dutch national register, a sample of 324 adults were chosen from the register. Of those sampled 28% were deemed to have a diagnosis according to the ICD-8 framework. In adults with severe and profound learning disability, this figure rose to 40% with the most common diagnoses being behaviour disorders, psychosis of uncertain-type and early childhood autism. 1%-

3% of the sample were said to have a diagnosis of schizophrenia, affective disorder, dementia and neurosis.
From the above studies, very similar results were found – especially in adults with severe and profound learning disability. In a more recent study Ballinger et al. (1991) randomly selected one hundred residential/institutional clients and reported diagnoses using ICD-9. From their sample Ballinger et al. found a diagnosis in 80% of cases with the most frequently occurring diagnoses being personality disorder (17%), conduct disturbance (15%) and childhood psychosis (12%).

3.7.2 Studies Incorporating DSM.

The study of Gostason (1985) incorporated DSM-III criteria with a mild to profound learning disability sample, which also included a non-learning disabled control group. Findings from the study showed that those within the mild to moderate range showed symptoms and diagnoses similar to the non-learning disabled group. Those within the severe and profound group showed differences from the other groups in that they had a higher frequency of multiple diagnoses with the common diagnoses being stuttering and atypical stereotyped movement disorder (Gostason, 1985).

Eaton and Menolascino (1982) reported on diagnoses made in a series of 168 referrals for psychiatric evaluation. Of these 168 referrals, 124 diagnoses were made, the most common being – schizophrenia (34), personality disorder (31), anxiety disorder (1), adjustment reaction (24) and organic brain syndrome (34).

The study of Sovner & DeNoyes-Hurley (1983) was interesting in that it examined DSM-III criteria in relation to diagnosis and applicability of diagnosis. A case was deemed "definite" if the client met DSM-III criteria, "probable" if a diagnosis was likely but not strictly with DSM-III criteria, and "doubtful" if there was a question of differential diagnosis.

Their conclusions were that the use of DSM criteria was suitable for persons in the mild to severe range, but other criteria such as behaviour pattern and family history should also be taken into consideration.

What is interesting to note from the above studies based on interviews and case note review is the similar pattern of results achieved from these studies in addition to the ability to replicate them. However Sturmey (1993) makes the point that "not one study reported the reliability of psychiatric diagnosis, although a few studies have reported the reliability of eliciting and recognising individual symptoms" (p.39; Ballinger et al., 1975; Bouras & Drummond, 1989 and Bouras et al., 1988).

A second point to note is that many of the studies reported used modified diagnostic criteria and did not adhere rigidly to ICD and DSM criteria. As Corbett (1977) has stated specifically in relation to ICD diagnoses: "the difficulty of applying the glossary definitions was so great that a fourth digit of .8 (other) or .9 (unspecified) could only be applied" (p.315). In this respect it is particularly difficult to draw specific conclusions about the research conducted on applying both DSM and ICD diagnostic criteria to persons with learning disability as any minor change in the diagnostic criteria used can lead to a significant change in diagnosis itself (Zimmerman et al., 1986).

Finally, problems of methodology are another area to be resolved. Many of the earlier published studies fail to give details about how a diagnosis was reached. The studies of Meadows et al. (1991) and Hucker et al. (1979) are exceptions to this as they state their methodology explicitly, whereas others have failed to do so.

3.8 Psychometric Measures/Behavioural Checklists.

As an alternative to clinical interviews and case note review, a number of psychometric measures have been developed in order to aid in the

diagnostic process. These psychometric measures have developed in the form of brief questionnaires and behavioural checklists in order to try and circumvent some of the many problems of assessment – the most difficult of these being that many persons with learning disability are unable to give reliable information about their mental state (Caine & Hatton, 1998). These questionnaires and checklists may be administered to the client themselves (provided they are verbal), but they are primarily used to facilitate assessment and gain information from a third party (i.e. a direct-care worker). One of the principle advantages of these scales is that they are brief to administer and score, and invariably do not require any form of training in administration. Most of the checklists available are explicitly related to either DSM or ICD criteria and "yield subscales that correspond to DSM-III disorders" (Sturmey, 1993, p.40).

Psychometric measures developed to date have taken two avenues: firstly those scales developed as "broad measures of psychiatric disorders" and secondly "measures of mental state"/assessments of specific disorders (Sturmey et al., 1991). For the purposes of the present review, the author will review briefly some of the most common broad measures of psychopathology. The interested reader is referred to the excellent review of measures as undertaken by Sturmey et al. (1991) and by Aman (1991), both of which examine in detail assessments of specific psychiatric disorders.

3.8.1 The Psychopathology Instrument for Mentally Retarded Adults – PIMRA

(Matson et al., 1984; Senatore et al., 1985). The PIMRA was initially developed by Matson and colleagues in 1984 and is based on the DSM-III classification system. It consists of 56 items organised into seven subscales which include: Schizophrenic Disorder, Affective Disorders, Psychosexual Disorder, Adjustment Disorder, Anxiety Disorders, Somatoform Disorders, Personality Disorders and finally Inappropriate

Mental Adjustment Disorder. Two forms of the PIMRA are available – the Self-report version (which can be administered to clients who are verbal and have the ability to describe how they are feeling) and the Informant version (for use with a third-party). Obviously as the name of the scale states, it is used primarily for adults with a learning disability. The psychometric properties of the PIMRA are average as reported internal consistencies were deemed modest by the study of Aman et al. (1986) and Watson et al. (1988). In the study of Iverson and Fox (1989), inter-rater reliabilities ranged from 70% to 95%, while the reliability of the presence or absence of a disorder was 89%. Finally from the studies of Senatore et al. (1985) and Sturmey & Ley, (1990), Sturmey et al. (1991) states, "this suggests that the PIMRA may be less robust than desirable" (p.144).

3.8.2 **The Reiss Screen for Maladaptive Behaviour** (Reiss, 1988a, 1988b).

The Reiss Screen is a measure of the likelihood that an adolescent or adult has a significant mental health problem. It is specifically designed for persons with learning disability within the mild to profound ranges, and is not deemed suitable for children under the age of twelve years (Reiss, 1988a). Appropriate uses of the Reiss Screen include:

⇒ Screening for dual diagnosis in all service areas. It provides an cost-effective means of identifying those individuals likely to need a mental health service.
⇒ Assessment of adolescents in high school who may be in need if psychiatric intervention.
⇒ To assist in "intake evaluations" at community mental health centres, outpatient mental health clinics and all forms of psychiatric facilities.
⇒ To be used as a research tool in dual diagnosis research.

(Taken from Reiss, 1988a, b).

The Reiss Screen is made up of 36 items, providing both a total score and a score on eight individual subscales. These subscales include: Aggressive behaviour, Psychosis, Paranoia, Depression (behavioural signs), Depression (physical signs), Dependent Personality Disorder, Avoidant Disorder and Autism. Psychometric properties of the Reiss Screen are adequate, but as Caine & Hatton (1998) note "data concerning the validity of the individual scales is questionable" (p.217; Sturmey & Bertman, 1995 and Sturmey et al., 1996).

3.8.3 The Diagnostic Assessment for the Severely Handicapped – DASH

(Matson et al., 1991). The DASH was developed in order to gain information on persons with severe and profound levels of learning disability. It contains a total of 83 items with 13 subscales which include: Anxiety, Depression, Mania, Pervasive Developmental Disability/Autism, Schizophrenia, Stereotypes/Tics, Self-injurious behaviour, Elimination disorders, Eating disorders, Sleep disorders, Sexual disorders, Organic syndromes and Impulse control/miscellaneous. Similar to the other scales mentioned, the DASH is to be completed by appropriate informants such as relatives or direct-care staff. It is made up of two main sections, the first of these being concerned with relevant background information (12 items), with the second being a behaviour rating component (96 items). Very little psychometric data are present for the DASH and what data are available are based on institutional service users and no test-retest reliability data is currently available. Aman (1991) upon reviewing the DASH states "the DASH is at a very early stage of development and it may be premature to subject it to review so soon ... this is an instrument which holds a great deal of promise, provided that the appropriate psychometric studies are carried out" (p.79).

3.8.4 The Psychiatric Assessment Schedule for Adults with a Developmental Disability: PAS-ADD, PAS-ADD Checklist & Mini PAS-ADD. Moss et al. (1996), Prosser et al. (1996).

The PAS-ADD schedules have been developed to aid diagnosis and detection of psychiatric disorders in persons with learning disability. Unlike the PIMRA (Matson et al., 1984), the Reiss Screen (Reiss, 1988, a, b) and the DASH (Matson et al., 1991) which are based on DSM criteria, the PAS-ADD schedules are based upon the ICD-10 (WHO, 1992) European classification system. The PAS-ADD schedules consist of:

1] **The PAS-ADD** – a semi-structured clinical interview for use with respondents who are verbal and with key informants. The PAS-ADD produces research diagnoses, and it involves a present state interview with the service user in question, followed by a similar interview with a key informant or direct-care staff. Completed interviews (service user or otherwise) can produce a diagnosis and in this respect, it is useful for clients whose linguistic ability does not permit an interview (Patel et al., 1993)

2] **The PAS-ADD Checklist** – a psychiatric symptom checklist which is used as a means of screening populations for mental health problems or to monitor symptoms of "at-risk" individuals. It is a relatively short checklist to be completed by relatives, family members or staff, placing emphasis on changes in behaviour and whether further assessment of mental health is required. It may be used as a screening tool or for regular monitoring of an individual focussing on the full range of mental health problems. The checklist produces a total of three scores which relate to: 1] Affective or neurotic disorder; 2] Possible organic condition and 3] Psychotic disorder. If completion of the PAS-ADD checklist yields a high score, further assessment can take place utilising the Mini PAS-ADD. This is now described.

3] **The Mini-PAS-ADD** – This is a more detailed assessment in comparison to the PAS-ADD checklist. Its purpose is to discriminate between those clients who do not have a mental health problem and those who may be presenting with the symptoms of a potential mental health problem. The Mini PAS-ADD therefore gives a much more detailed description of the persons presenting mental status and uses a glossary of definitions to aid diagnosis in the preliminary stages of psychiatric assessment. The Mini-PAS-ADD may be used by staff or professionals, once some training has been undertaken. It consists of 11 sections, each corresponding to the following psychiatric disorders: 1] Depression, 2] Anxiety, 3] Expansive mood, 4] Obsessive Compulsive Disorder, 5] Psychosis, 6] Unspecified Disorder and finally 7] Autism. Any individual who scores on or above the threshold scores should be referred for further psychiatric assessment. As all three schedules are very recently developed and are as yet in their infancy, information and published studies are currently being collected.

3.8.5 Other Psychometric Scales of Interest.

The above instruments are the most widely documented as they are designed specifically for use with the learning disabled population and their psychometric properties are reported in the literature. In addition to these, a number of other instruments exist which both examine global features of psychiatric disorders or which focus solely on specific disorders. Two global scales of psychopathology not mentioned in the present review but which may be of interest are the Emotional Disorders Rating Scale for Developmental Disabilities (EDRS-DD) developed by Feinstein et al. (1988) and the Clinical Psychopathology Mental Handicap Scale (CPMHS) developed by Bouras et al. (1987, 1988). Although these scales are as yet only in the preliminary stages of development and little if no data are available on them, they have proved useful tools in the assessment of disorders such as affective and mood

disorders (Sturmey et al., 1991), while also being of use in clinical practice (Bouras & Drummond, 1989).

Other measures specific to the assessment of mental state include The Mini-Mental State – (MMS) (Folstein et al., 1975), The Clifton Assessment Schedule (CAPE) and The Shortened Stockton Rating Scale (SSRS) as developed by Smith et al. (1981).

In terms of assessments utilised to assess specific disorders, a number of instruments designed and developed for the general population have been adapted for use with the learning disabled. As an assessment of depression scales adapted include The Beck Depression Inventory (BDI) (Beck et al., 1961), The Hamilton Rating Scale for Depression (Hamilton, 1960), The Zung Self-Rating Depression Inventory (Zung, 1965), the MMPI-D Scale (Hathaway & McKinley, 1967) and the Reynolds Adolescent Depression Scale (RADS) (Reynolds et al., 1987).

For anxiety disorders, specific scales adapted include The Children's Manifest Anxiety Scale (CMAS) (Castaneda et al., 1956), The Fear Survey Schedule (FSS) (Duff et al., 1981) and the Zung Self-Rating Anxiety Scale (Zung, 1971), while for the assessment of Personality disorders, scales which have been used include The Standardised Assessment of Personality (SAP) (Mann et al., 1981) and the Special Hospital Assessment of Personality and Socialisation (SHAPS) developed by Blackburn (1982).

Interestingly reviews of schizophrenia in learning disability have generated much interest but in terms of assessment, little if any specific information on assessment instruments is available. However scales such as the PIMRA (Matson et al., 1984) and the DASH (Matson et al., 1991) do have specific subscales, which relate to schizophrenia. As Reid (1989) cited in Sturmey et al. (1991) states "... in general there is nothing unique or esoteric in the symptomatology of schizophrenia in

mentally retarded people" (p.151). For a more in-depth analysis on the issue of schizophrenia in learning disability, the reader is referred to the review article by Turner (1989).

To conclude this section on assessment of psychopathology, one can see that of the available methodologies (i.e. clinical interviews; case note assessment and psychometric checklists), considerably more research has been conducted into the development of psychometric measures than any other form of assessment. However despite the number of psychometric tools available specifically for the assessment of psychiatric disorders in persons with learning disability, as yet the vast majority of these tools are in their infancy and require much work before their true benefits are recognised. There is no doubt but the number and diversity of tools available is quite large, but on reviewing the literature on these instruments, the majority have only been developed since 1984. This said however, many of these tools are adaptations of assessments used in the general population or are parts of existing assessment tools. In this respect Aman (1991) makes the point "most of them simply have not been evaluated for their utility as diagnostic instruments" (p.174). Common problems with these existing tools include: problems of sensitivity and specificity (Kleinbaum et al., 1982), problems pertaining to the precision of many of these tools ((Aman, 1991) or the lack of an available "Gold Standard" (Moss, personal communication) - thus the diagnostic accuracy of many instruments is untested. Finally the issue of inadequate standardisation of assessments still remains largely due to many of these instruments being developed on small-scale budgets and therefore large-scale standardisation studies prove exceptionally difficult.

3.9 Summary, Conclusions and Recommendations.

The present chapter had several foci of interest, which expanded upon issues discussed in the previous chapter on psychopathology. Any discussion on issues pertaining to psychopathology in persons with

learning disability warrants a discussion on the classification systems used and incorporated in the assessment and diagnostic phases. From this chapter, one can see that many problems are evident in incorporating a classification system (such as ICD or DSM) developed for the general population to the learning disabled. Although the learning disabled population do exhibit the full range of psychiatric disorders, these disorders are often presented in ways not usually seen in the general population. Existing classification systems like ICD and DSM simply do not cater for such "atypical" presentations and attempting to fit existing models of psychopathology (developed for the general population) in a learning disabled population does seem questionable at times.

The author presented empirical studies conducted in the learning disabled population which utilised both the DSM and ICD modes of classification. Despite many of these studies being methodologically sound and replicable, many important issues were left unanswered. Very often in such studies, no figures were available on the reliability of psychiatric diagnoses made – either through clinical interview, case note review or psychometric testing. Where clinical interviews and case note reviews were the methodology of choice, elevated figures have been reported frequently. A major flaw in many of the studies reported is that ICD and DSM criteria were modified in some way, thus having an impact on the diagnoses formed (Zimmerman et al., 1986).

Upon reviewing the current psychometric tests available to assess psychopathology in this population, numerous tests are available, but many of these are still only in the developmental phase and require much refinement (Aman, 1991). The author reviewed the four most common instruments available to date and gave a brief overview of each. The four instruments reviewed were: 1] The DASH - *Diagnostic Assessment for the Severely Handicapped* (Matson et al., 1991), 2] *The Reiss Screen for Maladaptive Behaviour* (Reiss, 1988a, b), 3] The

PIMRA - *Psychopathology Instrument for Mentally Retarded Adults* (Matson et al., 1984) and finally The PAS-ADD – *Psychiatric Assessment Schedule for Adults with Developmental Disabilities* (Moss et al., 1996, Prosser et al., 1996). Some of the principle points of each assessment were discussed in addition to the subscales included in each instrument. The present chapter on assessment, classification and diagnostic issues should not be viewed in isolation from the other theoretical chapters. Rather it should be viewed as a continuation of the issues discussed in the previous chapter on psychopathology. Although issues of appropriate classification are of paramount importance in the development of any framework (and especially so in terms of psychopathology), as it has wide ranging implications for assessment and diagnosis, but these issues need to be addressed in terms of the "broader picture" witnessed in the field of learning disability. From reading the previous chapter one can see that even if existing classification systems were deemed appropriate and accurate, it does not necessarily mean that the case identification will take place. If case identification does take place, assessment and diagnosis should not be based solely in terms of completion of a psychometric checklist, a clinical interview or case note review. Psychometric checklists for example offer the clinician the ability to assess current behaviour over a specific time period. These checklists do not assess in detail issues around developmental appropriateness of the behaviours in question, nor do they place emphasis on the client's history, which is often very valuable in formulating a diagnosis. Moss (1999) emphasises this point when he makes reference to the inclusion of "the wider aspects of individuals lives, such as their ability to cope with life transitions, and the adequacy of their support networks" (p.33). Frequently these issues are forgotten about or their significance is underestimated. In addition and specifically in relation to classification and diagnosis, Falloon & Fadden (1993 – in Moss, 1999) note that "diagnostic classification is likely to provide only partial guidance on the morbidity and quality of life experienced by individuals suffering from mental disorders" (p.34).

Finally, development of a more structured approach to the assessment and diagnosis of psychiatric disorders in the learning disabled population has facilitated a better means of communication between all those involved with this population. As was discussed in this chapter, traditional approaches to assessment and diagnosis have tended to place emphasis on clinical interviews and case note reviews - whose reliability has been questionable. With the development of semi-structured clinical interviews and psychometric instruments, reliability of diagnoses has improved considerably (Moss, 1995), through employing the same diagnostic criteria in all samples. Although many of these instruments need to be refined and further developed, they are greatly aiding the process of assessment and yielding far more accurate diagnoses than in previous times.

In an attempt to further develop and adapt the ICD-10 classification system for persons with learning disability the World Health Organisation (WHO 1996) has published the *ICD-10 Guide for Mental Retardation.* Einfeld & Tonge (1999) note that this guide was developed "in acknowledgement of the challenges posed by the diagnosis of mental disorders in people with intellectual disability" (p.408). Although publication of the Guide is both valuable and warranted, it does suffer from a number of inconsistencies and has its limitations, but as yet it is only in its first edition. Einfeld and Tonge (1999) report on its use in conjunction with ICD-10 in a sample of 106 persons with learning disability and behavioural and emotional problems. Although they found it a useful tool to be used in conjunction with ICD-10, many problems were evident in utilising each Axis, the most notable of these being Axis I and Axis II (severity of retardation and problem behaviours and associated medical conditions respectively).

However as Einfeld and Tonge (1999) summarise "The ICD-10 Guide for Mental Retardation provides a valuable first attempt to develop an official

descriptive system and taxonomy of associated health problems in people with ID. An examination of The Guide reveals a number of areas, particularly with regard to behavioural and psychiatric disturbances, which will benefit from further consideration in future editions ...".

There is no doubt but publication of the ICD-10 Guide for Mental Retardation is a major advancement for the field of learning disability. Up to this point, clinicians and researchers alike were formulating their diagnoses upon existing systems (ICD-10 and DSM-IV) – classification systems that were designed for use with the general population. What lies ahead for the field of learning disability now, is to further develop the ideas proposed in the ICD-10 Guide and engage in research investigating their reliability in order to develop an appropriate and reliable measure of psychopathology in this population.

CHAPTER FOUR

PRESCRIBING AND LEARNING DISABILITY: RESEARCH FINDINGS

4.1 Chapter Introduction

The issue of prescribing for clients with learning disability has had an emotive history over the past number of decades. Gualtieri (1991) cited in Crabbe (1994) notes "the epidemic of neuroleptic overuse among people with mental retardation is one of those tragic experiments that nature, or history, will sometimes play" (p.187). In terms of an historical overview, several problems are evident. There are two beliefs in terms of prescribing for clients with learning disability: firstly there are those who are firmly rooted in the medical model and believe that pharmacological intervention should be the technique of choice, and secondly, there are those who believe that the risks greatly outweigh the benefits in terms of prescribing of medication. This is especially true of psychotropic medication in clients with learning disability as the risk-benefit ratio can be difficult to determine at times. In the United States in recent years, there has been much litigation about psychotropic medication and many cases have been taken against organisations and institutions which cater for clients with learning disability, largely due to the many negative side effects of particular medications which were prescribed. In general, there is a much greater awareness and interest by professionals who work with clients with learning disability in relation to the prescribing practices for these clients. The implementation of the multi-disciplinary team in many organisations to review medication use is evidence of this heightened interest.

4.2 Aims of The Chapter

The present chapter has several foci of interest. It Firstly examines the relationship between the field of learning disability and the field of pharmacology and why medication is prescribed and administered to clients with various levels of learning disability. Although clients with learning disability have been prescribed medication for several decades, there are a number of significant factors which have occurred in the field

in the last decade which have had quite an influence, and will shape the field of prescribing in this population for some time to come. Such factors are discussed. As in most texts dealing with this area, a detailed history of the prevalence of prescribing for the learning disabled population will be discussed, making particular reference to some of the more pertinent drug prevalence studies which are frequently cited. Although a substantial volume of research has not been undertaken on the factors affecting prescribing in the learning disabled population, the present chapter will examine research undertaken on the general population and how this research may be applied to clients with learning disability. The issue of psychopathology, learning disability and prescribing of medication has received some attention over the years but it has not been examined in any great detail - research to date will be presented on this topic. Although the many positive aspects of prescribing will be dealt with throughout the chapter, there will also be reference to the many negative aspects of prescribing such as irrational practice and polypharmacy for example. Arising from the litigation surrounding psychotropic medication, the notion of the inter or multi-disciplinary team is very much in use, especially in the United States and it is slowly coming of age in Ireland and the United Kingdom. Such teams are being set-up in order to review medication use and to determine the effectiveness of such medications. Resulting from the development of the inter-disciplinary team, rigorous medication monitoring and the implementation of guidelines for medication use are being written into policy and becoming law in many states in America and elsewhere. Each is discussed in turn.

4.3 Definitions and Terminology

Before commencing any discussion on medication and prescribing, two important definitions must be outlined - the use of the term psychotropic drug and psychoactive drug will be used throughout the chapter and a definition of each is as follows:

Psychotropic drug: "any agent prescribed for the purpose of bringing about behavioural, cognitive or emotional changes". (the typical example given of this category of drug would be the antidepressants, anxiolytics etc.).

Psychoactive drug: "any agent that has these effects, regardless of the intent when prescribing the drug". (the typical example here would be the anticonvulsants or anti-epileptic drugs).

(Taken from Aman and Singh, 1991, p.348).

4.4 Issues in Psychopharmacological Research to Date

The use of psychopharmacological interventions in clients with learning disability has been hindered by a host of various factors (Lewis et al., 1996) including a marked lack of objectivity and reliability in terms of early research of the effects of medication in this population - thus the necessary empirical research base was lacking in this field up until quite recently. The field of learning disability in general has been a field which has been lacking from quality input from the field of psychiatry, although the medical model is still the dominant model. In terms of psychiatry and medication use in the field, there is still quite an air of subjectivity in relation to prescribing for clients with learning disability. Although the majority of drugs have specific uses and guidelines regarding their use, drugs such as the antipsychotics are still widely prescribed for both suppression of the symptoms of psychosis and mental illness, while also being administered for the purposes of behaviour control. Such widespread use of the antipsychotics in particular has brought about a very negative attitude by many professionals as prescribing in this respect is often unwarranted in many cases. In relation to the notion of subjectivity, the problem of accurate psychiatric diagnosis still remains in the field of learning disability. A major problem in relation to the diagnosis of psychiatric problems in clients is that many clients are non-

verbal and diagnoses are based on the reports of their carers, and secondly, a significant majority of individuals with a learning disability are within the severe to profound ranges of learning disability and assessment of these clients is extremely difficult due to the majority of these clients not being able to express how they are feeling even if they are verbal and have a means of communicating.

4.4.1 "Anti-Drug Sentiment" in the Field.

Since the early 1980's, there has been considerable emphasis placed on administration of medication in the learning disabled population. The main impetus of this heightened interest arose out of genuine concern by professionals in the field as firstly clients were being grossly overmedicated (over prescription), secondly the practice of polypharmacy was very much in vogue and used in many clients, thirdly there were frequent irrational prescription practices in operation and finally inadequate reviews of medication use inevitably lead to prolonged and unnecessary drug treatment (Fan, 1991).

Aman and Singh (1986) in a highly influential article wrote "in the last few years we have been struck by an apparent crystallisation of what we would characterise as 'anti-drug' attitudes in this field. Most often, this is conveyed more by the general tone of articles on the topic, rather than by bald statements of opposition to pharmacotherapy per se. Nevertheless, we believe that, in recent years, there has been a strong undercurrent of feeling that the net effect of most pharmacotherapy is adverse to the individuals being treated" (p.203). As mentioned above, perhaps one of the most significant factors which lead to an increased interest in the use of medication in the field of learning disability was the inappropriate use of psychotropic drugs for these clients. In previous times, psychotropic drugs were administered purely for the convenience of staff caring for these clients and such drugs were used as a method of

punishment due to their ease of use. Clearly such uses were both highly inappropriate and extremely unethical.

4.4.2 Negative Side Effects of Medication in the Learning Disabled Population

Another factor, which has lead to this "apparent negative attitude" toward medication use, has been the many negative side effects, which are evident in clients, which have been treated with certain classes of drugs. Neurological side effects such as tardive dyskinesia (which in many cases is irreversible) are evident in many clients who have been on long-term antipsychotic medication. Although clinical descriptions of tardive dyskinesia were reported as early as 1956, it was not until the 1970's that it had been documented in some detail (Campbell et al., 1983). Since this time various prevalence rates have been put forward from approximately 20% (Paulson et al., 1957) to 33% (Gualtieri et al., 1982) to an alarmingly high rate of over 80%, as was documented by (Kalachnik et al., 1984). If anything these figures pointed out to professionals in the field that there were substantial risks in relation to the use of medication, many of which were not envisaged before this time.

4.4.3 The Research of Stephen Breuning

The work of Stephen Breuning (Breuning, 1982; Breuning et al., 1982) also contributed greatly to the heightened interest in this area, as from his research, serious questions were asked as to the efficacy of drug usage in this field. However as will be mentioned in the paragraph below, the work of Breuning has itself being called into question and hence raises serious questions about the findings and implications of his research.

Many developments have taken place in the field of pharmacotherapy and learning disability in recent years, the majority being to the

advantage of the client with learning disability. Firstly, due to the heightened interest in this particular area, there has been a rapid increase in the number of publications on the topic of drug usage in the learning disabled population. From the mid-1970's to approximately 1987, there were about 30 published articles on the topic of drug prescribing for clients with learning disability (Aman, 1987). From 1987 to 1995, there have been at least another twenty publications on this topic in such a short space of time. The majority of the latter publications have been in respect to clients living in the community, rather than in institutional or residential facilities, as was the case with the majority of the older studies published (Aman, et al., 1995). The second major development was very much on the negative side and it pertained to the research of Stephen Breuning - which at the time of its publication was widely accepted and generated much interest. Breuning, in the early 1980's published a series of well-researched, methodologically "sound" studies (Breuning, 1982; Breuning et al., 1982) which examined the effects of neuroleptic drugs on individuals with learning disability. Findings from the research of Breuning showed clear-cut evidence in terms of the detrimental effects that such medication use was having on these clients - in terms of adaptive functioning and scope for learning etc. The research of Breuning "had a marked effect on the field, to the extent that at least one state modified its guidelines regarding the use of psychotropic drugs to be consistent with Breuning's findings" (Aman and Singh, 1988, p.vii; Holden, 1987).

4.4.4 Legislation and Litigation Regarding the Use of Medication

Due to the points above, especially in the United States, there have been major social and legal changes in terms of medication use in both residential and community facilities. Litigation surrounding the misuse of drugs in the field of learning disability has been widely documented and due to the many court cases use of medication in many States is now strictly controlled and subject to an annual audit by the multi-disciplinary

team. Another point of interest, especially with regard to the field of pharmacotherapy is that in recent times, the focus of attention and interest has been in relation to the negative side effects of drug therapy rather than the therapeutic effects of these drugs as was the case previously (Sovner & Hurley, 1984). The final point of interest (again very much related to the United States) is that there is increased interest at federal level in terms of drug prescribing and its effects. This interest has been developed in the setting up of special working parties and committees which examine a number of drug related issues in the learning disabled population.

4.5 Kalachnik's Theoretical Perspective on Psychotropic Prescribing

Kalachnik (1988) states in relation to the prescribing of drugs for the learning disabled that "psychotropic medication is prescribed for mentally retarded people primarily to suppress behaviour disorders (e.g. aggression, self-injury) or to alleviate the symptoms of mental illness (conditions such as psychosis or depression)" (p.231). He also notes a number of fundamental points with regard to the prescribing of such drugs to clients with LD in the fact that in the first case psychotropic drugs are frequently prescribed to this population, both within residential facilities and community facilities, secondly there has been much concern over prescribing to these clients over the past two decades and finally as a result of litigation and stringent regulations, in many States strict guidelines have been implemented and enforced which guard against the misuse of drugs in these clients. Kalachnik notes that implementation of such guidelines may require the following:

- Delineation of specific target behaviours.
- Written informed consent.
- Use of a minimum effective dose.
- Periodic attempts at dosage reduction.

- Integration of behavioural, educational and medical interventions.
- Monitoring for side-effects (tardive dyskinesia etc.)
- Interdisciplinary assessment of the need for medication
- Periodic data based evaluations of drug efficacy.

(taken from Kalachnik, 1988, p.231).

4.6 Prevalence rates of Prescribing in the Learning Disabled Population.

In one of the most widely documented drug prevalence studies cited in the literature, Lipman (1970) conducted a drug prevalence study involving 109 residential facilities in the United States. The results of this study were quite startling as 51% of clients were administered psychotropic medication. Resulting from the findings of this study, extreme concern was expressed by many professionals in the field that such a percentage of clients administered psychotropic medication was far too high a figure. In addition Lipman's study acted as a catalyst for further research on the topic of prevalence of prescribing for this population. Due to the increased volume of studies published since Lipman's study in 1970, there has since been far more accurate and well documented studies of this nature, which has inevitably lead to the heightened interest in this field.

Since the 1970's a considerable amount of interest has been drawn to the rates of prescribing for clients with various forms of learning disability, namely in residential facilities (Spencer, 1974; Hughes, 1977; Jonas, 1980; Aman et al, 1985a). It is only relatively recently in the UK that any studies pertaining to the prescribing practices for clients in community facilities have been published - one of the first of these to be published by Hemming (1984) and subsequently by Clarke et al. (1990).

As is noted by Aman and Singh (1991) clients with learning disability "are among the most medicated populations in our society" (p.348). In terms of the figures quoted for clients living in residential or institutional facilities, the figures have ranged from 30 to 50% for psychotropic drugs and in terms of anticonvulsant or antiepileptic medication, the figures have ranged from 25% to 35%. If one combines these totals, one is looking at an overall prevalence rate of between 50 and 70% (Aman and Singh, 1988).

When one looks to clients living in the community, the typical prevalence rates of prescribing are within the range of 20 to 36%. For anticonvulsant medication, the figures have ranged from 20 to 25%. For a total combined prevalence rate, the figures published for community clients are 36 to 48%. The figures quoted above are for adults with various forms of learning disability ranging from mild to profound.

When it comes to children with learning disability, considerably less research has been undertaken and the rates to date are quite low with school-age children in the community being prescribed psychotropic medication within the range of 3 to 7%, the figures for anticonvulsants being 12 to 17%, with the combined rates falling within the 18 to 21% range (Aman et al., 1985a; Gadow and Kalachnik, 1981).

4.7 Variables Studied in Relation to Prescribing Rates.

In terms of prescribing rates, many variables have been examined in order to ascertain which are of importance in relation to prescribing rates. Demographic variables such as gender, age and level of learning disability have been some of the more common demographic variables studied, while more recently Aman et al., (1995) undertaken in the USA, examined variables such as seizure condition, visual status, hearing status, level of mobility and race. Results to date which have examined the main variables such as gender, age and functional level have had

non-conclusive results, largely due to the small number of studies reported. The study of Aman et al., (1995) found that seizure disorder was associated with lower levels of prescribing of the neuroleptics, anticonvulsants (primarily for behaviour control rather than seizure control) and lithium. The more severe the level of learning disability, the less drugs these clients were administered which is quite a surprising result in light of previous research as was noted by Aman and Singh (1991). Unimpaired ambulation was positively linked with greater use of medication, while those with visual impairments were less likely to be administered medication. It is quite clear that further research is required to ascertain which variables are of significance in terms of prescribing for clients with learning disability.

Professionals and workers in the field of learning disability cannot ignore such figures and although many drug reduction programmes are in operation in many facilities, there is still the need to emphasise that much of the drug use in this population is unwarranted and must be called into question. The main evidence for this statement lies in the fact that discrepancies still exist between issues such as - is psychoactive medication prescribed primarily for the suppression of the symptoms of mental illness or purely for the purposes of behaviour control. If the latter is the case then stringent guidelines need to be enforced so as to oversee the effectiveness of medication in such cases. Not only does effectiveness need to be stringently measured, one also has to take note of the many negative side effects that such drugs may present mainly in terms of impairment of cognitive function and learning ability. As Aman and Singh (1991) have stated "the figures on prevalence indicate that pharmacotherapy is one of the most prevalent forms of treatment in the developmental disabilities... not only do these agents have important effects in their own right, but they have the potential to interact with other forms of treatment, such as special education and behaviour modification" (p.349).

Table 4.1 below gives some of the most frequently cited drug prevalence studies published since 1970, while Table 4.2 takes into account the setting and type of facility studied in terms of more recent studies published in the UK and the USA.

Table 4.1: A table depicting the prevalence of prescribing for residential and community clients with learning disability (psychotropic and anticonvulsant medication) from 1970 to 1987.

Authors	No. of persons surveyed	% receiving psychotropic medication	% receiving anticonvulsant medication	Total percentage
Residential				
Lipman, 1970	109 institutions	51	NR	NR
Spencer, 1974	585	22	24	51
DiMascio, 1975	1232	26	21	NR
	785	53	90	NR
Pulman et al., 1979	435	47	34	60
Craig and Behar, 1980	161	83	NR	83
White, 1983	415	19	36	51
Radinsky, 1984	1687	27	48	51

Intagliata and Rinck, 1985	171	54	42	76
Aman et al., 1987	531	37	41	58
	937	39	28	60
Community				
Hansen and Keogh, 1971	229	31	NR	NR
Radinsky, 1984	575	36	33	36
Martin and Agran, 1985	178	32	24	48
Hill et al., 1985	962	26	22	40
Gowdey et al., 1987	1389	20	23	40

Table 4.1 adapted from Aman and Singh, (1988), pp.3-4. (NR = not reported)

Table 4.2: A table depicting the prevalence of psychotropic medication prescribed to clients with learning disability according to setting, type of facility and country.

Authors	Setting	Facility	Country	Prevalence
Gowdey et al., 1987	Community	Residential	Canada	26%
Clarke et al., 1990	Community	Residential	UK	19%
	Community	Family home	UK	10%
Wressel et al., 1990	Hospital	Hospital	UK	24%
Zaharia and Struxness, 1991	Community	Residential	USA	19%
Harvey and Cooray, 1993	Hospital	Hospital	UK	37%
Lepler et al., 1993	Community	Residential	USA	18%
Branford, 1994	Hospital	Hospital	UK	44%
	Community	Residential	UK	19%
	Community	Family Home	UK	9%

Table 4.2 taken from Fleming et al., (1996) p.195.

4.8 Psychotropic drugs used in therapy.

4.8.1 The Antipsychotics

Antipsychotic drugs are the most frequently prescribed drugs to clients with learning disability living in residential facilities. Approximately half of clients in residential facilities and approximately 20% of clients in the community are administered these drugs (Hill et al., 1985; Intagliata and Rinck, 1985). Antipsychotic medications are prescribed for a range of different symptoms such as hyperactivity, aggression, antisocial behaviours and self-injurious behaviour. Although there are many well-

controlled studies which have reported the positive effects of such drugs, there is also quite a volume of literature which has examined the negative effects of such drugs (Aman et al., 1991).

4.8.2 The Antidepressants

Antidepressant medication is used in the learning disabled, although not to the extent of the antipsychotics. Antidepressant drugs include the tricyclic antidepressants, monoamine oxidase inhibitors, selective serotonin uptake inhibitors and 5-HT 1A agonists. Antidepressants have been used in children and adults for a range of different problems, the most common of these being phobias, encopresis, sleepwalking and enuresis. Antidepressants are used more frequently in clients living in the community (with mild and moderate levels of LD) and the trend seems to be that a greater proportion of females compared to males are administered this class of drug. In recent years, antidepressants are being used for more varied purposes, the typical example being Flouxetine (*Prozac*) which is now prescribed for depression, Bulimia nervosa and more recently Obsessive-Compulsive Disorder (1993).

4.8.3 The Anticonvulsants

Anticonvulsant drugs: although the primary reason for prescribing anticonvulsant drugs is for the control of seizures, there is now a growing body of literature which is recognising the psychotropic effects of many of these drugs. Even when anticonvulsant drugs are administered solely for the purposes of controlling seizures, their psychotropic properties are often clearly evident. In this way they have the ability to control behaviour as do the more common antipsychotics. Anticonvulsants also appear to have an effect on cognition in addition to behaviour. On the negative side, some clients when administered certain anticonvulsant drugs, after a period of time show reactions similar to clients on long-term antipsychotic treatment. The toxic effects of the anticonvulsants

build up and produce similar reactions to tardive dyskinesia. Prescribing rates for anticonvulsants have ranged form 25 to 35% for residential clients, while in community clients the figure is 20 to 25% - which is approximately the prevalence of epilepsy/seizure pattern in this population.

4.8.4 Carbamazapine for Behaviour Control

Within clinical practice, a small proportion of clients are administered anticonvulsant medication for the purposes of behaviour control, or as a mood stabiliser. The typical example here would be the administration of Carbamazepine (Tegretol) to clients who display aggression as this drug has strong psychotropic properties and has the effect of reducing aggression in a proportion of clients. Caution must be urged in such cases as there is a lack of research investigating the effects of this class of drug on behaviour. In addition there is a large range of antipsychotics available for the purposes of suppression of behaviour disorders with relevant research on their effectiveness. Many practitioners however still firmly believe that in many patients' aggressive episodes are a result of epileptic features and epileptic activity and in prescribing an anticonvulsant, one is reducing brain activity and thus reducing aggressive episodes. This said however, Evans et al., (1986) have stated that "carbamazepine has not yet been properly investigated with children having specific disorders and with attention to a number of relevant drug parameters to allow conclusions to be drawn" (cited in Aman and Singh, 1991, p.254).

4.8.5 The Anxiolytics

Anxiolytic or anti-anxiety drugs are relatively frequently prescribed, especially in residential settings but also in the community. Aman and Singh (1991) note that the Benzodiazepines are prescribed in approximately 8% to 13% of cases in residential care, while a similar

figure emerges in the community (8 to 12%). One of the issues with the prescribing of the anxiolytics is that they can be prescribed for a host of different problems such as anxiety primarily, they can also be used as an anticonvulsant (Diazepam) or they can be used for behavioural control (this is relatively uncommon however). This class of drugs can sometimes be administered to clients for the purposes of controlling muscle spasms although in more recent times this has tended not to be the case as more effective drugs are currently on the market. Intagliata and Rinck (1985) found that anti-anxiety drugs were not used primarily for the treatment of anxiety, but for conditions such as aggression, hyperactivity and disruptive behaviour. In more recent research, Aman et al. (1995) suggest that there is no clear and specific diagnosis for the use of anxiolytic drugs, and the prevalence of anxiety amongst those with LD may actually be under-reported, which is in itself a cause for some concern.

4.8.6 Other Drugs Prescribed

A host of other drugs are prescribed to the learning disabled population such as anticholinergics, stimulants and hypnotics. For the purposes of the present chapter, discussion of these drugs will be brief. In terms of the anticholinergic class of drugs, they are primarily prescribed due to the negative side effects of antipsychotic medication. In some reported studies, there has been an elevated rate of prescribing of anticholinergic drugs (higher rates than those recommended by the British National Formulary), but this is inevitably due to a high rate of prescribing of antipsychotics - especially in residential clients. The same figures for community clients are far less, some up to one third less than the figures quoted for residential clients. In terms of stimulants, at one stage these were prescribed quite infrequently to clients with LD. In more recent times however, the prescribing rates are increasing due to an increased number of children presenting with ADD-H (Attention Deficit Disorder with Hyperactivity) (Gadow, 1992) although concerns have been

expressed about use of this drug in children and adolescents. Hypnotic drugs, similar to the anxiolytics have been used to treat a range of disorders from hyperactivity to aggression, although primarily prescribed (short term) for disturbances in sleep. Hypnotics are prescribed to a small number of clients, within the range of approximately 4 to 6%.

4.8.7 Negative Side Effects/"Minimal Effective Dosage"

In more recent times, due to the concern expressed over high rates of prescribing to clients with learning disability, the emphasis has been on attempting to withdraw antipsychotic medication in as many cases as possible and developing guidelines regarding effective use of such drugs. Drug withdrawal studies have shown that Antipsychotics can be reduced in many clients without an increase in problem behaviour or without detrimental effects on social functioning. The work of Fielding (1980) is applicable in this respect as he introduced the notion of a "minimum effective dosage" and he works within the framework that "every attempt should be made to reduce the dosage gradually and ultimately to discontinue the drugs" (p.772). From research to date, the one behaviour that Antipsychotics do seem to have a positive effect on is stereotypy, although far more research is required to ascertain the actual effects on this behaviour disorder.

Another major problem with prescription of Antipsychotics for both behaviour disorder and suppression of psychiatric disorders is that in general, once a client is commenced on such therapy, it is long term rather than short term. One of the main problems associated with long-term use of Antipsychotics, especially the neuroleptics are neurological side effects such as Tardive Dyskinesia - which has detrimental effects on performance and learning (Lewis et al., 1996). Hence one has to be very cautious about over-use of Antipsychotics in a population such as the learning disabled in which many clients are non-verbal and are unable to report side effects.

4.9 Current Thoughts on Prescribing

A quote taken from Lewis et al. (1996) sums up the current thinking about use of drugs in clients with learning disability. "The appropriate use of medication in people with MR and developmental disabilities requires a sophisticated and data-based approach. This is especially true in light of the difficulty many clients have in articulating subjective experiences and the presence of adverse effects. The risks of treatment must be weighed against the costs of not using treatment" (p.340).

Two further quotes which sum up the appropriate use of psychotropic medication in relation to persons with learning disability are as follows.

Rivinus (1980) states "the same rules that apply to the use of psychotropic medications in adults and children of normal intelligence apply to retarded patients. Psychotropic drugs should be used to treat specific diagnoses, syndromes, or symptoms for which specific drug efficacy has been scientifically established" (p.195)., while in a similar fashion Szymanski and Crocker (1989) state, "psychotropic drugs work in the same manner and should be used in the same way whether the patients intelligence is average, above average, or below average ... psychiatric disorders, not specific symptoms, should be treated" (pp. 1659-1660).

4.10 Medication Monitoring Procedures.

As was mentioned briefly at the start of this chapter, the quote taken from Kalachnik (1988) emphasised the importance of medication monitoring procedures. In any monitoring process, there has to be strict criteria as to what exactly is being monitored and guidelines need to be set-up as to how the monitoring process is to be achieved. In 1983, in the States the Accreditation Council for Services for Mentally Retarded and Other Developmental Disabled Persons (ACMRDD) was set-up for

the specific purposes of determining the effectiveness of medication use and to prevent its miss-use. The Council worked under and adopted the following principles in the development of its standards:

4.10.1 Principles Involved in Medication Monitoring

- Medication is not used as ... a substitute for a programme.
- Drugs used for behaviour management are utilised only as an integral part of an individual programme plan designed by an inter-disciplinary team.
- Each programme plan utilising drugs for behaviour management ... specifies the behaviour to be modified .. and the data to be collected to assess progress toward the treatment objective.
- The individual's record contains written authorisation for the use of behaviour modifying drugs, signed by the individual if competent, or by the individual's parents or guardian.
- Each individual who requires medication receives medical supervision, which includes regular evaluation of the individual's response to the medication, including appropriate monitoring and laboratory assessment ... a drug treatment plan is prepared by the responsible pharmacist for inclusion in the individuals record and for use by staff. The plan includes .. a schedule of laboratory tests necessary to detect adverse reactions ... and ... noting, for the staff's information, any potential adverse reactions.

(Taken from Kalachnik, 1988, p.233).

Lewis et al. (1996) note the importance of "clinical hypothesis testing" in the process of drug monitoring. Seeing as there is essentially little information available and it is highly individualised, the process of formulating hypotheses regarding the effects a drug will have on an individual is an essential requirement. The psychiatric disorder or behaviour problem for which the particular psychotropic drug is prescribed should be well documented and any changes that occur in the

behaviour should be collected and analysed. Collecting data regarding both the positive and negative side effects of a drug is also an important factor and this data should also be incorporated into the hypotheses tested when the drug is reviewed. Perhaps one of the most difficult aspects which occurs in the monitoring of drugs is that many of the side effects are largely unknown and do not emerge until later on in treatment.

Any programme designed to assess the efficacy of prescribing medication will have as its focus the issue of an optimal effective dosage. If a drug is prescribed at a rate lower than the effective dosage, then the drug will invariably have a poor effect on the clients functioning. If one exceeds the optimal dose, then toxic side effects may be witnessed. The actual relationship between dose and target symptoms has not yet been fully examined although some research examining this relationship has been conducted with Stimulants (Gadow, 1992). The use of blood levels in determining clinical response has proved to be a useful indicator in certain drugs, but not so in others (Lewis and Mailman, 1988).

4.10.2 Rating Scales used in Medication Monitoring

The use of evaluation systems such as rating scales are used frequently in drug research and have proved quite useful in same. Rating scales have included General Purpose informant scales such as the ABC (Aberrant Behaviour Checklist) (Aman et al., 1985) the MABS (Maladaptive Behaviour Scale) (Thompson, 1988), the DBC (Developmental Behaviour Checklist) (Einfeld and Tonge, 1992), the Emotional Problems Scale and the Emotional Disorders Rating Scale (EDRS-DD) (Feinstein et al., 1988). General purpose self-rating scales include the Emotional Problem Scales: Self Report Inventory and the Adolescent Behaviour Checklist (Strohmer and Prout, 1991) but unfortunately neither has been fully validated in terms of drug research while rating scales developed to assess the negative side-effects of

psychotropic medication have included The Dosage and Treatment Emergent Symptom Scale (DOTES) (National Institute of Mental Health, 1985a) and the Monitoring of Side Effects System (MOSES) (Kalachnik and Nord,1985). The two instruments used to assess Tardive Dyskinesia have been the AIMS (Abnormal Involuntary Movement Scale) (National Institute of Mental Health, 1985b) and the DISCUS (Dyskinesia Identification System: Condensed Users System) (Kalachnik and Sprague, 1993).

To conclude this section, the immense amount of work undertaken on drug monitoring in the United States has been greatly welcomed by all countries as there is always the tendency to over-prescribe to clients with learning disability. In the setting up of any procedures to monitor the effects of drugs, one has to be realistic in what one wants to achieve. In this sense, Kalachnik (1988) has stated "drug evaluation procedures must ... strike a balance between the need for scientific rigor and the demands of real-world treatment settings. If they are too rigid or confrontational, they are unrealistic and will not be followed, and professionals will fight with each other instead of working for the benefit of the patient. If they are too loose, however, they will be abused and non-functional" (p.263).

The next and final section of this chapter will look at and examine the role of the inter-disciplinary team and its importance in reducing the inappropriate use of psychoactive medications, in improving the clinical information of clients and to review thoroughly all information pertaining to a client (behaviour, skills etc.).

4.11 Inter-disciplinary Teams.

Inter or Multi-disciplinary teams are a very important aspect within the field of Learning disability. The co-operation between the disciplines is exceptionally important within the learning disability field as there are

many modes of Service Delivery. Firstly Learning Disability includes many complex and varied conditions which need the expertise of several different professionals. Secondly, optimal service delivery and involvement with parents and guardians requires many different levels of involvement from each of the various professions which includes Psychology, Psychiatry, Nursing, Social Work, Child Care, Language Therapist, Occupational Therapist and possibly others (including counsellors, paediatricians etc.). Thirdly each of the disciplines and professions have had a considerable input into research and experimentation within the field of LD and all workers in the field must recognise the importance of the contributions that each profession has made. All professionals must recognise the importance of when to collaborate with other professionals in order to improve a person's quality of life by means of reducing inappropriate behaviours, teaching new skills or alternative methods of treatment (Cullinane and Crocker, 1992).

In terms of the purpose of interdisciplinary teams and medication use, this is a relatively new area and has only come into being since the 1980's. In 1980, the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons noted that psychoactive medication be administered as part of an overall individualised programme plan for the client with learning disability (Davis et al., 1998). Lepler et al. (1993) have commented that such teams have become more and more involved in the decision-making and monitoring process of psychoactive medication usage.

Although the notion of the Interdisciplinary team largely stemmed from the fact that there was need to monitor medication in these clients, the purpose of such teams has grown considerably over the past decade. Not only are teams now involved in monitoring medication use, they are also involved in gathering clinical information needed for the purpose of diagnoses and treatment of disorders. The individual clinician rarely has

the time to gather all necessary information and compile same whereas when interdisciplinary teams are in operation this process is made much easier and far less time consuming. Teams are also involved in the overall treatment philosophy of Organisations and constant attempts are needed to update and change philosophies which may often appear out of date and not to the individual clients advantage. Another purpose of teams is to help coordinate care for clients living in both residential and community care. Perhaps one of the major developments in the last two to three decades has been the move from residential to community living for clients with learning disability - not only involving more "able" clients but also for clients with more severe and profound levels of learning disability (Agran and Martin, 1982; Lepler et al., 1993).

Over the last number of years there has been increasing interest in the amount of work undertaken on the process of evaluation of services for those with learning disability. This is an area which has not been paid much interest over the years but recently it is gaining impetus and many services are now involved in this process and looking to how services can be improved for their clients. The interdisciplinary team has a large part to play in evaluation as "teams can be constituted to provide a vehicle for enhancing consumer choices and participation with regard to treatment issues" (Davis et al., 1998). Finally and was noted in the opening paragraphs of the chapter, with the increasing awareness and interest of medication use and monitoring at federal level, in the majority of States in the USA, interdisciplinary teams have been introduced to Organisations in order to audit and monitor the administration of medication use in clients as such audits are becoming mandatory in services for the learning disabled client.

4.12 Chapter Summary and Conclusions

To conclude, the present chapter served to address some of the more pertinent issues within the field of learning disability in relation to the

prescribing of medication for this population of clients. In an attempt to understand the rationale behind the prescribing of medication, the present author looked to the historical perspectives of medication administration to the learning disabled, the problems encountered and how such problems shaped the future patterns of prescribing - even to the present day. Large volumes of data have been published on prevalence figures of prescribing to date and such studies have produced clear evidence that in many centres and facilities, over-prescribing was in evidence in addition to polypharmacy, prolonged drug administration and irrational drug prescribing procedures. Resulting from legislation and litigation in the United States in particular, such problems have now been addressed and stringent guidelines are in operation and are proving successful. Gradually, such procedures and guidelines are being implemented in the UK and Ireland, although much work has yet to be done.

Despite the vast amount of research and experimentation undertaken on the topic of prescribing for the learning disabled population, definitive conclusions and recommendations are hard to come by. Aman (1987) further emphasises such thinking when he states, "after more than 35 years of research, it is regrettable to say that very little can actually be concluded about the precise nature of psychotropic drug effects in the mentally retarded" (p.127). Perhaps in a large part, the main problem lies in the fact that the majority of published reports have examined the prevalence of prescribing rather than examining effectiveness per se. In addition, a large number of the reported studies prior to the 1980's can be discounted largely due to problems of methodology. However in the last number of years studies examining the effects of medication in the learning disabled population have become far more methodologically advanced - for example the development of the Psychotropic Medication Efficacy Graph undertaken by Spirrison and Grosskopf (1991) and further developed by Jordan (1994) has contributed greatly to our

understanding of drug prescribing in scientific terms and typifies the type of objectivity which is required in the field.

Finally, the issue of psychopathology in relation to learning disability, and the many theoretical and practical considerations, which have yet to be addressed, are still a cause for some concern for all professionals working in the field. Whether or not psychotropic medication should be administered without the presence of the symptoms of mental illness is still controversial and there is still much disagreement among professionals regarding this issue (Deb and Fraser, 1994).

In conclusion, it is hoped that by addressing some of these issues that interest will be heightened among professionals of all disciplines working with the learning disabled population. The final two areas which were briefly examined in the present chapter were the issues of medication monitoring procedures and the notion of Inter-disciplinary teams which play such a vital role in the setting-up and constant review of medication in many facilities for the learning disabled. Although such teams are as yet in their infancy in many parts of the UK and Ireland, their presence is very strong in the United States and their work is proving of constant benefit to the client with Learning Disability who either displays challenging behaviour or has some form of mental health problem. Resulting from research and work to date in the field, there is no doubt but there is now the necessity for Organisations to initiate the setting up of interdisciplinary review teams to regulate and monitor the use of medication, while also to develop guidelines regarding its effectiveness.

CHAPTER FIVE

METHODOLOGY

5.1 Chapter Introduction

In the vast majority of drug prevalence studies, the method of recording data and information pertaining to A] the client (i.e. demographic data) and B] information regarding prescribing was obtained by means of questionnaire-type survey.

For the purposes of the present drug prevalence study, a survey technique was incorporated, while if any data on medication was absent, or the author was unsure of medication prescribed nursing staff were consulted and questioned regarding these queries. The Drug Survey form used can be seen in Appendix A.

5.2 Aims and Objectives of the present Study.

The main focus of interest for the present study was:

1] To gather information on all clients with the Brothers of Charity Services, Mid-Western region in both residential and community setting who were currently receiving some form of psychotropic and/or psychoactive drug.

2] To compare and contrast the patterns of prescribing for these two clients groups and to relate the findings achieved to published drug studies to date.

The present study was designed primarily to gather data on drug prescribing within an Irish Organisation so as to ascertain patterns of prescribing for both clients in residential and community settings. The study also served to contribute to the current knowledge of prescribing trends for clients with learning disability through screening virtually a complete population of clients in a residential and community setting. Such a technique is infrequently used in such research (very often data is based on sample populations).

5.3 Setting

The Brothers of Charity Services, Mid-Western Region.

The Brothers of Charity Mid Western region caters for a population in excess of 315,000. It currently provides a service to in excess of five hundred clients. This service is provided by means of A] Residential Placement and B] Community Placement: this incorporates both Community House Living and Day Placement (Workshop Setting). The Brothers of Charity run their service in conjunction with the Mid-Western Health Board and have been in operation since the early 1970's.

5.3.1 Residential Placement

The residential placement is based in Bawnmore Complex. Bawnmore is also the Headquarters for administration and Professional Services in the region. The residential programme in operation provides full-time and respite accommodation for adult clients who are unable to live at home with their families. It incorporates full attention to all their health and leisure needs. The Bawnmore residential campus is a village-type complex and consists of ten modern bungalows in Cedar Drive, five larger chalet-type bungalows in Ashgrove and Bart Ramsey House, which caters mainly for clients with more physical/nursing needs. Bawnmore campus currently caters for approximately one hundred and forty one clients, male and female, the majority of who have a severe and profound level of learning Disability.

5.3.2 Community Placement

Community placement (in terms of Community House Living) consists of a number of houses based in the community, which have been purchased by the Brothers of Charity. Community placement is based in the following areas within the Mid-Western region:

Limerick City

Ennis

Newcastle West

Kilrush

Foynes

Presently there are approximately one hundred and fifteen clients in all of the above areas who are in community placement. Each of these clients who are in community placement (living in a community house) attend a full-time Workshop/Day Placement in each of the Regional centres (Limerick city, Bawnmore, Ennis, Newcastle West, Kilrush and Foynes). These workshop settings cater for, and facilitate clients living in the community and those clients living at home. The significant majority of clients who have a Day Placement attend it on a full-time basis, with only a minority of clients attending on a part-time basis.

5.4 Population Base/Subjects

The Brothers of Charity, Mid-Western region provides a service to in excess of five hundred clients. Within the Mid-Western region, there are a total of six regional centres. These centres are 1] Bawnmore (The only residential facility studied); 2] Limerick City, 3] Ennis, 4] Newcastle West, 5] Kilrush and finally 6] Foynes (all Community Facilities).

In terms of the population of clients studied in the present study, the following tables below outline the demographic data obtained in relation to clients in both A] Residential Facility (Bawnmore) and B] Community Facilities within the Mid-West region

5.4.1 Demographic Data 1: Population Base Studied

The first table (Table 5.1) outlines the entire population base studied in each Regional setting. For the purposes of presenting the following data, both clients in Community Placement, Day Placement and those living at home and being provided a Day Placement were combined so that comparison of data would be somewhat clearer. In this respect, the

two sets of data which were compared were: A] Clients in Residential Placement and B] Clients in Community and Day Placement (termed "Community").

From Table 5.2 and throughout the remainder of the chapter, each Regional Setting (Limerick City, Ennis etc.) will no longer be referred to, instead "Residential" and "Community" will be the terms adhered to.

From Table 5.1 below, it can be seen that the largest service provided is based in Limerick city to a total of one hundred and seventy eight clients (178). The next largest service is that provided by Bawnmore Residential Placement - 141 clients. Ennis and Newcastle West provide a service to 92 and 73 clients respectively. The other two Regional Service areas were Kilrush and Foynes and these two areas provided a service to 20 clients in each region.

Table 5.1: A table depicting the Population Base within The Brothers of Charity Services, Mid-Western Region involved in the present Drug Prevalence Study.

Regional Centre	Limerick City	Bawnmore	Ennis	Newcastle West	Kilrush	Foynes	Total
Total Number of Clients	*178*	*141*	*92*	*73*	*20*	*20*	*524*

5.4.2 Demographic Data 2: Type of Setting and Level of Learning Disability

Table 5.2 below shows the collated data in relation to Setting and Level of Learning Disability. As can be seen from this table the majority of clients in Community Placement were within the Mild and Moderate range, while in the only Residential Placement to be examined (Bawnmore), the majority of clients were within the Severe and Profound ranges.

Table 5.2: A table depicting the ranges of Learning Disability (Mild to Profound) for both Clients in Residential and Community Facilities.

	Level of Learning Disability				
Type of Setting	*Mild*	*Moderate*	*Severe*	*Profound*	*Total No.*
Residential	*3*	*34*	*73*	*31*	*141*
Community	*103*	*228*	*38*	*14*	*383*
Total No.	*106*	*262*	*111*	*45*	*524*

5.4.3 Demographic Data 3: Type of Setting and Gender

The next table to be examined (Table 5.3) depicts the gathered data in terms of Setting and Gender. On observing this table, one can see that in both facilities studied, the ratio of Male to Female clients was greater. In the case of clients in Residential Placement (Bawnmore), there were triple the number of male clients in comparison to female clients (106 male to 35 female clients).

Table 5.3: A table depicting the gender of the population base studied in both Residential and Community Facilities.

	Gender		
Type of Setting	*Male*	*Female*	*Total*
Residential	*106*	*35*	*141*
Community	*229*	*154*	*383*
Total	*335*	*189*	*524*

5.4.4 Demographic Data 4: Type of Setting and Age Range

The final set of demographic data to be examined was in relation to Setting and Age Range. From Table 5.4 it can be seen that the youngest age of any client within the services is 18 years of age and is in Community Placement. The oldest client within the services is 75 years of age and is in residential care. The largest age range in the present

study falls in Residential Placement with the range being from 19 years of age to 75 years of age.

Table 5.4: A table depicting the Age Range (in years) for the population studied in both facilities within The Mid-Western Region.

Type of Setting	*Age Range in Years*
Residential	*19-75 years*
Community	*18-72 years*

5.5 Procedure – General

The vast majority of studies with regard to drug prevalence research have been undertaken using a survey method in conjunction with interviews with front-line care staff. The major advantage in incorporating the survey technique in countries such as the USA and certain regions of Great Britain is that large scale State and Regional drug databases are kept for all clients currently being provided any form of Service from and Agency or Organisation. Hence drug prevalence research can be undertaken routinely and access to all information is readily available. However in Ireland, such database systems do not exist in the majority of Organisations and Agencies. Drug Charts/Drug Kardex (written) are kept for each individual client and are located in the clients files in whichever setting or placement the client is based.

On account of there not being a Drug Database in operation within the Brothers of Charity Mid-Western region, all data gathered was taken from clients Drug Kardex from their individual files.

For any client where data pertaining to drug prescribing and/or demographic data was missing or unobtainable, the author consulted with nursing staff in the client's place of residence or Day Placement.

For clients in Residential Placement, the present author examined case files and Drug Kardex for each client in their respective bungalows (16

bungalows in all). All client files were consulted and the relevant data and information was recorded on hand-written charts (See Appendix A).

For clients in A] Community and B] Day Placement, the author examined their case files through whichever Day Centre/Workshop the client was attending. For clients living at home and clients living in Community houses, the necessary data is not available through their place of residence, but rather through their Day Centre. Resulting from this, no community house or none of the clients homes were visited in relation to the gathering of any data for the present piece of research.

5.6 Procedure - Data Gathering.

Ethical Constraints

Prior to any data being gathered, there were several ethical constraints to be considered. Firstly, the research project to be undertaken had to be overseen by the Brother Superior, Executive Director and Area Managers/Heads of Department. Once the project was cleared with the above, letters were sent to any relevant personnel with whom the author felt would b involved in the project (Group Leaders etc.).

Once the ethical constraints were fully discussed and all staff informed of the research to be undertaken, data gathering could then take place.

Data Gathering

Data collection took place by means of examining each client Case Files and Drug Kardex. Demographic data was taken from the main client file, while information on medications prescribed was taken from the clients Drug Kardex. Both sets of information were then recorded in the drug survey form. Where data was missing, unclear or unobtainable, nursing staff were consulted and questioned regarding such queries.
The following data was extracted from Case Files, Drug Kardex.

The Clients: *Name*
Age
Gender
Level of Learning Disability (as per most recent IQ assessment)
Type of Service Provided (i.e. Placement - Residential or Community)
Psychotropic Medication currently prescribed (taken from Drug Kardex)

Each of the Regional Centres were visited by the author over the period November 1995 to May 1996 in the Data collection phase of the study. If any further queries arose regarding medication prescribed, the Director of Psychiatric services/Medical Director was contacted and consulted regarding these queries.

Once all Regional Centres were visited and all data was collected data management and collation took place. All the hand-written Drug Survey forms were further examined and analysed and condensed into a hand-written Master-Sheet.

On completion of this Master sheet, the data was then coded and arranged into Therapeutic Categories according to drug type. A database was then created in MS Excel, which contained all data recorded in the Drug Survey Form in its coded form (see table 5.5 below for the coding system used).

Once the final database coding system was agreed upon, the MS Excel database was transferred into the SPSS programme (Statistical software). At this stage statistical analysis then took place using the SPSS programme.

5.7 Information and Codes Used in The Bawnmore Drug Database.

In the present study, for the purposes of statistical analysis the data had to be coded so as to facilitate this process. A Binary Coding system was incorporated in the present research. Data for gender was coded as being either Male (1) or female (0). For placement with service, data was coded as Residential (1) or Community (2). For data on medication, the coding system employed was: Present (1) – the client was administered this form of medication or Absent (0) – the client was not administered this form of medication. The only variable, which was continuous, was Age (as it ranged from 18 to 75 years of age) and the clients actual age was entered into the statistical analysis.

Table 5.5: A table depicting Information and Codes Used in The Bawnmore Drug Database.

Demographic Data	*Coding System*	*Coding System*
Age	*Continuous Variable*	*18 - 75 years of age*
Gender	*Male = 1*	*Female = 0*
Placement within Service	*Residential = 1*	*Community = 2*
Drug Data/Therapeutic Categories	*Present = 1; Client was administered the drug*	*Absent = 0; Client was not administered the drug*

Under Drug Data/Therapeutic Categories, there were a total of 11 separate categories. In addition to the 7 main drug categories, an additional 4 categories were included - Other Drugs Administered, Monopharmacy, Polypharmacy and Copharmacy. Definitions of monopharmacy, polypharmacy and copharmacy are included below.

Monopharmacy was defined as the administration of one drug only.

Polypharmacy was defined as the administration of 2 or more drugs from the same drug class.

Copharmacy was defined as the administration of 2 or more drugs from different drug classes.

CHAPTER SIX

RESULTS

6.1 Chapter Introduction.

The first stage of the present thesis was a drug prevalence study, which was undertaken in the Bros. Of Charity Services, Mid-Western region. The study examined patterns of prescribing for both residential (institutional) and community clients with varying levels of learning disability. The study first looked at the actual rates of prescribing of the range of drugs administered to residential clients and those administered to community clients. Demographic factors such as age, level of learning disability, gender and placement within the services were then examined to determine whether these variables had an impact on the rates of prescribing. As was mentioned in Chapter three, the present study served to address these issues in terms of the study being a "snapshot" view of prescribing in the present population.

6.2 Data Collection, Management and Analysis.

Drug data for the present study was initially collected on hand-written charts by the present author in each of the facilities where data was examined in conjunction with senior nurses or key-workers. The data was then transferred onto a database in Microsoft Excel. This database (The Bawnmore Drug Database) initially took several forms, until a final version was agreed upon, which was also compatible with statistical analysis. The MS Excel database was then transferred onto the SPSS programme where statistical analysis took place.

For the purposes of statistical analysis, the data needed to be coded into various categories so as to accommodate data entry and statistical analysis. In terms of the variables entered for statistical analysis, there were a total of 14 variables entered - 3 of these being demographic in nature (gender, age, level of LD and placement within the Services. **Gender** was classified as being either male or female and was given a coding of "1" for male and "0" for female. **Age** was a continuous variable in the fact that the age range stemmed from 18 years of age to 75 years

of age - each clients age was entered. **Level of Learning Disability** had four distinct categories: Mild, moderate, severe and profound. Each level was coded as being either a "1" (mild), "2" (moderate), "3" (severe) and "4" (profound). On initial analysis of the data obtained, there were too few subjects in the severe and profound ranges (who were currently being prescribed medication), for successful statistical analysis to take place. On account of this, the severe and profound categories were combined into one category before any analysis took place. Resulting from this, there were a total of three categories of learning disability (mild = 1), (moderate = 2) and (severe + profound = 3). **Placement within the Services** consisted of two main categories - residential and community. Residential was given a coding of "1", while community was given a coding of "2".

In terms of the drug data and drug categories analysed, there were a total of 11 in all. For each category of drug examined, the client was deemed to be either: A] administered a particular class of drug, or B] not administered that class of drug. For clients administered a class of drug, the client was given a coding of 1(drug was present). For clients not administered a class of drug a coding of 0 was given (drug was absent).

Thus for each variable included in the statistical analysis, all data entered was by means of the coding system outlined above (i.e. "0", "1", "2" or "3") - depending on the particular variable in question.

6.3 Demographic Data and Information.

In relation to the demographic data examined in the present piece of research, Tables 6.1 to 6.4 below outline the relevant data gathered. The population base, which was studied, consisted of a total of 524 clients with varying levels of learning disability within the Brothers of Charity Services, Mid-Western region. These 524 clients were provided some form of Service by the Brothers of Charity by means of Residential

Placement, Community Placement or Day Placement (workshop). Within the region studied, there are a total of six regional centres: 1] Bawnmore (residential), 2] Limerick City, 3] Ennis, 4] Newcastle West, 5] Kilrush and finally 6] Foynes - each with a population of clients with varying levels of learning disability, both male and female and all being from the ages of 18 years to 75 years of age depending on the centre. Table 6.1 below outlines the population base studied in the present study.

Table 6.1: A table depicting the Population Base within The Brothers of Charity Services, Mid-Western Region involved in the present Drug Prevalence Study.

Regional Centre	Limerick City	Bawnmore	Ennis	Newcastle West	Kilrush	Foynes	Total
Total Number of Clients	*178*	*141*	*92*	*73*	*20*	*20*	***524***

From the above table it can be seen that the two largest Services were in Bawnmore (the only residential service provided - 141) and Limerick city (178), which is part of the Community Service. Ennis and Newcastle West provided the next largest service - 92 and 73 clients respectively with Foynes and Kilrush providing a service to 20 clients each at the time of the study.

The next table (table 6.2) shows the varying levels of the clients Learning Disability which were involved in the present research. From this table it can be seen that in the residential setting (Bawnmore), the majority of clients were in the lower functioning ranges of the category of learning disability - moderate, severe (mainly) and profound. In comparison, clients in Community and Day Placement (termed "Community") were mainly within the mild and moderate ranges of learning disability.

Table 6.2: A table depicting the ranges of Learning Disability (Mild to Profound) for the population base studied in each Regional Centre.

	Level of Learning Disability				
Regional Centre	*Mild*	*Moderate*	*Severe*	*Profound*	*Total No.*
Limerick City	*41*	*113*	*20*	*4*	***178***
Bawnmore	*3*	*34*	*73*	*31*	***141***
Ennis	*24*	*61*	*7*	*0*	***92***
Newcastle West	*31*	*37*	*5*	*0*	***73***
Kilrush	*7*	*12*	*1*	*0*	***20***
Foynes	*0*	*5*	*5*	*10*	***20***
Total No.	***106***	***262***	***111***	***45***	***524***

Gender is the next set of demographic data to be examined. Table 6.3 shows the number of male clients in comparison to female clients in each of the regional centres studied. From this table it can be seen that in all except one regional centre (Kilrush), the ratio of male to female clients was greater. Kilrush differed in that out of a total of 20 clients in this particular service, sixteen are female while only 4 are male. However in all other centres examined in this study, male clients greatly outnumbered female clients, especially in the residential setting (Bawnmore), as the ratio was 3 male to 1 female client.

Table 6.3: A table depicting the gender of the population base studied according to each Regional Centre within the Mid-West Region.

	Gender		
Regional Centre	*Male*	*Female*	*Total*
Limerick City	*115*	*63*	***178***
Bawnmore	*106*	*35*	***141***
Ennis	*53*	*39*	***92***
Newcastle West	*44*	*29*	***73***
Kilrush	*4*	*16*	***20***
Foynes	*13*	*7*	***20***
Total	***335***	***189***	***524***

The final table to be examined is Table 6.4 which looks at the age range of clients in each of the Regional centres examined. All of the clients who were involved in the present research were adults above the age of 18 years. The centre with the greatest age range was Bawnmore with an age range of 19 to 75 years. On the other hand, the smallest age range was found in Foynes with the age range stemming from 18 years to 35 years.

Table 6.4: A table depicting the Age Range (in years) for the population studied in each Regional Centre within The Mid-Western Region.

Regional Centre	*Age Range in Years*
Limerick City	*20-72 years*
Bawnmore	*19-75 years*
Ennis	*19-54 years*
Newcastle West	*19-62 years*
Kilrush	*20-45 years*
Foynes	*18-35 years*

6.4 Overall Rates of Prescribing.

At the time of the study (November 1995 to May 1997) there were a total of one hundred and forty one clients in residential care within the Bawnmore complex and the total number of clients living in the community and at home amounted to three hundred and eighty four. The number and percentages of clients administered any form of medication out of the total population in the Mid-Western region is depicted in table 6.5 below:

Table 6.5: A table depicting the number and percentage of clients administered any form of drug from the total population of clients studied.

Client Population Setting	Total No. and % of Clients	No. and % of Clients receiving Medication
Residential	*141 (100%)*	*131 (92%)*
Community	*383 (100%)*	*73 (19%)*

From the above figures it can be observed that out of a total of 141 residential clients, 131 of these were administered some form of medication - this amounted to a percentage of 92%. In comparison the figures from the survey of community clients showed that only 73 (19%) out of a total of 383 clients were currently being administered some form of medication.

Table 6.6 below shows a breakdown of the number of clients administered medication according to category of learning disability (mild, moderate, severe, profound) and placement within the Services (Residential and Community). From the figures it can be seen that 19 clients out of a total of 103 living in the community with a mild level of learning disability were administered medication (18.4%). In terms of clients in the community with moderate learning disability 44 out of a total of 228 were currently administered some form of medication (19.2%) while with only 7 out of 38 clients (18.4%) with a severe learning disability were presently administered medication. Out of a total of 14 clients within the profound range 3 clients were currently administered medication (21.4%).

A far larger number of clients in residential care were administered medication. Table 6.6 outlines the figures obtained for clients in residential care. Out of a total of 141 residential clients, 131 were currently administered some form of medication. 2 clients in the mild range were currently administered medication (1.4%), 47 in the moderate range (33%) with 65 out of 73 clients in the severe range being administered some form of medication. Finally 17 out of 31 clients with a profound level of learning disability were administered medication.

Table 6.6: A table depicting the number of clients currently administered one or more forms of medication in relation to Placement within the Services and Level of Learning Disability.

	Level of Learning Disability									
Placement	***Mild***		***Moderate***		***Severe***		***Profound***		***Total***	
No. and % of Clients on Medication	No.	%	No.	%	No.	%	No.	%	No.	%
Residential	2	*1.4 %*	47	*33%*	65	*46%*	17	*12%*	**131**	*92%*
Community	19	*4.9 %*	44	*11.4%*	7	*1.8 %*	3	*.78 %*	**73**	*19%*
Total	**21**		**91**		**72**		**20**		**204**	

6.5 Breakdown of Drug Prescribing into Main Drug Categories.

As was noted in the methodology section, all drugs reviewed in the present study were assigned into therapeutic categories on the basis of their classification in MIMS & BNF. The main section which the remainder of this section will focus on is: Drugs affecting the Central Nervous System. There were a total of seven main categories which were examined:

Hypnotics
Anxiolytics
Antipsychotics
Antidepressants
Antiemetics
Anticonvulsants
Movement Disorders

Table 6.7: A Table Depicting the Number and Percentage (%) of Residential and Community Clients Currently Administered Medication (from the 7 Categories outlined below).

Drug Category	*Residential*	*Community*
1. **Hypnotics**	17 (13%)	4 (5.4%)
2. **Anxiolytics**	6 (4.5%)	5 (6.7%)
3. **Antipsychotics**	103 (78%)	24 (32.4%)
4. **Antidepressants**	16 (12%)	12 (16.2%)
5. **Antiemetics**	6 (4.5%)	0 (0%)
6. **Anticonvulsants**	81 (61.3%)	62 (83.7%)
7. **Movement Disorders**	44 (33.3%)	6 (8.1%)

6.6 Drugs Affecting the Central Nervous System

6.6.1 Hypnotics.

In terms of the first class of drugs, Hypnotics, a total of 17 residential were administered this class of drug - this corresponded to 13% of residential clients administered any form of medication. When one compares this figure to clients living in the community, only 4 clients (5.4%) were administered a hypnotic drug out of a total of 73 clients currently on medication.

6.6.2 Anxiolytics.

Anxiolytic drugs were administered to 6 clients living in residential care (5.4%) and to 5 clients living in the community - this amounted to 6.7% of the community population on medication.

6.6.3 Antipsychotics.

Of the clients currently administered Antipsychotic medication, 103 clients (78%) were administered some form of antipsychotic drug. This was the largest number of clients on any form of drug in the current

study. When one examines the corresponding figure for clients living in the community, 24 out of 73 clients were administered an antipsychotic drug (32.4%) - a figure under half the corresponding figure for residential clients.

6.6.4 Antidepressants.

Similar to the Anxiolytics, in the Antidepressant class of drugs, similar figures were achieved for both residential and community clients. A total of 16 residential clients (12%) were administered an antidepressant drug, while in terms of community clients, 12 individuals were administered this class of drug (16.2%).

6.6.5 Antiemetics.

Although the Antiemetics have been included in the present classification system incorporated, due to their relatively infrequent prescribing, and largely because they are administered to counter the negative side effects of the Antipsychotics in particular, their importance in the present research was minimal. A total of 6 residential clients (4.5%) and no community clients were administered this class of drug.

6.6.6 Anticonvulsants.

In the present population of clients studied, a total of eighty-one residential clients were administered an Anticonvulsant drug - 61.3%. If one looks to the number of community clients on an Anticonvulsant, this is the class of drug with the highest number of clients. A total of 62 community clients (83.7%) were administered an Anticonvulsant drug. If one compares this figure with the Antipsychotic figures, the Anticonvulsants were administered 2 ½ times more frequently than Antipsychotic drugs.

6.6.7 Movement Disorder Drugs.

The final class of drugs to be examined are the Movement disorder drugs. Upon examination of the figures obtained, it can be seen that forty four residential clients (33.3%) were administered this form of drug, whereas when one looks to the figures obtained for community clients, only six clients (8.1%) were administered same.

6.7 Breakdown of Drug Categories according to Individual Drug Type.

6.7.1 Hypnotics.

Table 6.8: A Table Depicting the Number and Percentage of Clients Currently Administered the Hypnotic Class of Drugs.

Name of Drug	No. and % of Residential Clients	No. and % of Community Clients
1] Dalmane	5 (3.78%)	3 (4.05%)
2] Mogadon	10 (7.5%)	0 (0%)
3] Zimovane	1 (.75%)	0 (0%)
4] Normison	1 (.75%)	1 (1.35%)

From the above data, it can be seen that for residential clients, a total of four hypnotics were currently being administered. The hypnotic of choice was Mogadon with a total of 10 clients being administered this drug. The next drug of choice was Dalmane with 5 clients being administered this drug. The remaining two hypnotics Zimovane and Normison were administered to one client each respectively. When one looks to community clients, only two drugs were currently being administered - Dalmane and Normison. 3 clients were administered Dalmane with only 1 client administered Normison.

6.7.2 Anxiolytics.

Table 6.9: A Table Depicting the Number and Percentage of Clients Currently Administered the Anxiolytic Class of Drugs.

Name of Drug	No. and % of Residential Clients	No. and % of Community Clients
1] Stesolid	1 (.75%)	0 (0%)
2] Atensine	0 (0%)	2 (2.70%)
3] Valium	4 (3.03%)	3 (4.05%)
4] Ativan	1 (.75%)	0 (0%)

A total of six residential clients were administered a range of 3 different anti-anxiety drugs. As would be expected Valium was the anxiolytic of choice with 4 clients being administered it. Only 1 client was administered Ativan and very interesting 1 client was on a current dose of Stesolid.

Only 2 drugs in this class were administered to community clients. Valium was administered to 3 clients with the only other drug administered being Atensine to 2 clients.

6.7.2 Antipsychotics.

In the present study, there were a range of various Antipsychotics administered, a total of eight for residential clients and also a total of eight for community clients.

Table 6.10: A Table Depicting the Number and Percentage of Clients Currently Administered the Antipsychotic Class of Drugs.

Name of Drug	No. and % of Residential Clients	No. and % of Residential Clients.
1] Melleril	53 (40.15%)	11 (14.86%)
2] Largactil	11 (8.33%)	1 (1.35%)
3] Serenace	28 (21.21%)	2 (2.70%)
4] Neulactil	2 (1.51%)	3 (4.05%)
5] Clopixol	3 (2.27%)	0 (0%)
6] Modecate	2 (1.51%)	1 (1.35%)

7] Sparine	0 (0%)	1 (1.35%)
8] Stelazine	2 (1.51%)	4 (5.40%)
9] Anquil	2 (1.51%)	0 (0%)
10] Depixol	0 (0%)	1 (1.35%)

As in most drug prevalence studies, Melleril was the first Antipsychotic drug of choice. 53 residential clients were administered this drug with only 11 community clients administered it. The next most frequently administered drug was Serenace and this drug was administered to a total of 28 residential clients. In terms of community clients, Serenace was administered to only 2 clients in total and interestingly and as can be seen from the above table it was not the second drug of choice after Melleril. For clients in residential care, Largactil was the third drug of choice with it being administered to 11 clients. Only 1 client in the community was administered this drug. Clopixol was the next drug of choice for residential clients - with 3 clients on the drug. No community clients were administered same. The four remaining Antipsychotic Drugs were Neulactil, Modecate, Stelazine and Anquil with 2 clients respectively (4x2) being administered each of these drugs. Interestingly for clients in the community, the third drug of choice was Stelazine with 4 clients administered this drug. The drug next in line was Neulactil (3 clients) with the remaining drugs administered being Modecate (1 client), Sparine (1 client) and finally Depixol being administered to 1 client only.

6.7.2 Antidepressants.

For residential clients, there was a large range of antidepressant drugs administered - 7 in total. For community clients, the corresponding figure was a range of 6 antidepressants.

Table 6.11: A Table Depicting the Number and Percentage of Clients Currently Administered the Antidepressant Class of Drugs.

Name of Drug	No. and % of Residential Clients	No. and % of Community Clients
1] Prozac	4 (3.03%)	2 (2.70%)
2] Surmontil	2 (1.51%)	0 (0%)
3] Tryptizol	3 (2.27%)	2 (2.70%)
4] Anafranil	3 (2.27%)	2 (2.70%)
5] Priadel	1 (.75%)	0 (0%)
6] Camcolit	1 (.75%)	0 (0%)
7] Prothiaden	2 (1.51%)	4 (5.4%)
8]Tofranil	0 (0%)	1 (1.35%)
9] Seroxat	0 (0%)	1 (1.35%)

For clients in residential care, the Antidepressant drug of choice was Prozac with a total of 4 clients being administered it. The next two drugs of choice were Tryptizol and Anafranil with 3 clients being administered each drug respectively. Surmontil and Prothiaden were the next most frequently prescribed antidepressants with 2 clients each administered these drugs. In the present population studied, only 1 client was administered Priadel with the remaining one client being administered Camcolit.

For clients in the community, a very different picture emerged. The first Antidepressant drug of choice was Prothiaden with 4 clients currently administered this drug. The next three drugs of choice were Prozac (2 clients), Tryptizol (2 clients) and Anafranil (2 clients). The remaining two drugs were Tofranil and Seroxat and 1 client was administered each respectively.

6.7.5 Antiemetics.

As was mentioned earlier in this section, although the Antiemetics were included in the classification system used in this study, this category of drug was not of immense importance in the present piece of research. The results obtained are included in Table 6.12 below.

Table 6.12: A Table Depicting the Number and Percentage of Clients Currently Administered the Anti-Emetic Class of Drugs.

Name of Drug	No. and % of Residential Clients	No. and % of Community Clients
1] Motilium	5 (3.78%)	0 (0%)
2] Maxolon	1 (.75%)	0 (0%)

As can be seen from the above table, only 2 Antiemetic drugs were currently being administered to residential clients - Motilium and Maxolon. 5 clients were administered Motilium with 2 clients being administered Maxolon. In community clients, there were no current administrations of Antiemetic drugs.

6.7.6 Anticonvulsants.

For both groups of clients (residential and community), this was a large category with it being the largest category prescribed for community clients and the second largest drug category prescribed for residential clients. In terms of residential clients, a range of 5 drugs was administered, with a range of 6 drugs being administered to community clients. This was the only category of drug in which the drug range was greater in community clients than in residential clients.

Table 6.13: A Table Depicting the Number and Percentage of Clients Currently Administered the Anticonvulsant Class of Drugs.

Name of Drug	No. and % of Residential Clients	No. and % of Community Clients
1] Tegretol	46 (34.8%)	28 (37.8%)
2] Lamictal	17 (12.87%)	9 (12.16%)
3] Epilim	14 (10.6%)	16 (21.62%)
4] Rivotril	2 (1.51%)	0 (0%)
5] Epanutin	2 (1.51%)	1 (1.35%)
6] Frisium	0 (0%)	4 (5.40%)
7]Phenobarb.	0 (0%)	4 (5.40%)

Tegretol was the first drug of choice for residential clients with 46 being administered this drug. This was a large percentage of clients in this

category as the next drug of choice , Lamictal, was administered to 17 clients. Epilim was next in vogue with 14 clients administered this drug. The remaining two drugs in this category Rivotril and Epanutin (the older Anticonvulsants) were administered to 2 clients each respectively.

For community clients, Tegretol was still the drug of choice with 28 clients administered it. Whereas Lamictal was the second drug of choice for residential clients, Epilim was the second drug of choice for 16 community clients, with 9 clients administered Lamictal. Interestingly and a cause for some concern is the fact that Frisium was administered to 4 clients in the community and also Phenobarbitone (a very old anticonvulsant and known for its negative side effects) was administered to 4 clients. Only one client in the community was administered Epanutin.

6.7.7 Movement Disorders.

This was the final category of drug to be examined. Movement Disorder Drugs (namely the Anticholinergics) are prescribed primarily to counter the negative side effects of the antipsychotic drugs.

Due to the high rate of prescribing of the Antipsychotics (especially in the residential population), the overall prescribing figure for Movement disorder drugs was quite high (33.3% residential; 8.1% community). The breakdown of this drug category is as follows:

Table 6.14: A Table Depicting the Number and Percentage of Clients Currently Administered the Movement Disorder Class of Drugs.

Name of Drug	No. and % of Residential Clients	No. and % of Community Clients
1] Akineton	4 (3.03%)	3 (4.05%)
2] Cogentin	38 (28.78%)	3 (4.05%)
3] Disipal	2 (1.51%)	0 (0%)

For clients in residential care, Cogentin was the most popular drug as 38 clients were administered same. Akineton was the next most popular drug with 4 clients on this drug and the remaining Movement Disorder drug was Disipal - being administered to 2 clients.

Community clients were administered a range of 2 drugs - Akineton and Cogentin - each being prescribed to 3 clients respectively.

6.8 Monopharmacy, Polypharmacy and Copharmacy Rates of Prescribing.

Upon completion of the gathering of all drug data, and once initial analysis had taken place, all drug categories were analysed in detail to determine the rates of Monopharmacy, Polypharmacy and Copharmacy. A definition of each category is given below:

Monopharmacy: The prescribing of one drug only from a single class of drug (i.e. prescribing of a single Antipsychotic drug).

Polypharmacy: The prescribing of more than one drug from the same class of drugs (i.e. 2 or more Antipsychotics)

Copharmacy: The prescribing of more than one drug from a differing class of drugs (i.e. 2 or more drugs such as 2 Antipsychotics + 1 Antidepressant + 1 Anticonvulsant).

Table 6.15: A Table Depicting the Number and Percentage of Residential and Community Clients Currently Administered Monopharmacy, Polypharmacy and Copharmacy.

	Residential: Total No.	*Percentage %*	Community Total No.	*Percentage %*
Monopharmacy	33	***25***	34	***45***
Polypharmacy	43	***32.5***	20	***27***
Copharmacy	66	***50***	20	***27***
2 - drug	20	*30.3*	9	*45*
3 - drug	28	*42.4*	9	*45*
4 - drug	10	*15.1*	1	*5*
5 - drug	6	*9*	1	*5*
6 - drug	1	*1.5*	0	*0*
7 - drug	1	*1.5*	0	*0*

From the above table of results, it can be seen that differences do emerge when one compares the rates of Monopharmacy, Polypharmacy and Copharmacy for residential and community clients. The following points can be made:

- Upon examination of the rates of monopharmacy, 25% of residential clients were administered monopharmacy (use of only 1 drug), whereas 45.9% of community clients were administered monopharmacy. This shows us that only ¼ of residential clients were administered a single drug but almost ½ of community clients were on single drug therapy.

- The differences in the rates of administration of polypharmacy when residential and community clients were compared were not as striking as in the monopharmacy range. 32.5% of residential clients were prescribed two or more drugs from the same class while the corresponding figure for community clients was 27.02%. This shows a difference of just 5% between residential and community clients.

- Perhaps the most notable difference to emerge was the rate of prescribing in the copharmacy range. For residential clients, this rate amounted to just 50% and in community clients the corresponding figure amounted to 27.02% (the same figure which emerged in the polypharmacy range).

Interestingly in the present study, not only was there 2 and 3 drug copharmacy combinations for residential and community clients, for clients in residential care the copharmacy rate ranged from 2-drug combination to a 7-drug combination for one client. A total of 20 residential clients were on a 2 drug copharmacy combination, 28 clients were on a 3 drug combination, 10 clients on a 4 drug combination, 6 on a 5 drug combination with the remaining 2 clients being on a 6 drug (1 client) and 7 drug (1 client) combination. The corresponding figures for community clients were: 9 clients administered 2 drug copharmacy, 9 clients administered a 3 drug combination, 1 client administered a 4 drug combination with the remaining 1 client on a 5 drug combination. No client in the community setting was on either a 6 or a 7-drug copharmacy combination.

6.9 Bivariate Analysis.

Prior to statistical analysis taking place, the data was organised into categories for each of the variables to be studied. For each of the variables (independent and dependent), the data was classified as either categorical or continuous - however the only continuous variable was age - ranging from 18 to 73 years. For each variable examined in the present study, a coding system was employed for the purposes of statistical analysis. The coding system used is outlined below:

4.9.1 Bivariate Analysis: Coding System Used.

Table 4.16: A Table Depicting the Coding System Incorporated for Statistical Analysis.

Variable Studied	Variable Type	Character Type	Coding System Used
Gender	Male Female	Categorical	***1*** ***0***
Placement	Residential Community	Categorical	***1*** ***2***
Handicap	Mild Moderate Severe	Categorical	***1*** ***2*** ***3***
Age (Range)	18-75 years.	Continuous	***Age in years***
Drug Category (11 in total)	Absent Present	Categorical	***0*** ***1***

All variables studied were easily categorised and coded. The one category which did cause a problem was that of learning disability. Although there were four levels in this category initially, due to small numbers in the profound range, the "severe" and "profound" levels were combined together and classified as "severe". Thus for the purposes of the statistical analysis, there were only three levels of Learning Disability.

In terms of each of the drug categories, the classification system used was Absent (0) or Present (1). In this respect for each client studied, they were deemed to be either: Administered the particular drug (classification = "Present") or Not administered the particular drug (classification = "Absent").

The dependent variable in each case was the drug category being either Absent or Present in relation to factors such as gender, placement, level

of Learning Disability and Age. For each drug category a Model was created (11 in total) and each of these Models will be examined in turn.

6.10 Bivariate Analysis: Model 1A Antipsychotic Drug.

Table 6.17: A Table Depicting the Results of Bivariate Statistical Analysis Completed on Data Pertaining to the Antipsychotic Class of Drugs.

	Absent	Present	Test Statistic	p-Value
Sample Size	115	89		
Gender:				
Male	75 (65.2%)	62 (69.7%)	.271	.603 NS
Female	40 (34.8%)	27 (30.3%)		
Placement:				
Community	53 (46.1%)	20 (22.5%)	11.170	.0008 ***
Residential	62 (53.9%)	69 (77.5%)		
Handicap:				
Mild	14 (12.2%)	7 (7.9%)	1.694	.429 NS
Moderate	53 (46.1%)	38 (42.7%)		
Severe	48 (41.7%)	44 (49.4%)		
Age				
Av. Rank	111.56	90.79	4075.5	.0126 ***
Median	35	32		

Of the 204 subjects studied, 89 were administered and Antipsychotic drug whereas 115 were not. Of the four variables studied, two variables came out of significance - Placement and Age. Placement was significant as significantly more residential clients were administered Antipsychotic drugs when compared to community clients (66 versus 20) with the p-Value being .0008. The other variable of significance was Age, with significantly more younger clients being administered and Antipsychotic drug in comparison with older clients (p-Value .0126). The other two variables in this model - Gender and Handicap were not of statistical significance.

6.11 Bivariate Analysis: Model 1b Hypnotic Drug.

Table 6.18: A Table Depicting the Results of Bivariate Statistical Analysis Completed on Data Pertaining to the Hypnotic Class of Drugs.

	Absent	Present	Test Statistic	p-Value
Sample Size	183	21		
Gender:				
Male	125 (68.3%)	12 (57.1%)	.618	.432 NS
Female	58 (31.7%)	9 (42.9%)		
Placement:				
Community	69 (37.7%)	4 (19.0%)		. .099 NS
Residential	114 (62.3%)	17 (81.0%)		
Handicap:				
Mild	19 (10.4%)	2 (9.5%)	4.698	.095 NS
Moderate	86 (47.0%)	5 (23.8%)		
Severe	78 (42.6%)	14 (66.7%)		
Age				
Av. Rank	99.91	125.1	1447	.064 NS
Median	33	37		

Of the 204 clients involved in the study, 21 clients were administered a Hypnotic drug, while 183 were not. Of the four variables examined, no one variable was of significance.

6.12 Bivariate Analysis: Model 1c Anxiolytic Drug.

Table 6.19: A Table Depicting the Results of Bivariate Statistical Analysis Completed on Data Pertaining to the Anxiolytic Class of Drugs.

	Absent	Present	Test Statistic	p-Value
Sample Size	193	11		
Gender:				
Male	131 (67.9%)	6 (54.5%)		.5099 NS
Female	62 (32.1%)	5 (45.5%)		
Placement:				
Community	68 (35.2%)	5 (45.5%)		.5276
Residential	125 (64.8%)	6 (54.5%)		
Handicap:				
Mild	17 (8.8%)	4 (36.4%)	13.749	.00103 ***
Moderate	91 (47.2%)	0 (0%)		
Severe	85 (44%)	7 (63.6%)		
Age				
Av. Rank	102.32	105.59	1027.5	.8582 NS
Median	33	34		

Similar to the hypnotic range of drugs, a very small number of clients were administered the Anxiolytic category of drugs. 11 clients were currently administered an Anxiolytic drug, while the majority of clients were not (193 Absent). Only one variable was of statistical significance in this drug category - level of Handicap. The results from this analysis were interesting in the fact that out of 11 clients administered this category of drug, 4 clients were in the Mild range, no client in the Moderate range was administered a drug of this type and in the Severe range (a combination of Severe and Profound), 7 clients were administered this drug category. These results were of significance in the fact that significantly more severe clients were administered such

drugs in comparison to mild and moderate clients - the p-Value for this category of significance was .00103. It is of interest to note that no client in the Moderate range was administered such drugs.

6.13 Bivariate Analysis: Model 1d Antidepressant Drug.

Table 6.20: A Table Depicting the Results of Bivariate Statistical Analysis Completed on Data Pertaining to the Antidepressant Class of Drugs.

	Absent	Present	Test Statistic	p-Value
Sample Size	178	26		
Gender:				
Male	126 (70.8%)	11 (42.3%)	.7101	.0077 **
Female	52 (29.2%)	15 (57.5%)		
Placement:				
Community	62 (34.8%)	11 (42.3%)	.275	.600 NS
Residential	116 (65.2%)	15 (57.7%)		
Handicap:				
Mild	17 (9.6%)	4 (15.4%)	1.670	.434 NS
Moderate	78 (43.8%)	13 (50.0%)		
Severe	83 (46.6%)	9 (34.6%)		
Age				
Av. Rank	99.13	125.58	1714	.0327 *
Median	33	38.5		

Of the sample of clients studied, only 26 out of 204 were currently administered an Antidepressant drug. Again two variables were of significance -Gender and Age. The category of Antidepressant drug was the only category in which Gender was of significance. What was also of immense interest was the fact that significantly more female clients were administered an Antidepressant drug when compared with male clients ($p >= .0077$). Again this was the only drug category where gender was

significant and where significantly more female clients were administered a drug. The second significant variable was Age - with significantly older clients being administered an Antidepressant drug than the younger clients (p >= .0327).

6.14 Bivariate Analysis: Model 1e Antiemetic Drug.

Table 6.21: A Table Depicting the Results of Bivariate Statistical Analysis Completed on Data Pertaining to the Antiemetic Class of Drugs.

	Absent	Present	Test Statistic	p-Value
Sample Size	198	6		
Gender:				
Male	133 (67.2%)	4 (66.7%)		1.0 NS
Female	65 (32.8%)	2 (33.3%)		
Placement:				
Community	73 (36.9%)	0 (0%)		.090 NS
Residential	125 (63.1%)	6 (100%)		
Handicap:				
Mild	20 (10.1%)	1 (16.7%)	5.01	.082 NS
Moderate	91 (46%)	0 (0%)		
Severe	87 (43.9%)	5 (83.3%)		
Age				
Av. Rank	101.93	121.25	481.5	.429 NS
Median	33	35		

As was mentioned before, this particular drug category was not of major interest for the purposes of statistical analysis. This was the one drug category with the least amount of clients administered any type of drug. Only 6 residential clients were administered any form of Antiemetic drug - no community clients were administered same. As a result of such factors, no variable was of significance in this drug category.

6.15 Bivariate Analysis: Model 1f Anticonvulsant Drug.

Similar to the Antipsychotics, there was a high rate of prescribing for the Anticonvulsants. A total of 96 clients were prescribed 1 or more Anticonvulsants with 108 clients not being administered this category of drug.

Table 6.22: A Table Depicting the Results of Bivariate Statistical Analysis Completed on Data Pertaining to the Anticonvulsant Class of Drugs.

	Absent	Present	Test Statistic	p-Value
Sample Size	108	96		
Gender:				
Male	70 (64.8%)	67 (69.8%)	.367	.54 NS
Female	38 (35.2%)	29 (30.2%)		
Placement:				
Community	32 (29.6%)	41 (42.7%)	3.235	.072 NS
Residential	76 (70.4%)	55 (57.3%)		
Handicap:				
Mild	6 (5.6%)	15 (15.6%)	10.229	.006 **
Moderate	58 (53.7%)	33 (34.4%)		
Severe	44 (40.7%)	48 (50%)		
Age				
Av. Rank	117.00	86.19	3618	.0002 ***
Median	35.5	31		

From the above data, it can be seen that two variables were of significance in the analysis conducted. The first variable of significance was level of Handicap, with significantly more moderate and severe clients being administered drugs than clients with a mild level of learning disability. Hence the more severe the level of learning disability, the greater the possibility that such clients would be administered this

category of drug. The p-Value obtained in this analysis was p >= .072. The second variable of significance was Age, with significantly younger clients than older clients being administered an Anticonvulsant drug (p>= 0.0002).

6.16 Bivariate Analysis: Model 1g Movement Disorder Drug.

For this category of drug, a total of 44 clients were administered this drug category out of the sample of 204 clients. The majority of these clients were residential clients (38) with the remaining 6 clients being from the community.

Table 6.23: A Table Depicting the Results of Bivariate Statistical Analysis Completed on Data Pertaining to the Movement Disorder Class of Drugs.

	Absent	Present	Test Statistic	p-Value
Sample Size	160	44		
Gender:				
Male	103 (64.4%)	34 (77.3%)	2.051	.152 NS
Female	57 (35.6%)	10 (22.7%)		
Placement:				
Community	67 (41.9%)	6 (13.6%)	10.778	.0001 ***
Residential	93 (58.1%)	38 (86.4%)		
Handicap:				
Mild	21 (13.1%)	0 (0%)	7.509	.023 *
Moderate	72 (45.0%)	19 (43.2%)		
Severe	67 (41.9%)	25 (56.8%)		
Age				
Av. Rank	103.57	98.63	3349.5	.623 NS
Median	33	33		

Again two variables were significant in the present analysis - Placement and Level of Handicap. For the variable Placement, significantly more

residential clients were administered a Movement Disorder drug than community clients (p Value = .001). The other variable of significance was Level of Handicap, with significantly more moderate and severe clients being prescribed this drug category than clients in the mild range of Learning Disability. Hence similar to the Anticonvulsants, the more severe the level of Learning Disability, the greater the possibility that a client will be administered such a drug - especially if such clients are also prescribed an Antipsychotic drug.

6.17 Bivariate Analysis: Model 1 h Monopharmacy Drug.

The final three models included in the analysis were Monopharmacy , Polypharmacy and Copharmacy Drug. These variables were included in the statistical analysis in order to determine whether significance emerged between the factors when the data was combined. Definitions of Monopharmacy, Polypharmacy and Copharmacy can be found earlier in this chapter. For Polypharmacy and Copharmacy, overall rates are reported rather than breaking down each drug category (Antipsychotics etc.) and then classifying these in Monopharmacy, Polypharmacy and Copharmacy. Thus once a client was administered a singe, 2 -drug or more combination, classification took place on this basis alone.

Table 6.24: A Table Depicting the Results of Bivariate Statistical Analysis Completed on Data Pertaining to Monopharmacy.

	Absent	Present	Test Statistic	p-Value
Sample Size	144	60		
Gender:				
Male	95 (66%)	42 (70%)	.15567	.69318 NS
Female	49 (34%)	18 (30%)		
Placement:				
Community	36 (25%)	37 (61.7%)	23.20954	.000 ***
Residential	108 (75%)	23 (38.3%)		

Handicap:				
Mild	14 (9.7%)	7 (11.7%)	8.04168	.01794 NS
Moderate	56 (38.9%)	35 (58.3%)		
Severe	74 (51.4%)	18 (30%)		
Age				
Av. Rank	100.59	107.09	4044.5	.4730 NS
Median	33	33.5		

From the above table of data, it can be seen that 60 out of the 204 clients were administered Monopharmacy (1 drug for 1 condition). Out of these 60 clients administered Monopharmacy, 37 were community clients with the remaining 23 being residential clients. Of the variables examined Placement was the only variable which reached statistical significance with significantly more community clients being administered Monopharmacy than residential clients. This was the only variable in which significantly more community clients were administered a "drug category" than residential clients. It has to be noted however that the Mono, Poly and Copharmacy were not actually "drug categories", and that Monopharmacy, by its definition, was administration of 1 drug only. Hence as was expected, significance was reached in this variable by community rather than residential clients.

6.18 Bivariate Analysis: Model 1i Polypharmacy Drug.

Polypharmacy was defined as "the administration of 2 or more drugs for the treatment of a single condition/disorder". 62 clients in total were administered Polypharmacy - with 42 of these being residential and 20 being based in community facilities.

Table 6.25: A Table Depicting the Results of Bivariate Statistical Analysis Completed on Data Pertaining to Polypharmacy.

	Absent	Present	Test Statistic	p-Value
Sample Size	142	62		
Gender:				
Male	95 (66.9%)	42 (67.7%)	.000	1.00 NS
Female	47 (33.1%)	20 (32.3%)		
Placement:				
Community	53 (37.3%)	20 (32.3%)	.287	.592 NS
Residential	89 (62.7%)	42 (67.7%)		
Handicap:				
Mild	15 (10.6%)	6 (9.7%)	.516	.773 NS
Moderate	61 (43.0%)	30 (48.4%)		
Severe	66 (46.5%)	26 (41.9%)		
Age				
Av. Rank	105.41	95.83	3988.5	.2859
Median	34.0	32		

For this category of drug administration, no variables were of statistical significance. It was thought that placement would be a variable of significance but a considerable number of both residential and community clients were administered Polypharmacy so significance was not reached. Similarly with level of Learning Disability (Handicap), no significance was reached which showed that Polypharmacy was independent of level of Learning Disability, no matter what type (drug category) of Polypharmacy a client was administered.

6.19 Bivariate Analysis: Model 1j Copharmacy Drug.

Copharmacy was defined as "the administration of 2 or more drugs for the treatment of 2 or more conditions/disorders". The results of this analysis are outlined in Table 4.26 below:

Table 6.26: A Table Depicting the Results of Bivariate Statistical Analysis Completed on Data Pertaining to Copharmacy.

	Absent	Present	Test Statistic	p-Value
Sample Size	82	122		
Gender:				
Male	55 (67.1%)	82 (67.2%)	.000	1.00 NS
Female	27 (32.9%)	40 (32.8%)		
Placement:				
Community	50 (61.0%)	23 (18.9%)	36.005	.000 ***
Residential	32 (39.0%)	99 (81.1%)		
Handicap:				
Mild	12 (14.6%)	9 (7.4%)	16.311	.00029 ***
Moderate	47 (57.3%)	44 (36.1%)		
Severe	23 (28%)	69 (56.6%)		
Age				
Av. Rank	102.22	102.69	4979.0	.9556 NS
Median	32.5	33		

Again two variables came out as being of significance - Placement and Handicap. Placement was of significance in the fact that significantly more residential clients were administered Copharmacy when compared to community clients (p Value = .000) and when the Level of Learning Disability was examined, significantly more moderate and severe clients were administered Copharmacy than clients in the mild range. Hence

the more severe the level of Learning Disability, the greater the possibility that these clients will be administered Copharmacy.

6.20 Bivariate Analyses: A Summary of findings

To conclude this section on bivariate analyses, the table below (Table 6.27) is a summary table which shows each of the significant variables which emerged for each of the drug categories studied.

Table 6.27: Summary Table of Bivariate Analysis indicating the Variables of Significance for each Drug Category.

Drug Category Studied	Variables of Significance
• Hypnotic/Sedative	----------
• Antipsychotic Drug	*Placement and Age*
• Anxiolytic Drug	*Handicap*
• Antidepressant Drug	*Gender and Age*
• Antiemetic Drug	----------
• Anticonvulsant Drug	*Handicap and Age*
• Movement Disorder Drug	*Placement and Handicap*
• Monopharmacy	*Placement*
• Polypharmacy	----------
• Copharmacy	*Placement and Handicap*

As can be seen from the above table, there were only two actual classes of drug in which there was no variable of significance - Hypnotic drug and Antiemetic drug. Possible explanations for this result are discussed in the following chapter – chapter five. In addition, upon completion of data analysis, in the Polypharmacy category there was no variable of significance. In the remaining drug categories analysed, a variety of variables came out as being of significance, the most notable of these being *Handicap* (i.e. Level of Learning Disability) and *Placement* (i.e. Placement within the Services) as both emerged on four occasions throughout the analysis. When the Antidepressant class of drugs were analysed, *Gender* and *Age* were the two variables of significance and this was the only occasion when Gender was a significant variable. In conclusion, while many interesting results emerged from bivariate

analysis of this data set, the author will now report on the findings of multivariate analysis.

6.21 Multivariate Analyses

While bivariate analyses examines the variables within the data set in isolation or independently, multivariate analyses examines and analyses the entire data set in order to determine which variables are of significance when the complete set of variables are examined together (and not in isolation as with Bivariate analyses). Multiple regression allows one to find the best fitting and most parsimonious model to describe the relationship between the dependent variable and a set of independent or predictor variables, when the dependent variable is to be measured at the interval or ratio level (Hazard-Munro, 1993). However when the outcome measure is categorical, and there are more than two outcome categories then it is not possible to use multiple regression analyses. In relation to the usefulness of logistic regression analyses, Hazard-Munro states "people are reporting logistic regression, especially when the outcome measure is dichotomous ... logistic regression is better suited to the data, and the results include odds ratios that lend interpretability to the data. The odds of an outcome being present as a measure of association has found wide use, especially in epidemiology, because it approximates how much more likely (or unlikely) it is for the outcome to be present given certain conditions" (pp.229-230). In this respect multivariate analysis examines the predictive effect of a variable within the context of its covariance with other predictors, in addition to examining the potential interactions with other variables in the prediction of psychotropic/psychoactive prescribing decisions.

As can be seen from the above sections reporting the findings from Bivariate analyses, the outcome measures are categorical in that either a drug category is "present" or "absent" (i.e. either a person is prescribed a drug category or they are not). Just as in bivariate analyses and multiple regression, for the purposes of logistic regression, it was necessary to

code the categorical independent variables. Hence "dummy" (indicator) variables were designed and introduced in order to determine which actual variables were of significance. For the purposes of the present statistical analysis, only one set of "dummy" variables were designed and entered into the equation. The introduction of these set of "dummy" variables can be seen with the variable "Level of Handicap", in which there were three levels – Mild, Moderate and Severe. (The category "Severe" consisted of those clients in both the severe and profound ranges of disability as there were insufficient numbers in the latter category for the purposes of the present analyses). Because there were three levels of handicap, two dummy variables were set-up, Hand1 and Hand2. On the basis of this, a number of *IF-THEN* statements were developed and entered into the statistical equation. For example: *IF* level of handicap was equal to 1, *THEN* this was classified as "mild" in the statistical equation. However where the dummy variables were necessary was if level of handicap was greater than 2. In such a case, the dummy variables were necessary as they acted as a classification system in themselves. In the case of level of handicap being greater than 2, then the category of handicap was classified as being the combination of "severe" and "profound", hence it was classified as "severe". In this sense, the new variable Hand1 was 0 if the level of handicap was mild, and 1 if it was not mild, while the new variable Hand2 was 1 if the level of handicap was severe and 0 if it was not severe.

The equations used when dummy variables were incorporated were as follows:

Standard Equations	**Dummy Variable Equations**
IF handicap = 1, THEN handicap = 1.	Hand1 = 0 Hand2 = 0
IF handicap = 2, THEN handicap = 2	IF Handicap > 1, THEN Hand1 = 1
IF handicap > 2, THEN handicap = 3	IF handicap > 2, THEN Hand2 = 1

6.22 Stepwise Logistic Regression

The method of logistic regression analyses used in the present thesis was stepwise logistic regression. By this it is meant that each variable was taken and entered into the statistic equation in a stepwise manner. Depending on the number of variables that were entered into the equation, this is what determined the level of significance, when examined in conjunction with all other variables examined. As an example "age" could be of significance when "level of handicap" was entered, but when "Handicap" was removed from the equation, "Age" may no longer be of significance.

6.23 Stepwise logistic regression analysis: Hypnotic Drug

Table 6.28 below depicts the results upon completion of logistic regression analysis for Hypnotic Drug.

Table 6.28 A table depicting the results of stepwise logistic regression analysis for Hypnotic Drug.

Step No.	Variable entered	df	Log likelihood	*Improvement*		*Goodness of fit*	
				Chi-square	*P-Val*	*Chi-Square*	*P-Val*
0			*-67.626*			*100.876*	*0.980*
1	*Hand2*	*1*	*-65.419*	*4.413*	*0.036*	*96.463*	*0.990*
2	*Age*	*1*	*-62.199*	*6.440*	*0.011*	*90.023*	*0.997*

Interestingly from the above table, in contrast to Bivariate analysis, it can be seen that two variables were of significance when stepwise logistic regression was undertaken. These two variables were Hand2 and Age, which indicate that those in the severe range of learning disability were significantly more likely to be prescribed this drug category (Chi Square (1) = 4.413; p-value 0.036) than were clients in either the mild or moderate range of disability. In addition, younger clients were significantly more likely to be administered this drug category than were older clients in the service (Chi Square (1) = 6.440; p-value 0.011).

6.24 Stepwise logistic regression analysis: Antipsychotic Drug

Table 6.29 below depicts the results upon completion of stepwise logistic regression analysis for Antipsychotic Drug.

Table 6.29 A table depicting the results of stepwise logistic regression analysis for Antipsychotic Drug.

Step No.	Variable entered	df	Log likelihood	*Improvement* Chi-square	P-Val	*Goodness of fit* Chi-Square	P-Val
0			*-139.741*			*182.695*	*0.002*
1	*Place*	*1*	*-133.478*	*12.524*	*0.000*	*170.171*	*0.012*
2	*Age*	*1*	*-128.453*	*10.050*	*0.002*	*160.121*	*0.037*

From the above table, it can be seen that in a similar fashion to Bivariate analysis completed & reported earlier, the two variables which were of significance were Place 9placement within the services) and Age. The present findings indicate that clients within the residential services were significantly more likely to be administered an Antipsychotic drug than were clients who live in community facilities (Chi Square (1) = 12.524; p-value 0.000). As predicted from the literature, Age was also of significance in the present analyses, with younger clients more likely to be administered Antipsychotic medication than were older clients (Chi Square (1) = 10.050; p-value 0.002).

6.25 Stepwise logistic regression: Antidepressant Drug

Table 6.30 below depicts the results upon completion of stepwise logistic regression analysis for Antidepressant Drug.

Table 6.30 A table depicting the results of stepwise logistic regression analysis for Antidepressant Drug.

Step No.	Variable entered	df	Log likelihood	*Improvement* Chi-square	P-Val	*Goodness of fit* Chi-Square	P-Val
0			*-77.829*			*120.467*	*0.755*
1	*Gender*	*1*	*-73.918*	*7.821*	*0.005*	*112.646*	*0.875*

6.24 Stepwise logistic regression analysis: Antipsychotic Drug

Table 6.29 below depicts the results upon completion of stepwise logistic regression analysis for Antipsychotic Drug.

Table 6.29 A table depicting the results of stepwise logistic regression analysis for Antipsychotic Drug.

Step No.	Variable entered	df	Log likelihood	*Improvement*		*Goodness of fit*	
				Chi-square	*P-Val*	*Chi-Square*	*P-Val*
0			*-139.741*			*182.695*	*0.002*
1	*Place*	*1*	*-133.478*	*12.524*	*0.000*	*170.171*	*0.012*
2	*Age*	*1*	*-128.453*	*10.050*	*0.002*	*160.121*	*0.037*

From the above table, it can be seen that in a similar fashion to Bivariate analysis completed & reported earlier, the two variables which were of significance were Place 9placement within the services) and Age. The present findings indicate that clients within the residential services were significantly more likely to be administered an Antipsychotic drug than were clients who live in community facilities (Chi Square (1) = 12.524; p-value 0.000). As predicted from the literature, Age was also of significance in the present analyses, with younger clients more likely to be administered Antipsychotic medication than were older clients (Chi Square (1) = 10.050; p-value 0.002).

6.25 Stepwise logistic regression: Antidepressant Drug

Table 6.30 below depicts the results upon completion of stepwise logistic regression analysis for Antidepressant Drug.

Table 6.30 A table depicting the results of stepwise logistic regression analysis for Antidepressant Drug.

Step No.	Variable entered	df	Log likelihood	*Improvement*		*Goodness of fit*	
				Chi-square	*P-Val*	*Chi-Square*	*P-Val*
0			*-77.829*			*120.467*	*0.755*
1	*Gender*	*1*	*-73.918*	*7.821*	*0.005*	*112.646*	*0.875*

While bivariate analysis found two variables of significance in relation to the Antidepressant drug category (Gender and Age), upon completion of logistic regression analysis, which examined all variables, only Gender was of significance (Chi Square (1) = 7.821; p-value 0.005). The present finding indicates that female clients rather than males were significantly more likely to be administered Antidepressant medication. With respect to age, which was significant with bivariate analysis, it was not deemed to be a significant factor upon completion of stepwise logistic regression analysis.

6.26 Stepwise logistic regression: Antiemetic Drug

Table 6.31 below depicts the results upon completion of stepwise logistic regression analysis for Antiemetic Drug.

Table 6.31 A table depicting the results of stepwise logistic regression analysis for Antiemetic Drug.

Step No.	Variable entered	df	Log likelihood	*Improvement*		*Goodness of fit*	
				Chi-square	*P-Val*	*Chi-Square*	*P-Val*
0			*-27.069*			*42.990*	*1.000*
1	*Place*	*1*	*-24.463*	*5.213*	*0.022*	*37.777*	*1.000*

In Bivariate analysis, for the category of Antiemetic drug, no variable was of significance. In the present stepwise logistic regression analysis, one variable was of significance and this was Place (placement with the services), with significantly more residential clients than community clients being administered this form of medication (Chi Square (1) = 5.213; p-value 0.022).

6.27 Stepwise logistic regression analysis: Anticonvulsant Drug

Table 6.32 below depicts the results upon completion of stepwise logistic regression analysis for Anticonvulsant Drug.

Table 6.32 A table depicting the results of stepwise logistic regression analysis for Anticonvulsant Drug.

Step No.	Variable entered	df	Log likelihood	*Improvement*		*Goodness of fit*	
				Chi-square	*P-Val*	*Chi-Square*	*P-Val*
0			*-140.921*			*198.240*	*0.000*
1	*Age*	*1*	*-135.366*	*11.110*	*0.001*	*187.130*	*0.001*
2	*Hand1*	*1*	*-132.980*	*4.773*	*0.029*	*182.357*	*0.002*

In the case of the Anticonvulsant drug category, stepwise logistic regression yielded two variables of significance. These two variables were Age and Hand1. In the case of age, younger clients were significantly more likely to be administered an Anticonvulsant drug than were older clients (Chi Square (1) = 11.110; p-value 0.001), for the purposes of the control of epileptic seizures. The second variable of significance, Hand1, indicates that those clients with a greater than mild level of handicap were more likely to be administered this form of drug than were those in the mild range of handicap (Chi Square (1) = 4.773; p-value 0.029).

6.28 Stepwise logistic regression analysis: Movement Disorder Drug

Table 6.33 below depicts the results upon completion of stepwise logistic regression analysis for Movement Disorder Drug.

Table 6.33 A table depicting the results of stepwise logistic regression analysis for Movement Disorder Drug.

Step No.	Variable entered	df	Log likelihood	*Improvement*		*Goodness of fit*	
				Chi-square	*P-Val*	*Chi-Square*	*P-Val*
0			*-106.364*			*128.482*	*0.570*
1	*Place*	*1*	*-99.629*	*13.470*	*0.000*	*115.012*	*0.839*
2	*Hand1*	*1*	*-97.074*	*5.110*	*0.024*	*109.902*	*0.910*

Upon completion of logistic regression analysis for the category of Movement Disorder Drug, two variables emerged as significant in relation to this category. Place and Hand1. In relation to placement with the services, significantly more residential clients were likely to be administered a movement disorder (or Anticholinergic drug) than were community clients (Chi Square (1) = 13.470; p-value 0.000). In addition those clients with a greater than mild level of handicap were more likely to be administered this form of medication (Chi Square (1) = 5.110; p-value 0.024). Interestingly, and as will be discussed in the proceeding Discussion chapter, movement disorder drugs are primarily administered to delineate the side effects of antipsychotic medication, so it is not unusual for there to be an association between placement with the service for the variables of Antipsychotic Drug and Movement Disorder Drug, as significantly more residential clients were administered antipsychotic medication than were community clients.

6.29 Stepwise logistic regression analysis: Monopharmacy

Table 6.34 below depicts the results upon completion of stepwise logistic regression analysis for Monopharmacy Drug.

Table 6.34 A table depicting the results of stepwise logistic regression analysis for Monopharmacy Drug.

Step No.	Variable entered	df	Log likelihood	*Improvement*		*Goodness of fit*	
				Chi-square	*P-Val*	*Chi-Square*	*P-Val*
0			*-123.583*			*183.512*	*0.002*
1	*Place*	*1*	*-111.457*	*24.251*	*0.000*	*159.261*	*0.047*
2	*A*B*	*3*	*-107.231*	*8.453*	*0.038*	*150.808*	*0.082*
3	*A*B*	*1*	*-108.523*	*2.585*	*0.108*	*153.393*	*0.070*
4	*Age*	*1*	*-110.262*	*3.478*	*0.062*	*156.871*	*0.054*
5	*Gender*	*1*	*-111.457*	*2.390*	*0.122*	*159.261*	*0.047*

The category of Monopharmacy Drug, as can be seen from the above table, is the only category to emerge throughout the present analysis to show an interaction effect. Upon completion of bivariate analysis, the only variable to emerge of significance was placement within the services, with more community clients being administered monopharmacy than residential clients. However upon completion of logistic regression analysis, Place, Age and Gender emerged as the significant variables with an interaction taking place between Age (A) and Gender (B) (as depicted by A*B). Findings from this analysis show that significantly more community clients are administered monopharmacy (one drug only) than are residential clients (Chi Square (1) = 24.251; p-value 0.000). In relation to Age, for the purposes of the present model, older clients are significantly more likely to be administered monopharmacy than are younger clients (Chi Square (1) = 3.478; p-value 0.062). With the variable Gender, it is significantly more likely that female clients will be administered one drug only in comparison to male clients (Chi Square (1) = 2.390; p-value 0.122).

A significant interaction effect is also observable from the above table, between the variables of Age (A) and Gender (B). This can be seen from the stepwise analysis above with the interaction entering the equation at step 2 and 3, which indicates that at differing stages throughout the present analysis for Monopharmacy Drug, the interaction between gender and age was significant. A possible meaning for this interaction could be that as age increases, gender becomes a significant variable in that more older males may be prescribed monopharmacy, whereas younger males are more likely to be administered two or more drugs than are older males.

6.30 Stepwise logistic regression analysis: Copharmacy

Table 6.35 below depicts the findings upon completion of stepwise logistic regression analysis for Copharmacy Drug.

Table 6.35 A table depicting the results of stepwise logistic regression analysis for Copharmacy Drug.

Step No.	Variable entered	df	Log likelihood	*Improvement*		*Goodness of fit*	
				Chi-square	*P-Val*	*Chi-Square*	*P-Val*
0			*-137.455*			*202.939*	*0.000*
1	*Place*	*1*	*-118.316*	*38.277*	*0.000*	*164.662*	*0.025*

In terms of stepwise logistic regression analysis for the category of Copharmacy Drug, only one variable was of significance in the present model and that was Placement within the services. While bivariate analysis showed placement within the services and level of handicap as being of significance, when all variables were taken into consideration and entered into the statistical equation, only placement was of significance. Thus there were significantly more residential clients being administered copharmacy, than there were community clients (Chi Square (1) = 38.277; p-value 0.000). This finding is in line with the above analysis for Monopharmacy Drug, as in that case significantly more community clients were administered one drug (monopharmacy) than were residential clients.

6.31 Chapter Summary and Conclusions

As can be seen from the above set of findings, a different pattern of results emerged when all the variables were entered into the various statistical equations in logistic regression analyses. As noted in section 6.21, multivariate analyses examines and analyses the entire data set in order to determine which variables are of significance when the complete set of variables are examined together (and not in isolation as with bivariate analysis).

Table 6.36 below outlines the variables of significance for each drug category upon completion of stepwise logistic regression analyses.

Table 6.36 Variables of significance for each drug category upon completion of stepwise logistic regression analyses.

DRUG CATEGORY STUDIED	*VARIABLES OF SIGNIFICANCE*
1. HYPNOTIC DRUG	HAND2 & AGE
2. ANTIPSYCHOTIC DRUG	PLACE & AGE
3. ANTIDEPRESSANT DRUG	GENDER
4. ANTIEMETIC DRUG	PLACE
5. ANTICONVULSANT DRUG	AGE & HAND1
6. MOVEMENT DISORDER DRUG	PLACE & HAND1
7. MONOPHARMACY DRUG	PLACE, GENDER, AGE, INTERACTION EFFECT BETWEEN GENDER & AGE
8. COPHARMACY DRUG	PLACE

The usefulness of undertaking multivariate analyses can be seen from the above table as it shows the reader the actual variables of significance when all variables were entered into the statistical equation together, and not in isolation as with bivariate analyses. Rather than discussing these findings in the present chapter, the following chapter

will discuss these findings while also discussing the implications of these results when compared to previous research undertaken in this area.

CHAPTER SEVEN

DISCUSSION, CONCLUSIONS AND IMPLICATIONS FOR FURTHER RESEARCH

7.1 Chapter Introduction

Following the survey undertaken by Lipman in 1970, there has been a vast amount of interest generated in the issue of prescribing for people with a learning disability. The findings from Lipman's survey indicated that in excess of 51% of all people with learning disability in residential-type care were receiving some form of psychotropic drug with 39.2% currently receiving an Antipsychotic drug. Since the research of Lipman has been published, there have been numerous other publications on this topic with very similar results to those of Lipman (1970).

Aman and Singh (1991) note that "mentally retarded people are among the most medicated populations in our society" (p.348). These authors also note that on average, when one surveys the drug prevalence literature, between 30% and 50% of people with learning disability are prescribed some form of psychotropic drug mainly an Antipsychotic, 25% to 35% receive some form of Anticonvulsant drug, with 50 to 70% receiving some form of psychoactive drug (Aman and Singh, 1988; Branford, 1994).

Lynch (1989) notes that for people with learning disability, medication which affects the Central Nervous System (CNS) is now a commonplace practice. He states "when people with mental handicaps are considered as a group, they seem to be at even greater risk than other people of being placed on medication that acts on the CNS either directly or indirectly" (p.123). The reasons for this, are as yet, still unknown, but there are several factors which are of interest and importance. As Kalachnik (1988) notes, psychotropic drugs are prescribed primarily for the purposes of treating some form of psychiatric disorder - such as schizophrenia or alternatively for the purposes of producing behaviour control. However when one examines this statement, major disagreement lies with the notion of treating behaviour problems with medication ("chemical restraint") and how often this is appropriate.

The number of studies which have examined the factors associated with drug prescribing are increasing in recent times - the most notable of these being the study of Aman et al. (1995) in which 1,101 clients were surveyed in relation to their current medication and its association with demographic and psychiatric variables. More recently, the study of Gralton et al. (1998) found that on reviewing the use of Antipsychotic medication in children between the ages of 5 and 18 years, a positive relationship existed between a diagnosis of Autism and the prescribing of an Antipsychotic drug. The study of Bates et al. (1986) showed that when psychotropic prescribing was examined in terms of appropriateness for diagnosed conditions 55% of patients were inappropriately prescribed a psychotropic drug. In terms of the prescribing of psychotropic drugs for challenging behaviour and emotional problems, the findings of Tu and Smith (1983) indicate the six most common problems they found to be associated with psychotropic prescribing:- Aggressiveness (29%); Hyperactivity (24%); Self-injury (19%); Excitability (12%); Screaming (10%) and Anxiety (8%).

Clearly there is conflicting evidence when one compares the literature on psychotropic prescribing for A] Psychiatric disorders and B] Behaviour control/challenging behaviour. Although the rate of challenging behaviour is quite high amongst the learning disabled population (in general) especially so for clients in residential care, there is still a substantial number of clients in community care being prescribed a psychotropic drug. If one looks to the literature on prevalence rates of psychiatric disorders amongst those with learning disability, the prevalence of schizophrenia is not said to be in excess of 4% for clients in residential care (Reid, 1972; Heaton-Ward, 1977,; Wright, 1982). In terms of affective disorder, the figure is said to be less than 4% (Wright, 1982).

On examining the above figures, Wressell et al. (1990) note that "there is a substantial majority of patients receiving neuroleptics who do not have

an affective psychosis or schizophrenia ... (and) ... while neuroleptics are commonly used to treat mentally handicapped people with 'problem' behaviour, it is difficult to draw conclusions about the specific effects of these drugs" (p.101).

On the basis of some of the above concerns and due to the fact that the vast majority of published studies to date have been mainly in the USA and the UK, while also including New Zealand (White, 1983); Australia (Sachdev, 1991); Finland (Linaker, 1990) and Canada (Gowdey et al., 1984), it was felt that a drug prevalence survey undertaken in an Irish setting which would examine patterns of prescribing for clients with learning disability in both residential and community (non-residential) settings would be of interest and immense value.

7.2 Aims and Objectives of the present Study.

The main focus of interest for the present study was: 1] to gather information on all clients with the Brothers of Charity Services, Mid-Western region in both residential and community setting who were currently receiving some form of psychotropic and/or psychoactive drug. 2] To compare and contrast the patterns of prescribing for these two clients groups and to relate the findings achieved to published drug studies to date.

As stated above the present study was designed primarily to gather data on drug prescribing within an Irish Organisation so as to ascertain patterns of prescribing for both clients in residential and community settings. The study also served to contribute to the current knowledge of prescribing trends for clients with learning disability through screening virtually a complete population of clients in a residential and community setting. Such a technique is infrequently used in such research (very often data is based on sample populations).

Also of interest is the fact that varying figures of drug prescribing have been reported in the literature, depending on the country studied. As was mentioned earlier, Aman and Singh (1991) report an overall figure of prescribing of between 30 and 50%, but when this figure is analysed in greater detail, figures have been either quite high (Intagliata and Rinck, 1985 - 70% in Illinois) or quite low at 19% as was shown by the study of White (1983) in New Zealand. In all of the studies cited in the literature, no figures are given for any setting (residential or community) in Ireland. On this basis, it was felt that a comparison with the literature and figures to date was overdue and necessary.

One of the principle shortcomings of many of the drug prevalence studies to date is "one of breadth" (Spreat et al., 1997, p.80). By this it is meant A] studies have looked solely at clients in either residential or community settings only, and B] perhaps an area that is often not picked up on is that only certain classes of drugs have been examined (namely the Antipsychotics). The main problem with failing to examine all drug categories (i.e. all drugs affecting the CNS) is that comparison of data is difficult. Similar classes of drugs may be examined and compared in isolation but when one looks to an "overall" figure of prescribing for this population, quality "all-encompassing" data is difficult to find.

Due to the above consideration, it was felt necessary to gather data on all drugs affecting the CNS currently administered to clients in residential and community settings. On this basis data was collected on clients who were currently administered any drug(s) from the following classes of drugs:

Hypnotics
Anxiolytics
Antipsychotics
Antidepressants
Antiemetics
Anticonvulsants
Movement Disorders

By including all of the above classes of drugs, it was hoped that the present research would be a good indicator of providing a figure for overall rates of prescribing within the Organisation, as well as providing figures for each class of drug, while also answering some of the short-comings of past research.

7.3 Discussion of Results From The Present Study.

In all, 524 clients were reviewed in the present study. This amounted to a complete population of clients who were availing of a service within the Brothers of Charity, Mid-Western region. This population comprised of adults only, with the ages ranging from 18 to 75 years of age. All levels of learning disability from mild to profound were examined.

The total number of clients in residential care which were administered a psychotropic drug amounted to 131 out of 141 clients in total (81%). The corresponding figure for clients in community care was 73 out of 383 (33%).

The present study examined all psychotropic drugs administered to clients in the Mid-Western region. It was similar to the study of Branford (1994) in the fact that it examined all drug forms, and not drugs prescribed solely for the purposes of controlling behaviour - as was the study of Clarke et al. (1990). Therefore this study examined drug prevalence according to drug groups and not according to reasons for prescribing that drug.

The figures obtained in this study are consistent with drug prevalence figures from similar populations of clients undertaken to date. What is of interest however, is that degree to which psychotropic drugs are prescribed within our Organisation in the Mid-West. Figures obtained from the present study indicate that 81% of residential clients are administered a psychotropic drug and 33% of community clients are administered same. When one examines the figures obtained to overall average figures, one can see that the rates of prescribing are quite

elevated as average figures from a residential perspective amount to between 30 and 50%. From a community perspective, figures have amounted to between 20 and 36%. Quite clearly the residential figures achieved are quite alarming in terms of previous research. Figures from the community are within the average range but are still quite high in comparison.

Some of the major points of interest which emerged from the study are as follows:

7.3.1 Antipsychotic Medication.

On examining overall rates of prescribing of the Antipsychotics, figures have ranged from 30 to 50% (Aman and Singh, 1988). When one looks to the figures reported in the UK figures have tended to be somewhat lower - Fischbacher (1987) reports a rate of 32%, while the study of Wressell et al. (1990) reports a rate of 24%. As mentioned previously Clarke et al. (1990) examined prescribing of psychotropic drugs for behaviour purposes - they do not however report on the figures obtained for Antipsychotic drug prescribing.

In the present study, the author expected a high rate of prescribing for the Antipsychotic class of drugs - largely due to the fact that there is a high rate of problem behaviour in many of the bungalow settings within the residential facility. What we did not expect however, was the frequency in which Antipsychotic drugs were prescribed for these residential clients. In total 73% of our residential clients were administered some form of Antipsychotic drug. When one looks at this figure in some detail, it can be seen that out of the 141 clients in residential care, 103 were prescribed an Antipsychotic drug. When one looks to those residential clients who were administered any form of psychotropic drug (this amounted to 131 out of the 141 clients), the percentage of clients which were prescribed an Antipsychotic drug was 78%. The corresponding figure for community clients was 32% or 24 clients in total.

There is no doubt but this figure is alarmingly high and is one of the highest figures of Antipsychotic drug prescribing to be witnessed for some time. When one examines the figures of Lipman in 1970, great concern was expressed over the high rates of prescribing of psychotropic drugs in residential clients at the time. Lipman's findings showed that in excess of 51% were receiving some form of psychotropic drug and in terms of Antipsychotic drug prescribing, the figure was 39.2%.

Therefore, the present findings for antipsychotic prescribing in our sample of residential clients raise many questions in terms of the following:

A] Why the Antipsychotics were prescribed with such a high frequency.

B] the reasons for their use - behavioural or for mental illness??

C] the efficacy of prescribing such drugs to such a high degree.

D] On the basis of such results, there now seems to be a definite need for a formal review process to ascertain whether such drugs are required, whether they are advantageous to the client or whether such clients would benefit from alternative therapies.

These are the questions which need to be addressed with some urgency, in particular for residential clients.

In a similar fashion to similar studies published to date, the Antipsychotic drug which is most widely used is Thioridazine (*Melleril*) for both residential clients (White, 1983; Fischbacher, 1987; Wressell et al., 1990) and clients living in the community (Aman et al. 1985; Intagliata and Rinck, 1985; Lepler et al., 1993). The figures obtained in the present study for the use of Thioridazine for residential clients was 40.15% (53 clients) and for community clients 14.86% (11 clients). The two other Antipsychotics which were used quite frequently were Chlorpromazine (*Largactil*) and Haloperidol (*Serenace*), a finding again consistent with previous studies to date (Branford, 1994b).

7.3.2 Anticonvulsant Medication.

Figures cited for the prescribing of Anticonvulsants have ranged from 25 to 45% on average (Aman and Singh, 1989). UK figures to date show prevalence rates from 24% (Sheppard et al., 1987), 36% (Fischbacher, 1987) and Lynch (1989) found that on reviewing prescribing patterns from 1978 to 1987, the rate of Anticonvulsant prescribing increased from 48% to 51% in that 9-year period. Di Mascio (1975) reports a figure of 90% receiving 1 or more Anticonvulsant drugs.

Present figures obtained from the population base studied showed that of the 141 clients in residential care, 81 clients were currently receiving 1 or more Anticonvulsants drugs - when one examines this figure in terms of those receiving any form of psychotropic medication, the figure amounts to 61%. The corresponding figure for clients in community care amounted to 62 out of 383 or 16% overall. Out of the 73 community clients on any form of psychotropic drug, 62 clients (or 83.7%) were administered an Anticonvulsant. This figure shows that epilepsy is by far the most common problem/disorder which requires medication as epilepsy is one of those conditions for which medication is required or "essential" for the control of seizures.

Some Anticonvulsants, most notably Carbamazepine (Tegretol) has strong psychotropic properties and this drug is very often used as a means of "behaviour control" or for problem behaviour, because of such properties. In many studies because this drug is classified within the Anticonvulsant class of drugs, interpretation of prevalence figures can be problematic because of its variety of uses. In the present study however, this problem did not arise because any Anticonvulsant prescribed in this study was for the purposes of seizure control and not for problem behaviour.

In terms of the Anticonvulsant drugs prescribed, for both residential and community clients, Carbamazepine was the first drug of choice with Lamotrigine and Sodium Valproate being the next most frequently prescribed drugs. On a positive note, drugs such as Frisium and Phenobarbitone were not administered to any residential client, but in the community, these drugs were administered to a total of 8 clients (such drugs being noted for their negative side effects).

7.3.3 Hypnotic and Anxiolytic Medication.

In the present study, Hypnotic drugs were prescribed to 17 residential clients, with only 4 clients in the community being administered same. Of the variables examined in relation to this class of drug, none were of significance. This finding was also borne out by the study of Branford (1994a).

The Anxiolytic drugs were prescribed to an even lesser extent in the present population. Only 6 clients in residential care, and 5 clients in the community were administered any form of Anxiolytic drug. Present findings would suggest that a greater proportion of severe and profound clients were administered such drugs in comparison to the higher ranges of learning disability.

The Committee on Safety of Medicines (1988) - CMS has expressed some concerns over dependency on such drugs and the problems associated with withdrawal. The study of Aman et al.(1995) found a lack of specific diagnosis in relation to the prescribing of Anxiolytic drugs - they state that "the absence of an association between anxiety disorders and the use of Anxiolytics is curious and raises the question of whether practitioners tend to discount internalising problems in people with mental retardation" (p.507). In this sense, it could be the case that the rates of anxiety disorder may be grossly underrepresented in this population, although it is strange that in the population studied, the

variable which was of significance was level of learning disability in that people with a more severe level of LD were more likely to be administered an Anxiolytic.

7.3.4 Antidepressant Medication.

As was mentioned earlier, gender is a variable which is generally not of significance in terms of psychotropic prescribing. This said however, the present study found an association between the prescribing of Antidepressant medication and gender. Age was also of significance. Gender was a significant variable in that significantly more females were administered this class of drugs in comparison to males.

Age was of significance in this study in that older clients were much more likely to be administered an Antidepressant than were younger clients. A possible interpretation of such a finding could be that there is a greater occurrence of depressive-type disorders in older clients - especially in clients with Down's Syndrome where there is a higher prevalence of Alzheimer like changes. Despite such a finding, caution is urged as the present study is a single isolated study, bearing in mind that the majority of research to date has found no relationship between prescribing (of any form of drug) and gender.

7.3.5 Movement Disorder and Antiemetic Medication.

The Antiemetic class of drugs were administered to only 6 clients in residential care, with no client in the community being administered same. Hence no variables were of significance in relation to the Antiemetics.

In relation to the Movement Disorder class of medication, this category of drug consisted solely of the Anticholinergics - drugs prescribed in order to counteract the extrapyramidal side effects of the Antipsychotics. As

was expected, because there was a high rate of prescribing of the Antipsychotics, there was a considerable number of residential clients administered such drugs - 44 in total. Only 6 clients in the community were administered such drugs. On the basis of this result, Placement was of significance as more residential clients were administered Anticholinergic medication in comparison to clients in the community. In addition significantly more moderate and severe clients were on such medication in comparison to those within the mild range of learning disability.

7.4 Chapter Summary and Conclusions.

There has been widespread concern over the use of psychotropic medication for people with learning disability. Such concern has grown due to the fact that many clients were being grossly overmedicated (over prescribing), the practice of polypharmacy was, and still is widespread, irrational prescription practices are frequently in practice and due to inadequate reviews of medication, prolonged and unnecessary drug treatment is still in operation (Fan, 1991).

Despite the vast amount of research and experimentation conducted into the effects of psychotropic medication, and especially Antipsychotic medication, there remains little evidence that such drugs are of benefit to clients with challenging behaviours. However, the fact remains that the Antipsychotics are widely prescribed to clients with challenging behaviour as a means of trying to reduce such behaviours.

The present study was undertaken in order to gather information on all clients within our Service who were currently receiving any form of psychotropic drug. We then wanted to compare and contrast the patterns of prescribing for residential and community clients and to relate the findings to previous research.

Several points of interest emerged from the present study. If one looks to each drug class examined, the present findings are similar to many other studies to date. The Hypnotics and Anxiolytics were prescribed to a minimal degree. Whether such findings are an accurate reflection on the presence or absence of Anxiety disorders remains to be seen in this population of clients. However these results are consistent with the findings in the UK of Branford (1994) and Aman et al. (1995) in the USA.

The use of Antipsychotics in this population needs to be addressed with some urgency. The fact that 103 out of a total of 141 clients in a residential setting are prescribed one or more Antipsychotics certainly raises many questions with regard to the efficacy of such frequent use. Clearly there is a great need to develop specific guidelines and review procedures in terms of the prescribing of Antipsychotic drugs.

In relation to Antipsychotics and the present study in general, one of the major flaws and methodological failings was that "reason for use" of any medication prescribed was not collected. The Antipsychotics are one class of drug whereby it would have been necessary and essential to collect such information. The question now remains whether clients are prescribed Antipsychotic medication as a means of controlling behaviour or to alleviate the symptoms of mental illness. Either way, Antipsychotic medication was prescribed to clients in residential care to a very high degree. Whether such a rate of prescribing could be seen to be excessive remains to be answered. What is now required is a study to determine whether such prescribing is both necessary and appropriate, and if not, how it can be reduced.

Resulting from the high rate of Antipsychotic drug prescribing, there was also a high rate of prescribing of Anticholinergic medication in our residential clients. Drug studies to date have tended not to report the figures for Anticholinergic medication, so comparison of results is extremely difficult. Branford (1994a) reported a rate of Anticholinergic

prescribing of 24 and 29% (for 2 different settings). Findings from the present study showed that for residential clients, 44 out of 141 were administered such drugs, while for clients in the community, the figure was just 6 clients (8.1%). The study of Hill et al. (1985) which examined a sample of community clients found a rate of Anticholinergic prescribing of 4.2%. Other studies to date have reported rates of between 2% (James, 1983) and 15.4% (Fischbacher, 1987).

In respect to Anticholinergic prescribing, it would be of interest to see if the rate of prescribing of these drugs would fall in proportion to a decrease in Antipsychotic prescribing. A point also worth receiving interest is that the Antipsychotic drug Thioridazine is a drug associated with a minimal amount of extrapyramidal side effects (Branford, 1994a). This if Thioridazine is used as the Antipsychotic drug of choice (as is the case in the present study), there is less need for the presence of Anticholinergic medication and due to these two factors, Branford (1994a) states that these "should both be predictors of a low prevalence of Anticholinergic drug prescribing" (p.584). However in the case of the present study, this does not seem to be the case as there is both a high prescribing rate of the Antipsychotic drug Thioridazine and the Anticholinergic class of drugs.

The Anticonvulsants are a drug class which are often prescribed to a high degree in the learning disabled population. These drugs are seen as "necessary" in the fact that they are required in the control of seizures. Withdrawal of such medication will invariably lead to an increase in seizure pattern. The main problem with regard to the Anticonvulsants is that there is a high rate of polypharmacy (2 or more drugs) and the need for same is very often not warranted.

Rather than examining rates of polypharmacy (2 or more drugs from the same class) and copharmacy (2 or more drugs from a different drug

class) for each individual drug class, we examined the overall rates for each.

Again comparison of results from research to date is difficult as different definitions of polypharmacy and copharmacy have been used. For example if polypharmacy is defined as administration of 2 or more drugs in the treatment of one condition, it can have a very different result than if polypharmacy is defined as the administration of 2 or more drugs from the same drug class. In the present study the latter definition was adopted largely because we were not able to ascertain the reason for use of each drug for all individuals in the study. In this respect, it is difficult to compare the present results achieved to research to date.

If one examines the rates of copharmacy in our population, one can see that copharmacy extended up to, and included a 7-drug combination for one client in residential care. For those in the community, the majority were administered 1 drug only (monopharmacy - 45%), with 1 client being administered a copharmacy of 5-drugs. The rate of copharmacy administered is another area which needs to be highlighted and addressed urgently and one needs to be cautious in terms of which definitions one incorporates in future research of this kind.

To conclude many issues have been highlighted in the present piece of research. The most notable of these is the fact that a high percentage of clients in residential care are administered Antipsychotic medication and the prescribing of such medication to such a degree must be called into question.

Very different patterns of prescribing emerged when clients in the community were compared to clients in the residential facility. In all drug classes examined, there was a greater percentage of residential clients administered each drug in comparison to clients in the community. Such a finding is consistent with the many drug prevalence studies to date.

Perhaps the point, which must be emphasised most, is that there is a great need for the setting-up of an interdisciplinary team in order to undertake formal reviews of all medication prescribed.

Whereas much of the research to date has focused on the Antipsychotics, the present study shows that there is widespread prescribing of all types of medication, some to a greater degree than others, especially in residential clients. Constant reviews are required in order to determine if such prescribing is excessive, appropriate or necessary for the clients in our care.

PART TWO

CHAPTER EIGHT

ISSUES IN MEDICAL DECISION MAKING

8.1 Chapter Introduction.

The issue of decision-making is a very significant element in relation to medicine and, the topic under study in the present thesis, prescribing and mental health. Not only has the mental health professional to assess and diagnose the patient, but they also have to plan an appropriate treatment plan for that patient. The patient on the other hand has to decide whether he or she wants to seek help for their problem in the first place, and secondly depending on the course of treatment suggested, the patient may, or may not adhere to the treatment plan formulated and suggested by the mental health professional. At all times during the above process, decisions have to be made on the part of the professional and on the part of the patient and this decision process is a combination of a complex inter-play of factors. All decisions which are made, have an impact and they determine the quality of care provided for the patient and at what cost to the service, to the state or to the individual.

The present chapter reviews the current literature on decision-making in health care. It seeks to provide an overall basis for issues addressed and discussed in later chapters of this thesis, specifically chapter nine. While the present chapter should not be viewed as an all-encompassing overview of medical decision making, its specific aim is to provide the reader with a brief overview of this topic, prior to discussing specific studies of prescribing in general practice, in the following chapter, chapter nine. Although a limited literature exists on the topic of decision-making within Psychiatry and learning disability, the author will refer to a number of studies whereby similarities may be drawn between prescribing for the general population and prescribing for persons with learning disability. In essence it is vital to have an understanding of the concept of decision-making and its theoretical underpinnings in attempting to understand and study decision-making as applied to specific populations. The present author will firstly give an overview of research in decision-making. Secondly the issue of shared decision

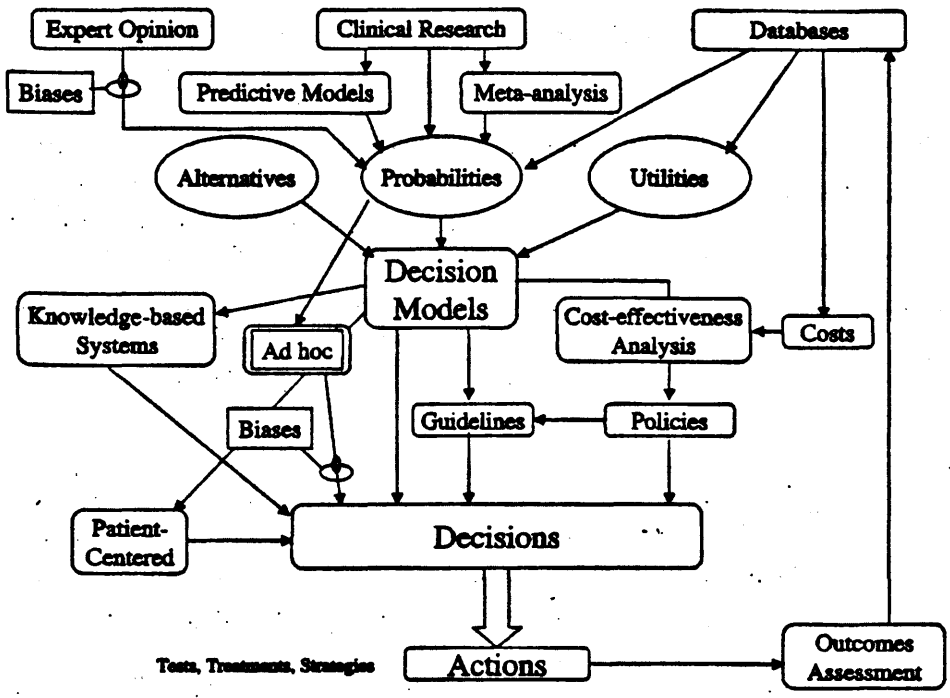
making in medicine will be discussed before moving onto a discussion of team decision making, a process which is frequently used, yet poorly researched within the field of learning disability.

8.2 Elements of Medical Decision-Making.

Chapman & Sonnenberg (2000) distinguish between three different forms of decision research – normative, descriptive and prescriptive models. Normative decision research asks the question of how best decisions can be made. The descriptive question asks how decisions are actually made, while the prescriptive question asks how decision theory can be utilised to improve decision making (p.3). For the purposes of the present thesis, the author is specifically interested in how decisions are made and the psychological aspects of this decision making. In making any decision, the clinical is armed with a host of information about the patient, ranging from the patients history, their behaviour and in many instances results from psychometric assessments or laboratory tests. In forming a decision, the clinician has to use all the information provided and balance "the severity of a possible bad outcome with its low probability" (Chapman & Sonnenberg, 2000). Where relevant all the available information must be used in order to formulate a diagnosis for that patient and plan a treatment programme. In cases where contradictory evidence may appear, differential diagnosis should be undertaken and alternatives ruled out. Especially in the case of decision-making in mental health, many difficulties arise in terms of difficulties with diagnostic accuracy, how best to use the information at hand and how best to plan a course of treatment. Very often, the clinician is relying on third-party reports , which are well known for their inaccuracy and many seemingly standardized assessment tools have been criticised for their poor reliability and validity (Faraone & Tsuang, 1994). In such cases making appropriate and accurate decisions can be difficult and subject to many biases (Miller et al., 2000). These issues will be discussed later in the present chapter. Firstly the author will present an overview of the many elements that are part of medical

decision making. Figure 8.1 below (taken from Chapman & Sonnenberg, 2000) gives a graphic representation of the elements of medical decision making.

Figure 8.1: Diagrammatic representation of the elements of Medical Decision Making.



From the above figure, it can be seen that many elements exist in the above equation. Resulting from a decision is an action which may be a specific treatment, a form of test or a combination of the two. In coming to a decision, a number of specific factors may come into play. In a large number of cases, decisions may be made in an ad hoc manner, where the clinician relies upon his or her knowledge or their experience in treating similar cases, what it is their colleagues do within their service and what their level (and style) of training has been. In addition to such factors, clinicians are guided by clinical guidelines,

policies and procedures, patient-centred approaches and knowledge-based systems (Chapman & Sonnenberg, 2000). For each decision model employed there are a number of direct inputs which may be alternatives, probabilities or utilities. Probabilities may arise directly from expert opinion (which may be subject to biases), clinical research, or clinical research which has been modified by predictive models or meta-analysis. Utilities in turn may be obtained from databases of outcome measures rather than scientific research per se.

8.3 Decision Analysis in Medical Decision-Making.

Decision analysis is increasingly used to address difficult medical problems. It is an effective technique which over the past two decades, has been receiving increasing interest in the medical literature but perhaps more importantly is being utilized more frequently in terms of clinical practice (Sarasin, 2001; Pauker & Kassirer, 1987; Eckman & Kassirer, 1991, Sarasin et al., 1995 and Bennett et al., 1997).

Clinical decision analysis has been defined as "an explicit quantitative, prescriptive approach to decision making under conditions of uncertainty. The process breaks the problem into its component parts which are represented in the form of a decision tree. The likelihood of chance events is represented by explicit probability values. The desirability of outcomes is expressed by utility values. Using this structure, the component parts of the problem are analysed and recombined in a systematic way to suggest a decision" (Dawson & Cebul, 1990, p.52).

Essentially decision analysis is the quantitative application of probability and utility theory to decision making under conditions of uncertainty. Within the clinical practice of medicine, many decisions involve little doubt and the resulting treatment or test employed reflects a "tried and true" approach which is based on a sound clinical and empirical rationale. However as is noted by Sarasin (2001)

if the "optimal approach" is unclear, or the scenario faced by the clinician is a unique one, then a formal analysis in the form of clinical decision analysis is warranted. In such cases where a difficulty arises, decision analysis can examine the "trade-off" between the risks and benefits of testing (Bennett et al., 1997), of subsequent treatment (Eckman & Kassirer, 1991), while also synthesizing data from diverse sources and considering multiple attributes of health outcomes. As stated by Sarasin (2001) decision analysis "provides insight into the dynamics of a decision problem and allow us to analyse the impact of changes in either our assumptions or the data used in the analysis" (p.172).

Quantitative techniques have been used increasingly to aid clinical decisions for both individual patients and also for groups of patients. Such techniques have also been used in formulating health policies and advances in these techniques have given a greater fidelity to the many problems that they simulate (Dawson & Cebul, 1990). Advances in clinical decision analysis has allowed for far more detailed analysis of complex medical problems and with the advent of decision trees and sub-trees, models which are far greater in scope and depth can be generated.

In many complex medical decision making cases, physicians may perform poorly if they rely on their own clinical judgement. The concept of relying on one's own intuition will inevitably lead to a bias and over-simplification as the clinician cannot simply incorporate all components of a decision at once (Dawes et al., 1989; Kassirer, 1989). Hence the usefulness of clinical decision analysis. Clinical decision analysis involves a total of seven steps. These seven steps taken from Sarasin (2001) can be summarized as follows:

1. The question is framed precisely and explicitly.

2. The problem is structured in a type of flow diagram called a decision tree, which consists of three basic types of events (choices, decision points), chances and outcomes.

3. For each chance event, estimate the probability or range of probability of it occurring.

4. Place all outcomes on a single scale to provide a relative ranking of their utility or disutility.

5. Calculate the best strategy using two rules:- when a choice is possible, take the option with the highest expected utility; at chance events, assign the utility to be a weighted average of the utility of all possible outcomes, in which the weighing factors are the probabilities of each event's component.

6. Examine all the assumptions of the analysis and vary the central ones over clinically plausible ranges to determine whether this affects the apparent best choice. This is termed a sensitivity analysis.

7. Interpretation of results.

In terms of the interpretation of results, in the case of prescribing a certain drug type, the clinician may decide on the basis of the above steps to either a) prescribe the drug, b) withhold the prescribing of the drug or c) a very close call in which case it makes little difference which option is chosen. In deciding on an option, one has to take into account the size of the difference between the options in the equation. In cases where there is very little difference, it is then between the patient and the physician to weigh up the options and determine which is best for the patient. Resultant outcome values may be expressed as life years, quality-adjusted life years (QALY's), causes of the disorder or

complications prevented or utilities. A utility may be defined as "a measure of a decision maker's relative preference for an outcome, expressed as a single value between zero and one, usually assessed relative to two extremes" (Sarasin, 2001, p.173).

As a tool in decision making, decision analysis is being used more frequently over the past two decades. It has not however, been without its criticisms. Initial concerns included the excessive amount of time that decision analysis can take in forming a decision, the use of incomplete or inappropriate data and the failure to use meaningful utilities (Schwartz, 1979, Cebul, 1984; Dawson & Cebul, 1990). However each of these criticisms during the 1980's has since been rectified with the use of large computer databases, the development of computer programmes to assist decision analysis, and while the issue of utilities may be difficult, they are superior to clinician perceptions (Elstein et al., 1986). The assumption that utilities remain constant over time has also been challenged and the debate still continues as to whether this is the case or not (Chapman & Sonnenberg, 2001).

In essence the purpose of research in medical decision making is to ascertain how decisions are made and to inevitably improve the outcomes of decisions for patients. To study clinicians or physicians as information processors is important as the majority of decisions are made by clinicians based on their judgements. If one knows how such decisions are made then it is possible to study how such decisions may be improved. In addition, by studying how experts make decisions or judgements, it is possible to further comprehend what elements of the decision problem experts' focus on. Such research has implications not only in terms of the treatment strategy employed but also in terms of estimates of prognosis and predictions of disease.

To conclude this section on clinical decision analysis, what has been presented has been an overview of the technique of decision analysis. Decision analysis

has proved most useful in settings where there is greater than usual uncertainty, poorly established efficacies of treatment, situations where a patients preferences are critical and unique or rare instances where novel problems are encountered (Plante et al., 1986). Although the aim of the present section was not to provide the reader with a detailed overview of the literature, it does give a broad overview of the technique of clinical decision making and its usefulness as applied to medical decision making. The next section to be examined is the area of shared decision making. This will be discussed prior to discussing decision-making processes within the discipline of psychiatry or team decision-making, which is commonly undertaken within the field of learning disability.

8.4 Shared Decision Making.

The opening sections of the present chapter are largely based on the more traditional paternalistic model of decision making, which place emphasis on the doctor making the decision for the patient. This model of decision-making is increasingly becoming outdated (Stephenson et al., 2000) and the role of the patient in this decision-making process is becoming more emphasized, through patient-centred models of care. Shared decision making may be defined as "a process by which patients and providers consider outcome probabilities and patient preferences and reach a health care decision based on mutual agreement. During the process the provider-patient dyad considers treatment options and consequences and explores the fit of expected benefits and consequences of treatment with patient preferences for various outcomes" (Frosch & Kaplan, 1999, p. 285).

Over the past number of decades there has been a significant emphasis placed on the patient becoming more involved in decision making. While more paternalistic models of decision making do not involve the patient, shared decision making moves away from this model and places emphasis on the role of the patient in the decision process. While informed consent and providing the

patient with facts about the procedure to be undertaken are essential components of any treatment plan, shared decision making involves informing the patient about all treatment options and consequences and how these options fit with the patients preferences. Once all these options and consequences are discussed, a treatment decision can then be made on mutual agreement (Charles et al., 1997).

While shared decision making has many similarities with patient centred medicine, the main difference between the two approaches is that shared decision making includes the patients active involvement in any treatment decision (Katon & Kleinman, 1981; Coulter, 1997; Charles et al., 1997). The main characteristics of shared decision making may be outlined as follows:

1. the atmosphere must be conducive to active patient participation.
2. the physician must make patients feel that their contributions are valued.
3. Patients need to be honest about their preferences and goals for treatment
4. the physician assists the patient in determining how the patients goals fit with available treatment options.
5. an agreement is reached on which treatment option to implement.

Although not all patients may wish to be involved in decision making about their condition, it is still very important to get the views and wishes of the patient and take these into consideration prior to a decision being made (Guadagnoli & Ward, 1998).

8.4.1 Patients involvement in decision making.

In taking into account the above factors, it raises the question of the extent to which patients wish to be involved in the decision making process. Studies from the early 1980's onwards have examined the extent to which patients wish to be

involved in treatment decisions. The study of Cassileth et al. (1980) examined the extent to which patients with cancer wished to be involved in decisions about the treatment. While most patients expressed a wish to be involved, clear age differences emerged. 87% of those aged between 20 and 29 years expressed a preference to be involved in decision making while in those aged 40 to 59 years, this figure fell to 62%. In those aged over 60 years, this figure amounted to 51%. In addition patients who had feelings of hopelessness and despair were less likely to be involved in decision making about their condition.

Strull et al. (1984) studied hypertensive patients with a mean age of 59 years regarding decision making about their condition. Of those studies 19% expressed a wish to be involved in this process of decision making. 41% of participants in the study would have preferred more information about their condition and overall physicians were found to be poor judges about their patients need for information and discussion about their condition. In 28% of patient-physician encounters, the physician underestimated the patients desire for discussion regarding treatment. Interestingly in terms of socio-economic statues, the study of Pendleton and House (1984) found that low-income inner city diabetic patients had little interest in decisions about their medical treatment for their condition and in a similar fashion Ende et al. (1989) found that their was a low level of interest in medical decision making among general practice outpatients, as assessed by means of a questionnaire. Of these patients studied, younger patients showed a greater interest in medical decision making than did older patients. In a follow-up study, Ende et al. (1990) studied preferences in medical decision making when the patients themselves were physicians. While statistically significant differences emerged between physician-patients and non-physician controls, findings were deemed as of "minor importance". In the above two studies, the authors concluded that as the medical condition under study became more serious, the desire to become involved in decision making declined.

In 1997, Mazur and Hickam studied patients desire to become involved in shared decision making, when treatment involved an invasive medical procedure such as surgery. 68% of patients studied showed a preference for shared decision making and similar to the studies discussed earlier, interest in shared decision making declined with patient age. The study of Waterworth & Luker (1990) found that patients were not interested in becoming involved in shared decision making and based on interviews conducted with twelve patients, these patients preferred to comply with their physicians judgments in order to avoid negative repercussions by other hospital staff.

Upon reviewing these studies on shared decision making, there is a substantial volume of evidence to suggest that shared decision making is not feasible in many cases, while in others, patients simply do not wish to be involved in this process. On reviewing such findings, Deber (1994a, 1994b and 1996) suggests that many such studies fail to recognize the differences between medical problem solving and medical decision making. In the case of medical problem solving, the treatment of any medical problem involves diagnosis and formulation of treatment alternatives. These specific tasks require much expertise on the part of the physical and such tasks are the role of the physician and precede actual decision making. Medical decision making on the other hand involve the criteria outlined earlier in this chapter and such criteria involve both the physician and the patient. Hence in this respect, many of the studies which have apparently examined shared medical decision making, have in fact not differentiated between medical problem solving and medical decision making. On this issue Kaplan (1991) distinguishes between treatment outcomes – which should be in the control of the patient, and means to these outcomes – which is the role of the physician (treatment options).

Of those studies which have found that patients are not interested in the process of shared decision making, few if any, have recognized that most lay people feel that medicine is an exact science and that there may in fact be a number of

possible treatment options, rather than just one. Many patients may feel that the option which was outlined to them by their physician is the only option available. As a result there is a need to educate patients regarding treatment choices and how such choices can affect their treatment outcome (Barry et al., 1995).

To conclude this present section on shared decision making, there is conflicting evidence regarding the extent to which patients wish to be involved in shared medical decision making. While a considerable number of patients do wish to be involved in this process, a significant number do not wish to do so. The distinction between medical problem solving and medical decision making is an important one, and one which needs to distinguish between the technical aspects of problem solving (which are the role of the physician) and the decisions which involve treatment outcomes (involving both patient and physician). Interestingly what can be drawn from the literature is the fact that younger patients seem to be more involved in the decision making process than older patients, and this finding has important implications as life expectancy increases. On a positive note, the research of Greenfield et al. (1985; 1988) has shown that patient attitudes in medical encounters are readily changed and increased participation in medical decision making has a positive effect on treatment outcome. Such studies showed that where patients were more involved in decision making, they were more assertive with their physician, elicited more information from their physician and ultimately had an improvement in subjective well-being and lost fewer days of work to their illness. The increasing use of decision aids for patients and shared decision programmes is proving useful but there is a need undertake systematically designed randomised trials in order to determine their true effectiveness. In addition shared medical decision making under stress and shared medical decision making involving the family has not been addressed in any great detail. Interestingly for the purposes of the present thesis, this is an area of interest as in many clients with learning disability, shared decision making does not occur frequently and where family members are involved, it is often

after the decision has been made, either by an individual or by the team, that family are involved or informed.

As a result of this the next area to be addressed in this chapter is the issue of team medical decision making and how groups make decisions.

8.5 Team medical decision making.

While a large volume of research and data has been produced on how individuals make decisions and the factors which are involved (Elstein et al., 1978; Miller et al., 1982), in more recent times, there has been growing interest into decision making in the group context and whether decisions made in groups are superior to those made by individuals (Christensen & Abbott, 2000). One of the principle implications of the question of whether group decision making is superior to individual decision making is whether organizations should place more emphasis on group decision making. From the research to date, it has been strongly supported that group decision making does out-perform individual decision making (Hill, 1987; Vollrath et al., 1989; McGrath, 1984), although Christensen & Abbott note that in relation to group decision making "decisions are often not as good as they theoretically might be" (p. 268).

On reviewing the literature on the topic of whether groups make more accurate decisions than individuals, Kerr et al. (1996) found that there is no answer to such a question. While a "gold standard" (or agreed upon outcome) might apply to certain areas of medical decision making, this is not the case within decision making in psychiatry (Farone and Tsuang, 1994). Kerr and colleagues found that the biases that occur in individual decision making also apply to team decision making and the presence or error was based on a number of factors including a) size of the group, b)magnitude of the individual bias, c) location of the bias, d) definition of the bias, e) the normative ideal and finally, f) the nature of the group process (Kerr et al, 1996; Christensen & Abbott, 2000).

When examining team decision making, as opposed to individual decision making, two factors are of significance. Firstly in team decision making there is a far greater emphasis on distribution of information as instead of being undertaken by on individual, within a team it is carried out by different persons. Hence workload is shared and a larger amount of information may be disseminated. In a similar fashion to what was mentioned in shared decision making, the issue of medical problem solving is now undertaken by a group of physicians or clinicians, each with their own areas of expertise and each with their own information about a particular case. It is the sharing and integration of all this information which is important in team decision making. In integration all this information, it raises the issue of shared versus unshared information about a patient. In the case of shared information, all physicians would have read all information about a particular patient, whereas with unshared information, perhaps only one or two physicians in the team have read all the information. Research to date has suggested that team decision making over-relies on shared information, while unshared information is not discussed in as much detail, and may not be considered in the decision making process (Larson et al., 1994; Stasser, 1991; Stasser & Titus, 1987).

The other important factor in team decision making is the issue of each team members characteristics. In any team, a wide variety of expertise and backgrounds are brought together. Different team members have had different levels of training and build up expertise in a range of different clinical settings. Ones status within the group is an important factor and is generally based on one's level of training and subsequent experience. As is noted by Christensen & Abbott (2000), although status is no guarantee that effective decisions will be made, the evidence to date does suggest that high status groups have more influence than low status groups (Davis, 1980; Kirchler & Davis, 1986).

The dynamics of the group are also of significance in how decisions are made. Gender and ethnic background are increasingly impacting on team decision

making. The greater number of female graduates in medicine has changed the more traditional group dynamics in medicine, while the research on ethnic background has suggested that culturally diverse groups make more conservative decisions than do culturally homogenous groups when examined from a non-medical perspective (Watson & Kumar, 1992). This has important implications in everyday practice as there are an increasing number of ethnically diverse groups operating within the medical services and also within medical training facilities.

8.5.1 Team decision making and disability issues.

The issue of disability, be it physical or learning disability is an area where team decision making is very much in evidence. Despite multidisciplinary team decision making taking place, this is an area which has largely been ignored by the scientific literature up until recently. In particular the issue of disability assessment is an area which involves the multidisciplinary team (Davie, 1993; Rosenfield & Gravois, 1999; Ysseldyke et al., 1982). According to Bartolo et al. (2001) "the recommended assessment procedure is transdisciplinary, consisting of the simultaneous assessment of the child by professionals by different disciplines. This should lead to a comprehensive undertaking of the child's difficulties, involve the parents closely, and be linked to intervention" (p.499).

Salvia & Ysseldyke, (1991) note the importance of team decision making in the assessment of disability as such decision making has important implications for the child's life opportunities and indeed for the parents of the child. Such decisions need evaluation not only in terms of life opportunities but also in terms of cost effectiveness for such teams (Gutkin & Nemeth, 1997). While much of the research to date on this topic has been based on inconsistency, bias and unhelpfulness of team decision outcomes, clear objective outcomes are needed (Glaun et al., 1998).

Such naturalistic team assessment decisions according to Woods (1993) are better evaluated on the basis of the quality of the decision making process rather than on any other criteria. The issue of ecological validity in any such assessment is of importance as laboratory-type research has not taken into account such ecological issues (Zsambok, 1997). The research of de Mesquita (1992), Ysseldyke et al. (1982) and De Bruyn (1990) have criticized team decision making processes for not following rational organizational group decision making procedures. These authors suggest than such processes such as case conferences should follow the sequential diagnostic procedure of: Complaint -> Problem -> Diagnosis -> Treatment. They suggest that many teams do not follow this logical sequence of steps and so their team decision making may be inaccurate, may not take into account all possible alternatives and may decide on a particular placement despite such a placement being rationally inconsistent with clinical findings (Zsambok, 1997).

To quote Elstein (1995) "clinical decisions will continue to be made by clinicians using their best judgement, and it is crucial to understand their judgement and decision processes better" (p.1). In this respect there is a need for further research on the topic of decision making, not only in the assessment of disability but also in terms of many other areas of disability, such as placement issues (deinstitutionalisation) and more specifically in relation to the present thesis, how decisions are made in relation to mental health issues – both diagnosis and treatment issues.

Moving on from the issue of team decision making, the author will now briefly review issues pertaining to decision making in psychiatry and the many problems which emerge in relation to diagnosis of psychiatric problems in the general population. Such a discussion will prove useful in light of the fact that many of the problematic issues which are inherent in psychiatric diagnosis in the general population are also very much in evidence in persons with learning disability, and possibly to an even greater extent. Hence as mentioned in chapters two and

three of the present thesis, diagnosis of mental health problems in persons with learning disability is exceptionally difficult and how decisions are made in relation to mental health problems in the general population is important in our understanding of decision making for persons with learning disability.

8.6 Issues in diagnostic decision making in psychiatry.

Since the advent of the Diagnostic and Statistic Manual for Mental Disorders (DSM), published by the American Psychiatric Association, there has been much debate as to the many imperfections in the nosologies and the diagnostic tests which are used in psychiatry (Zarin & Earls, 1993). There are two schools of thought regarding the issue of whether psychiatric disorders are distinct entities in themselves or not (Kendell, 1989). Some theorists argue that this is the nature of psychiatric disorders, that they are discrete entities, hence they are not amenable to improvement. Others feel that the way psychiatric disorders are conceptualised and the tools used in psychiatry are inaccurate, hence there is room for improvement in regard to diagnostic decisions, and how subsequent treatment decisions are based on such decisions. The present section will review issues regarding diagnostic decision making and methods used in this process, while the following chapter, chapter nine will review in more detail, studies which have examined drug prescribing in the general population and how such findings inform practice and may be of use in studying decision making in the learning disabled population.

Earlier in this chapter, the author discussed the principles involved in decision analysis in medical decision making. Decision analysis has been used effectively in the areas of clinical problems (Kassirer et al., 1987; Braun, 1980 and Pauker, 1976) and also in the area of addressing policy issues (Berwick et al., 1980). However it is only relatively recently – since the mid-1980's that decision analysis has been applied to the psychiatric literature (Mossman & Somoza, 1989; Murphy et al., 1987; Weinstein et al., 1989 and Berwick et al., 1991). The

studies of Zarin & Pass (1987), Landau et al. (1991) and Fombonne (1991) have addressed specifically the issues of decision making in specific psychiatric problems in adults and adolescents, most notably, bipolar mood disorder.

Despite the effective use of decision analysis in psychiatry, psychiatrists in general have been slow to appreciate the vale of decision analysis and they continue to routinely use both formal and informal clinical interviews to assess patients, add to their existing body of knowledge on that client, and form diagnoses, which in turn inform subsequent treatment. Diagnostic decisions faced by psychiatrists have much in common with therapeutic decisions which face other areas of medicine. These diagnostic decisions share the following features: a) several strategies may be delineated, b) the possible consequences of each strategy are known in general, but the specific consequences are more difficult to determine and c) the implications of each outcome can be assessed. Zarin & Earls (1993) put forward a case example of such diagnostic decision making when they state " consider a therapeutic decision that involves the treatment of a depressed person. The possible strategies might be as follows: treat with antidepressant medication alone; treat with psychotherapy and antidepressant medication; or treat with psychotherapy alone. The outcome with each strategy could be determined as the percentage of people who recover without untoward side effects within a given amount of time. The best strategy would then be the one associated, on average, with the best outcome" (p.198). Alternatively a diagnostic decision involving the identification of depression in a client, may involve use of a number of diagnostic tools and alternative approaches to scoring them. The outcome of such a diagnostic decision is to identify correctly whether the patient has a particular disorder, such as depression, or to differentially diagnose another disorder.

The issue of the absence of a "gold-standard" of evaluation within psychiatry is of importance here. Although the concept of a gold standard is somewhat idealistic, any medical diagnostic procedure is subject to error. This is especially true

within psychiatry and the mental health professions, as both human error and technical error is unavoidable. Despite the absence of a gold standard however, Faraone & Tsuang (1994) call for the validity of psychiatric diagnoses through the process of diagnostic accuracy analyses. Diagnostic accuracy according to these authors may be defined as "the degree to which a diagnostic procedure correctly classifies people who are truly ill and those who are not" (p.650). Although such research on the accuracy of psychiatric diagnoses is still in its infancy, the fruits of this research will prove useful in terms of our understanding of how accurate diagnoses can be made and how such diagnostic information is used to plan treatment strategies for individual clients.

8.7 Chapter conclusions.

The principal purpose of the current chapter was to provide a brief overview of issues pertaining to medical decision making. While a comprehensive overview of the literature, focusing on all aspects of medical decision making was beyond the scope of this chapter, the author chose to highlight a number of key areas of interest to the present thesis. Firstly an overview of the elements of medical decision making were presented and discussed briefly. Secondly, the area of decision analysis in medical decision making was discussed. Decision analysis provides a number of structured steps in formulating a decision. This technique has proven useful, not only in relation to medical decision making but also in relation to policy issues and policy planning. The next area of interest was the issue of shared decision making. Shared decision making is increasingly been seen as an effective alternative to the more paternalistic model of decision making seen in medicine. The use of shared decision making in general practice has proven useful and with the advent of informed decision making and advocacy for persons with learning disability, this model of decision making should be introduced for all persons with learning disability. The issue of team medical decision making, and the factors involved were then discussed. Interestingly, and as will be discussed later, team decision making is a common

mode of decision making within learning disability, although considerably less is known about team decision making in learning disability as opposed to the field of medicine. The final area to be addressed relates to the area of diagnostic decision making within psychiatry. The author discussed some of the many problems inherent in diagnostic decision making in psychiatry and why there is a need to determine the accuracy of such diagnoses. If these diagnoses are not accurate, then subsequent treatment regimes may in fact be inappropriate, based on the underlying diagnosis.

A discussion of these issues has proven useful, as in the proceeding chapter entitled prescribing and decision making: perspectives from general practice, the author will review the literature on issues regarding prescribing in general practice and the difficulties encountered in decision making. Many of the issues discussed in this chapter will be of relevance in chapter nine, and those issues of relevance will be further discussed, in terms of their implications for practice in the final chapter of this thesis.

CHAPTER NINE

PRESCRIBING AND DECISION-MAKING: FINDINGS FROM GENERAL PRACTICE

9.1 Chapter Introduction.

As a mode of treatment, prescribing of medication can be said to be the mainstay of medical treatment. From the findings drawn from chapter two of this thesis, considerably little systematic research has been conducted on the factors affecting prescribing for persons with learning disability. Where any such research has been undertaken, it has been based primarily on the issue of drug prevalence and more recently on issues regarding the appropriateness of such prescribing. Despite the emphasis of the research shifting from drug prevalence to drug appropriateness, the number of such studies are relatively small, they suffer from problems of methodology and they still fail to account for the significant variation in prescribing of psychotropic medication for persons with learning disability. Even more interesting is the fact that these studies, whose primary aim is to study appropriateness of prescribing, fail to draw on findings from the general population, where a literature does exist which examines appropriateness of prescribing from a general practice perspective. Although prescribing of medication from a general practice perspective is considerably different from the perspective of those prescribing for the learning disabled population, the same basic principles of appropriateness should be applicable. In addition it should be noted that quite a number of General Practitioners do in fact prescribe for persons with learning disability, and such prescribing should be no different than prescribing for the general population.

Throughout the present chapter a number of issues will be addressed. The first of these will examine how we define and examine appropriateness of prescribing from a general practice viewpoint and how such principles may be applied to the learning disabled population. Although quantity of prescribing has been examined in detail in chapter two, the author will briefly make reference to the issue of prescribing quantity from research conducted within the general population. Of more interest to the present chapter is the issue of quality of prescribing and how this may be examined and determined in any patient being

prescribed medication. The issue of quality of prescribing is linked directly with appropriateness of prescribing. However in determining the quality or appropriateness of any prescribing, it is necessary to examine the factors which underlie the decision making processes around prescribing. A number of studies have been undertaken in general practice which examine the process of decision making in prescribing. However within the field of learning disability, no such attempts of a similar nature have been conducted or as yet attempted. This served as the impetus for the present piece of research, while also serving the need to account for the findings from part one of the thesis.

9.2 Appropriateness of Prescribing – A Definition.

If as Rivinus (1980) has stated "the same rules that apply to the use of psychotropic medications in adults and children of normal intelligence apply to retarded patients. Psychotropic drugs should be used to treat specific diagnoses, syndromes or symptoms for which specific drug efficacy has been scientifically established" (p.195), then the same principles which apply to appropriateness of prescribing for the general population, should apply also to the learning disabled population. However from examining the literature to date, where appropriateness of prescribing has been the core issue of studies, reference has not been made to research conducted from general practice. The reasons for this are as yet unclear, but it may be due to the fact that studies examining appropriateness or effectiveness of psychotropic medication in the learning disabled population have tended to originate in the States (Aman et al., 1995), and considerably less research has been conducted in the UK, while studies examining appropriateness of prescribing in general practice have originated in the UK (Parish, 1973, Barber, 1995, Buetow et al., 1996).

Barber (1995) notes that "there are few reports on what constitutes 'good prescribing'. What is more, the existing guidance tends to imply that right

answers exist, rather than recognising the complex trade offs that have to be made between conflicting aims" (p. 923).

If one looks to Parish's (1973) definition of good prescribing, it states that prescribing should be "appropriate, safe, effective and economic" (p.213). According to Parish, "appropriateness" in its original sense meant that the drug prescribed should suit the patient. Regarding "safety" and "effectiveness", such terms imply absolutes which are probably not possible in prescribing (for any population), while "economic" is a term which is not easy to define in itself. Granted for the purposes of prescribing in certain populations, economics is an important aspect, but there are many ways to determine and assess the costs of medication and how to assess their outcome. In this sense, a number of criticisms can be made of Parish's definition. Prescribing is a complex phenomenon and to apply any one definition across time (Parish's definition is now twenty-seven years old) is by no means an easy task and any definition must be subject to change and modification due to the complex facets involved.

Barber (1995) suggests an alternative to Parish's definition. Rather than seeking a definition of good prescribing, Barber believes prescribers should be attempting to produce a definition of what a prescriber is trying to achieve. In this respect he defines what constitutes good prescribing in terms of four main aims, as follows: "to maximise effectiveness, to minimise risks, to minimise costs, to respect the patient's choices" (p.923). Taking these two definitions as a starting point, one will now examine the literature in terms of quality of prescribing how this relates to appropriateness of prescribing.

9.3 Quality of Prescribing.

Bradley (1992a, b, c) provides a comprehensive and interesting literature review on the topic of prescribing and decision making processes. In his review he focuses on issues of quality, decision making processes which

include the drug selection process and finally the decision of whether to treat or not. Despite Bradley focussing on general practice perspectives, the findings may be also applied to prescribing in the learning disabled population. The present author will aim to apply the studies undertaken in general practice to the field of learning disability and tease out common variables of interest and significance.

The study of Mapes (1977) investigated prescribing of medication in terms of effectiveness and safety of the medication being prescribed by young doctors. In the study prescribers were assigned into two main categories of either "conservatism" or "incautious" based on the medications they prescribed and determined as "effective" by means of standard texts of pharmacology (British National Formulary (BNF) for example). "Incautious" prescribing was judged to occur when the medications prescribed had unwanted side effects and where a more suitable alternative existed. Findings from the study indicated that five factors were associated with the author's measure of prescribing quality. These factors included gender of the prescriber, the proportion of prescriptions written by the doctor themselves, membership of the Royal College of General Practitioners, the number of prescriptions written with no instructions or inadequate instructions and finally the prescribers use of commercial sources of drug information. A positive relationship existed between a better quality of prescribing and male gender and membership of the Royal College of General Practitioner's, while the remaining variables were associated with incautious prescribing.

Eaton & Parish (1976) used as a measure of quality (in addition to patient questionnaires) – the proportion of drugs used after their introduction within the first year, the proportion of proprietary medications prescribed and completeness of instructions given to the patient. Findings from the study indicated that London graduates used less proprietary medications than foreign doctors, while doctors practicing for a longer period of time tended to use a higher number of medications for proprietary reasons..

Taylor (1978) created an index of quality determined by means of the number of prescriptions which were deemed undesirable, those drugs which could be prescribed and which were deemed appropriate in limited circumstances and finally those drugs which were deemed to be obsolete. Each category of drug was given a weighting dependent on its undesirable effects and doctors were scored on their prescribing behaviours of these drugs. Interestingly the study found no relationship between Taylor's index of quality and doctor or patient variables studied, and in addition the index was not associated with cost of medication.

An alternative criteria for assessing quality of prescribing has been posited by Van Zwanenberg et al. (1987). These authors quality criteria were 1] the proportion of doctor-patient consultations which did not arise in a prescription, 2] the proportion of drugs written in their generic form and finally 3] those drugs which were included in a general practice essential drugs list. Of the twenty-one practitioners studied, there was a high variation in the prescribing rate and after the introduction of education regarding rational prescribing, the prescribing behaviours of these doctors changed towards a more improved quality of prescribing.

Studies conducted in the USA on quality of prescribing have yielded similar results to studies conducted in the UK. Common problems emerging in drug prescribing were excessive quantity of a drug, prescriptions being issued too frequently, while in addition it was noted that multiple prescriptions (polypharmacy) were being issued, for which no indications were given on possible drug interactions or unwanted side-effects (Maronde et al., 1971).

Haayer (1982) conducted an interesting study in which doctors were given eight case studies and asked whether they would prescribe for each case or not. If so, participants were asked to complete a full prescription for the case involved. Prescribing rationality was based on whether doctors had prescribed a first-line or second-line drug, whether the drug prescribed was deemed to be of dubious safety or finally

whether the drug was deemed very unsafe. Dosage and duration of the drug prescribed was also taken into consideration by a panel of expert general practitioners and clinical pharmacologists. Interesting results were achieved in that: a] younger doctors, b] doctors who refer to, and read more professional journals and c] doctors who relied less on drug company resources were deemed more rational prescribers.
More recently the study of Buetow et al. (1996) examined inappropriate long-term prescribing in general practice over a fifteen-year period. The authors reviewed sixty two studies of appropriateness of prescribing, and generated five dimensions of how appropriateness can be examined. These five dimensions covered indication, choice of drug, drug administration, communication and review (Buetow et al., 1996). The authors also note that "lack of consensus among doctors about the best way to practice medicine may help to account for the unexplained variations as general practice lacks accepted standards of appropriate prescribing" (p.1371). Findings from the study indicated that prevalence of prescribing varied according to indicator and chronic condition. The highest rates of inappropriateness were related to drug dosages outside of the therapeutic range specified for that drug. In terms of the first dimension – Indication, nine studies either failed to state the indications for treatment or they were invalid, long-acting Benzodiazepines were prescribed and there was also an under-reporting of prescribing for some conditions (asthma, hypertension). Relating to the second dimension – Choice of drug, the authors noted an underprescribing of generic medication, prescribing of unsafe or hazardous drugs, concurrent prescribing of Benzodiazepines for long term use, while also contraindicated drugs were being prescribed. Drug administration issues included underprescribing resulting in death, inappropriate drug dosages were prescribed, while excessive durations of Benzodiazepine prescribing were reported.

Communication, the third dimension, tended to be reported as poor due to patients poor understanding of their condition (particularly asthma), while very often instructions written on prescriptions were inadequate and

included errors. With respect to medication reviews, the final dimension, the principal flaws were failure of a drug to control certain conditions (hypertension and asthma), failure to review repeat prescriptions for elderly patients which included drugs for severe asthma, anticonvulsants drugs and the mood stabiliser Lithium. Findings from the study acknowledged that while it is difficult to determine what is deemed appropriate prescribing in general practice, under the dimensions studied, there was widespread inappropriate prescribing taking place in the UK between the years 1980 to 1995.

In a similar study conducted in Canada with general practitioners, Lexchin (1998) attempted to ascertain whether Canadian GP's were prescribing in an appropriate fashion. Means used in the study to examine appropriateness included assessing appropriateness of prescribing against predefined criteria, while in addition the author used an existing administrative database to evaluate prescriptions received by populations. Findings from the study showed that a level of inappropriate prescribing does take place among Canadian GP's in terms of maximising effectiveness and minimising risks, while in terms of respecting the patient's choices, Canadian GP's fell short in terms of their level of communication with their patients. In an attempt to further examine the process of prescribing and how to improve it Lexchin (1998) found that two principal causes of inappropriate prescribing related to the physicians knowledge base and the physicians practice patterns. Physicians knowledge base was concerned with the range of drugs being prescribed by GP's and their familiarity with these drugs and with newer novel medications, while physicians practice patterns was concerned with whether the GP was employed in a Government funded community health centre (which was associated with more appropriate prescribing) or in fee-for service group practice (associated with a lesser degree of appropriate prescribing).

From the evidence produced on quality of prescribing in General Practice, there seems to be no doubt but there is a level of inappropriate prescribing taking place, not only in the UK but also in countries such as

the US and Canada where studies have been conducted. However a word of caution is necessary when interpreting the findings of such studies on inappropriateness of prescribing. As Bradley (1991) has noted it is difficult to ascertain a single criterion of prescribing quality due to the complex nature of the phenomenon under study and due to the many facets associated with prescribing. Of the studies cited above, many of the criteria used to determine appropriate prescribing were novel in nature and were not subject to rigorous scientific validation. In addition, differing measures of appropriateness will be required across different populations in order to measure accurately appropriateness of prescribing. Finally as Bradley (1991) states "it is probable that all doctors are guilty of inappropriate and sub-optimal prescribing from time to time and the propensity may differ between one therapeutic class and another for each doctor rather than being an overall characteristic of the doctor. It is also true that the current state of understanding of some therapies in general practice is insufficient to allow judgement to be passed" (p.278).

9.4 Decision-Making Factors in the Prescribing Process.

Reviewing the literature on appropriateness of prescribing from a General Practice perspective has been useful for the purposes of the present thesis. Not only does it give researchers and clinicians in the field of learning disability a perspective from where and how to initiate such research, but it has outlined a useful framework of the means of how to examine appropriateness, other than those already in existence (i.e. Aman et al., 1995 – which has relied primarily on the links between psychotropic prescribing and the presence of a diagnosis or diagnostic label).

Despite this however, we are no nearer in accounting for the findings from Part One of this thesis. Determining the quality of prescribing is a far more theoretical process and it still does not account for the huge

variation in the types and ranges of psychotropic drugs prescribed for the learning disabled population.

In this respect, the author again draws on research from General Practice relating to the decision making processes that are involved in prescribing. Drawing on such research allows the researcher or clinician an alternative means of examining prescribing behaviours and the theoretical assumptions which may underlie such prescribing. It also takes into account the more complex factors (other than pharmacological factors) which may determine whether a drug will be prescribed or not.

Essentially there are three types of decisions that are highly influential from a General Practitioners perspective. These are as relevant for Consultant Psychiatrists in the field of learning disability as they are for the General Practitioner. These considerations are as follows:

1] The decision on whether or not the presenting condition should be treated by means of prescribing a drug.

2] Once the decision to prescribe has been taken, the prescriber now needs to make decisions about what form of medication(s) need to be prescribed.

3] Other decision processes which need to be made over a time period and not necessarily within one consultation – issues such as whether to start a newer drug, drug reduction or drug cessation.

9.4.1 The Decision of Whether to Treat or Not.

Research on decision-making processes around the issue of whether or not to treat is quite sparse. Historically, research on prescribing from a General Practice perspective has tended to examine decision-making processes pertaining to the types of drugs prescribed rather than on examining the rationale of whether to prescribe a drug or not. There are

many complex facets associated around the decision to treat. In a sense many people go to the GP in order to receive a prescription. If a prescription is issued, the patient feels satisfied that something has been done. From a research dimension as Bradley notes "once a prescription has been issued there is something tangible to study" (1991, P. 284). In this respect past research has focussed on issues around types of drug prescribed and the reasons for their prescription rather than why a prescription was not issued. The other principal reason for the lack of research on this issue is related to the opening sentence of the current chapter which states – *prescribing of medication can be said to be the mainstay of medical treatment.* In this sense, the author takes note the more traditional perspective of the "medical model" of which prescribing is one of its core components. If a patient is presenting with a problem then a prescription is issued. Finally, and relating to this second point is the fact that the literature on this topic is medically orientated and based on research conducted in hospital settings, again where prescribing is frequent and routine. The option of not prescribing is seen to a far lesser extent in such a setting.

Where research has been conducted on the decision making processes around the decision to prescribe (or not), the findings are of immense interest. One of the first researchers outside of the medical field to examine this area was Parsons (1952). Parsons noted that approximately three quarters of those who go to their doctor leave with a prescription being issued. From a sociological perspective Parsons found this of interest and posited a role-relationship between the patient and the prescriber. Each has a role and a responsibility – both the patient and the prescriber. The patient's role is to seek help and visit the doctor, while it is the obligation of the doctor to help the patient. The issuing of a prescription is powerful in its symbolic sense and both the patient and the prescriber are living up to the role in society.

Despite Parsons model being of interest, it has been criticised on several grounds. The first of these criticisms has come from Bloor & Horobin

(1975). These authors note that Parsons model fails to account for the potential for conflict which arises between the patient and the doctor. The issuing of a prescription according to Bloor & Horobin will result in the resolution of any conflict between the two. Hall (1977) further elaborates on the model posited by Parsons (1952) in that both the doctor and the patient are obliged to give and to receive gifts. As Bradley (1991) states "the prescription functions as a gift and a doctor is obliged to both give and receive gifts. Refusing to give is the same as refusing to accept" (p.284).

A further criticism of Parsons model is that it fails to take into consideration the issue of uncertainty, which is commonplace in medical practice. A doctor may be faced with many complex decisions throughout the course of a day-to-day practice and the issuing of a prescription leads the doctor to avoid this uncertainty and hence he avoids discomfort (Scheff, 1963).

However what any of these models fail to take into account is the issue of the patient influencing the doctor to prescribe. Although Parsons (1952) model does recognise the relationship between the doctor and patient, it does not take into account the fact that very often a patient has expectations prior to a consultation. In the study of Stimson and Webb (1975), the authors interviewed patients regarding what they expected from consultations prior to meeting with the doctor. While patients expected a prescription in 51% of cases, they received one in 66% of consultations. However due to methodological problems with the study, caution is urged in accepting these findings at face value as there are numerous other reasons for an individual visiting a doctor other than the treatment of a particular condition or disease.

In a more recent study Britten & Okoumunne (1997) investigated the influence of patients hopes of receiving a prescription on doctors perceptions and their decision to prescribe. The study aimed to measure the expectations of patients and how such expectations affect General

Practitioners decision to prescribe. The methodology employed was a questionnaire type survey in which doctors were asked to complete a brief questionnaire and the end of each consultation. Information included in the questionnaire related to demographic data, whether the doctor perceived that the patient wanted a prescription, whether the doctor felt under pressure to prescribe and if a prescription was written details about same and whether "the prescription was 'strictly indicated on purely medical grounds'" (p. 1506). Each patient was issued with a questionnaire which asked them for demographic details, details pertaining to the presenting condition(s) and whether they had an expectation of receiving a prescription from the doctor on that day. Results from the study indicated that 67% of patients hoped for a prescription to be issued while 65% expected a prescription to be issued.

From the perspectives of the doctors involved in the study (which spanned over 15 General Practitioners) doctors perceived that 56% of patients wanted a prescription and these perceptions were strongly associated with patients hopes of a prescription. Resulting prescriptions amounted to just over 59% which meant that one quarter of those patients who hoped for a prescription did not receive one. The findings of this study were comparable to a study conducted in Australia by Cockburn & Pit (1997) using a similar methodology.

The study of Weiss et al. (1996) examined pressures on GPs to prescribe and decision making factors which are involved. The authors examined GPs prescribing in relation to four main indices – GPs sense of burden, financial constraints and incentives, prescribing as a coping strategy and finally patient demand. Findings from the study indicated that General Practitioners were concerned about pressures to prescribe although the only variable strongly associated with actual prescribing was the possible adverse effects of financial constraints on medical decisions which resulted in prescribing. Practitioners did note however that burnout was common amongst GPs in addition to low morale which was associated with public expectations of the practitioners themselves. This

invariably led to feels of hopelessness, powerlessness and frustration. Other factors which practitioners felt were influential in the prescribing process were patient demand and expectation to prescribe – however these variables were not of significance in the study.

What was of immense interest was the issue of the influence of workload in relation to prescribing. Many studies from General Practice have reported a relationship between workload, lack of consultation time and an increase in prescribing rates (Bandyopadhyay et al., 1994; Iliffe & Munro, 1993; Keeley, 1993; Hope et al., 1993; Gilley, 1994; Howie et al., 1989 and Bradley, 1992a, b, c). However the study by Weiss et al. did not find a similar result. In relation to this the authors have noted: "many GPs acknowledged their use of a prescription to cope with workload although, with the current emphasis on 'rational prescribing', many GPs felt guilty about using a prescription in such a 'non-pharmacological' manner" (1996, p.437).

Following on from the earlier studies of patients influence on prescribing & doctors expectations of same, the study of Stephenson et al. (1999) examined General Practitioners perceptions of patient influence on prescribing by means of interviews with twenty one GPs. In the interview GPs were asked about their perceptions of patients expectations in addition to influences on their costs of prescribing and any means by which they had reduced such costs. Findings from the study showed that a relationship did not exist between GPs beliefs that their patients expected a prescription and whether they were over their budget or under their budget. All GPs interviewed in the study mentioned that they had experienced pressure to prescribe from patients and they prescribed "when they would not otherwise have done so" (p.260). Finally as the authors have stated "this study indicates the multi-faceted nature of GPs views of patients expectations for a prescription ... the influence of GPs perceptions of patient demand is complex, yet the effect of patient demand itself may not only be overestimated but also perpetuated by doctors' belief in its existence" (p.260).

From the research to date, numerous reasons have been put forward for the issuing of a prescription apart from the actual need to prescribe. Some of these reasons include the ending of a consultation, to impress the patient, to fulfil a need, as a means of coping with uncertain or complex cases, to comply with the wishes of another doctor or as a means of satisfying the urge to give (Melville, 1980; O'Hagan, 1984; Ryde, 1981and Drury, 1984). Despite the vast amount of reasons given, little empirical evidence exists as support for such reasoning.

To conclude this section on whether to treat with a prescription or not, much evidence has accumulated with regard to the non-pharmacological factors which influence prescribing. If one turns to the work of Parish in the 1970's, he notes that prescribing is as much a social entity as it is a medical one. The General Practitioner is possibly the first person that a patient comes to see and this in itself is a complexity as there is a sense of pressure or responsibility to be seen to do something. Whether this results in a prescription or not is dependent on a host of factors, many of which are not purely medical. Many of these issues have just been discussed and later in the conclusion of this chapter it will become evident how such research is of interest to prescribing within the filed of learning disability, which should be subject to the same principles of rational prescribing as in the general population.

The next issue to be examined is in relation to the second decision-making consideration as outlined above. This is the issue of drug choice and selection once the decision to prescribe has taken place. Let us now turn the focus of attention to the literature on this topic.

9.4.2 Drug Choice & Selection (once the decision to prescribe has taken place).

As was mentioned at the outset, the vast majority of the literature included in the present chapter has been taken from research conducted with the field of General Practice. No such similar attempts have been

published in the literature on learning disability, despite the similarities existing between the two areas. For the purposes of the remainder of this section, the author will focus on issues relating to drug selection and the factors influencing same in General Practice.

As a means of attempting to understand the factors involved in prescribing (once the initial decision had been taken to prescribe), the research focussed on studying why doctors prescribe certain drugs for individual cases.

The study of Zelnio (1982) examined the influences on doctors prescribing and how such influences were related to the influences of other doctors. Participants included 250 doctors in the US who were asked to rate the importance of eight criteria in the choosing of a drug related to a paired comparison method. The eight criteria included: efficacy, side effects, contraindications, dosage forms available, source of information on the drug, cost, manufacturers reputation and frequency of administration. Findings from the study indicated that of the eight criteria above, efficacy, appropriateness and safety were judged by practitioners to be most important. Issues such as the therapeutic class of the drugs were also seen as important to doctors while the issue of brand were deemed of less relevance. In relation to these criteria, the study found two groups of doctors emerging based on their responses. There were those doctors who attached more significance to efficacy, safety profile and frequency of administration of a drug, while the other group were concerned with drug information and issues relating to the manufacturers reliability and reputation. As Bradley (1991) has stated "this study agrees with others that doctors, when asked, attach greater importance to the efficacy and safety of drugs than to their brand characteristics such as cost. However, how this relates to actual prescribing behaviour is not clear" (p.281).

As a means of attempting to understand the findings of Zelnio (1982), the work of Knapp & Oeltjin (1972) is of relevance. In their study the authors

constructed four hypothetical cases of hypertension of which all patient variables were similar apart from the degree of hypertension. A hypothetical drug was then devised which resembled the types of drugs then available for hypertension. Doctors involved in the study were asked how they would change their management of the case if the potential risk or benefit of the drug had changed. In this respect the issues studied were the seriousness of the disease, the risk of side effects, the probability of benefit of the drug prescribed and the speciality of the doctor. From the analysis results showed that disease seriousness and speciality of the doctor were of significance in terms of decision-making process regarding the drug.

Similar to the criticisms made earlier regarding hypothetical cases, the above studies may be criticised on such grounds. A case of prescribing in the real-world setting may employ far different decisions in comparison to those made for hypothetical cases and caution must be urged in taking the findings of such research at face value. The study of Helper et al. (1982) aimed to overcome some of the shortfalls of the earlier research on drug selection. In their study the authors examined real cases of prescribing in an attempt to gain understanding of the decision making processes employed. The study related to the prescribing of antibiotic medications within an acute medical inpatient setting. Prescribing of antibiotics were assigned into the categories of – prophylactic, therapeutic and empiric, with empiric being defined as "antibiotic prescribing where the prescriber believed there to be an acute infection and proceeded to prescribe without awaiting the results of culture and sensitivity" (Bradley, 1991, p.281). Over the course of in excess of six thousand patient days, a total of 103 instances of such "empiric" prescribing arose. As a follow up the authors interviewed the majority of prescribers associated with such prescribing in an attempt to gain their rationale for prescribing in this way. Prescribers were asked their reasons for prescribing, their reasons for choice of drug and for the dosage they chose to use.

Findings from the study showed nine themes emerging. The majority of these themes were related to the prescriber's beliefs about the treatment and outcome of prescribing with the drug. Other themes of interest were related to issues such as information sources, level of training and reference to the literature. Such themes were linked to a classification of "past clinical experience" (Helper et al., 1982), in that prescribers tended to use perceptions of outcomes related to the beliefs about the links between the actions of the drug prescribed and its outcome for the patient in choosing a drug. In this respect the authors tended to see the data as fitting a cognitive model of prescribing rather than a more traditional behavioural model (where the prescribing would be seen as more habitual). Where the behavioural model fails to account for the data is with respect to the prescriber's beliefs and values, hence the value of the cognitive model in attempting to explain prescribing of antibiotics in this study.

Leading on from such research and the introduction of both behavioural and cognitive models of prescribing, the research of Segal and Helper (1982) proposes a theory of prescribing termed the "Drug Choice Model". This model is based on the cognitive model above and is based on the premise that choice of drug would be influenced by the doctor's belief about the possible effects of the drug and the value associated with possible outcomes. The authors interviewed twelve doctors regarding the possible outcomes associated with drug treatment choices and on initial analysis formed seventeen possible outcomes, leading to six main outcomes. These outcomes included control of the disease, patient compliance, cost to the patient, side effects, satisfying patient demand and criticism from colleagues. A further sample of fifty doctors were asked to rate each possible outcome (in a hypothetical case of hypertension) on a twenty point scale ranging from "avoid at all cost" to "most valued", in addition to a final open ended question about how they would treat the patient.

The study yielded interesting results in that the drug choice model predicted in excess of 70% of the doctors responses, which is well above average. In essence what the study tells us is that although the drug choice model is useful in its predictive sense, the choice of treatment made by a doctor is influenced by what they may think might happen with a given treatment in addition to they way they may feel if the outcome actually comes about (Segal and Helper, 1982).

In a later study Segal and Helper (1985) further expanded on their earlier research on the drug choice model. In the study the authors were interested in further elaborating and testing their model. The authors used both real and hypothetical cases (based on actual cases) of the treatment of diabetes and hypertension by forty doctors. Findings showed that predictive value was again strongly associated with the model and that the outcomes for hypothetical cases was similar to real cases presented. In this respect the doctors perceived probability was a strong enough indicator in itself to predict actual drug choice in practice.

Building on the work of Segal and Helper (1982, 1985, Denig et al. (1988) have developed a model around prescribing and decision-making termed the "Expectancy-Value Model". In this model the authors sought to get doctors' beliefs about outcomes in terms of likely risks and benefits. The conditions used for the purposes of the project were renal colic and irritable bowel syndrome and the authors interviewed 169 general practitioners from Holland. In addition to questioning doctors about their beliefs of possible outcomes they also questioned doctors about the six outcome measures of the study of Segal & Helper (1982). The responses obtained were then compared to replies from an open ended question of how these doctors were currently treating such conditions in practice. Results showed high levels of prediction for renal colic but poor predictive value for irritable bowel syndrome. However the authors note that irritable bowel syndrome is a complex condition for which there is no effective treatment, unlike hypertension or renal colic for which effective treatments exist.

Producing a model as a means of attempting to explain and predict prescriber's behaviour is a useful process in that it allows one to examine and study the underlying influences which lead to the prescribing of a particular drug. Although the models discussed to date in this chapter do fall short in some respects, they do provide a useful insight in the decision making processes that general practitioners engage in. Although these models are formed around general practice and for specific drug categories and conditions, they provide a useful framework on which to build further theories. Of particular interest to the present thesis is the study of Raynes (1980). It is of interest in that she examined psychotropic prescribing in terms of attempting to develop a behavioural model around this. Although findings from the study supported the notion that prescribing was not related to diagnosis, it was however related to the doctors routine for questioning their patients. In this respect Raynes' findings posit a largely behavioural model but it comes under scrutiny and criticism in that although it may be a behaviour which is learnt, but it may also be related to flawed cognition.

Later in the chapter the author will review briefly two further theories/models around the issue of decision-making in prescribing, a "Clinical Judgement Analysis" – based on the work of Harries et al. (1996) and the Actor-Spectator Paradox as developed by Lilja et al. (1997).

The third consideration in the prescribing decision making process is the issue of other decision processes (which need to be made over a longer period of time than a single consultation and which are complex decisions around addition of a newer drug, drug withdrawal or drug cessation). Such considerations will now be discussed.

9.4.3 Other Drug Decision Processes (decisions made over the course of numerous consultations pertaining to drug introduction, reduction or cessation).

Studies examining other drug decision processes have tended to look at issues pertaining to drug innovation and early adopters of novel drugs. We will now examine briefly the literature on this topic.

Coleman et al. (1966) investigated drug innovation by examining the introduction of a new drug to general practice and the social variables, which were influential in this drug being prescribed by doctors. In the study doctors were asked to name those persons whom they most often turned for advice when needed, those whom they discussed they cases with each week and those whom they were friends with from their colleagues. Findings from the study showed that those doctors who were mentioned by their colleagues in answering the above questions used the novel drug more frequently and earlier than those who were not mentioned. Where the drug was used, the findings pointed to the influence of professional contacts in the early initiation and prescribing of the drug. The role of friendship was seen as being influential later on. In the case of doctors who had not prescribed the drug by the sixth month of the study, the impact of networks was said to be of minimal impact.

A second major finding of the study was the identification of prescribers who were seen as "innovators" – in that they prescribed the novel drug from a very early stage. The authors portray an innovator as a heavy prescriber of certain types of drugs, a reader of professional journals and those who were interested in medicine as a science, although they were not dubious in using novel drugs. The process of "adoption" involved two stages for doctors. Stage 1 involved increasing awareness surrounding the drug in which doctors relied heavily on information from the pharmaceutical industry, while stage 2 involved legitimisation of the drug and doctor colleagues played a large part in this process. Hence early adopters went through these phases quite slowly issuing relatively few

prescriptions of the new drug while late adopters went through the process faster and thus issued more prescriptions.

In contrast to the study of Coleman et al. (1966), Marshall (1973) undertook a similar study across a broad range of drugs being prescribed. Results showed that although early and late adopters could be seen for particular individual drugs, this did not apply across a broad range of drug categories. Hence doctors could be early adopters for some drugs and late adopters for others dependent on the type of drug prescribed.

Williamsons' (1975) study pointed to the non-pharmacological factors at work in terms of a novel drug being introduced to doctors. In the study doctors were asked whether or not they would adopt a new drug in terms of the degree of perceived risk, and if they would adopt the drug based solely on information received from a commercially sponsored source. Doctors indicated that where there was a low degree of perceived risk, they were willing to prescribe based on commercially sourced information. As the degree of perceived risk increased, doctors relied more heavily on professional sources for advice. Interestingly drugs that were British were associated with a lesser degree of perceived risk than those that were foreign and if the drug had a novel mode of action, it was again associated with a higher degree of perceived risk.

As mentioned before, Williamsons study was based on hypothetical questions, so it does lead one to question the applicability of the findings. The study of Peay & Peay (1988) does lend some credibility however to Williamsons study. The authors examined the degree of perceived risk of the introduction of Tamazepam in Australia and found that throughout all stages of drug adoption the role of the drug representative is paramount, and placed less emphasis on the role of professional sources as was indicated in the study of Williamsons (1975).

Studies of drug relinquishment ("the dropping of a drug which professional journals and official agencies no longer consider to be safe or desirable and its replacement with an alternative which medical consensus considers to be superior" (Mapes, 1977, p.619)) have proved useful in the study of decision making processes. Mapes (1977) examined the prescribing behaviours of twelve young doctors in terms of psychotropic prescribing and relinquishment of hypnotic medication. Findings showed that doctors who referred to pharmacological references tended to relinquish quicker than those with a greater patient value orientation at the time.

The study of Taylor & Bond (1991) combined the study of drug adoption and relinquishment in a sample of Scottish general practitioners. Over the course of one year, practitioners, whenever they issued a prescription, made a duplicate copy and indicated whether the prescription was for an "established" drug, a drug new to their practice, or for a drug, which was superseded by a newer drug. Results showed that drug innovation was comparatively rare (one in one thousand face to face consultations), while the impact of drug company representatives influenced just over 17% of prescriptions issued for a specific class of drug in particular (anti-infectives). In terms of other influences, general practitioners saw their hospital colleagues as having a more influential role in prescribing of all drug categories, than fellow general practitioners or patients. Overall, findings from the study show that the profile of those general practitioners who perceived themselves to be influenced by a commercial source tended to be higher prescribers of novel drugs while also prescribing a wider range of these drugs. They also saw themselves as being more clinically autonomous and being less affected by economic issues in prescribing and on this basis Taylor & Bond developed the prescribing profile of a "developer" or a "conserver" (1991).

In conclusion, one can see the wider social influences that come into being when one examines in detail the prescribing behaviours of doctors.

Not only do some general practitioners base their prescribing on perceived risk, but this perceived risk may be based on information from those sources supplying these drugs. In the case of the introduction of a novel drug, this does warrant caution. Perceived risk in itself is not sufficient evidence on which to base a prescription. Although a number of the studies cited here did rely on hypothetical cases, much of the evidence comes directly from actual cases of prescribing.
From the evidence provided on the three aspects of decision making in prescribing, there is no doubt but prescribing is a complex process and is subject to many social variables, or at least, many variables which are non-pharmacological in nature. The next issues to be examined related to the development of recent models around prescribing. These will be reviewed briefly for the purposes of the development of a model of prescribing based on the findings of the present thesis in relation to prescribing and learning disability. Finally before concluding this chapter, the author will review a number of recent studies specific to the present thesis based on methodological similarities.

9.5 Recent Models of Prescribing – A discussion of their Usefulness?

9.5.1 Clinical Judgement Analysis.

The first of these models to be examined is that of Harries et al. (1996), originally developed by Hammond in the 1960's, which is termed "Clinical Judgement Analysis". This model of decision making in prescribing is based on the principles of Social Judgement Theory as developed by Brehmer & Joyce (1988). Social Judgement Theory when applied to a medical context is termed Social Judgement Theory and it has been used by a number of authors within the medical context (Wigton, 1988), Stewart and Joyce (1988) and Engel et al. (1990). It involves subject being involved in a large number of multi-cue judgements which are then subjected to statistical analysis in order to identify the implicit or tacit policies underlying the judgements that subjects make. Although this

model has been in existence for some time, it is relatively new to the field of medicine and the study of Harries et al. (1996) explores its usefulness when applied to prescribing decision processes in general practice. The authors note than on reviewing the literature in terms of medical decision making, many of the studies having failings in terms of their methodology used, as they have attempted to study medical decision making from a "conventional" perspective. They note "this points to an important but inconvenient conclusion for the study of medical decision making: conventional methods of investigation based on questionnaires or other means of self-report, may be of limited practical value" (p.88). On the basis of this conclusion, Harries et al. utilised the clinical judgement analysis in an attempt to further understand the prescribing decision processes of general practitioners, by asking them to make judgements about their likelihood of prescribing a drug. The study differed from other studies which used the technique in that the authors were interested in considering management decisions rather than just focussing on diagnosis.

Subjects consisted of thirty five general practitioners from the Plymouth region in the UK. The study involved presenting doctors with cases in which they were asked to make judgements on. There were three possible tasks for doctors to complete, each with 130 cases, which differed on thirteen distinct cues. The two main tasks included information regarding Lipid and Migrane treatment and each differed in the number of cues provided (the Lipid sequence having more cues available to doctors). For each of the two tasks, doctors were asked to indicate the likelihood of them prescribing either a lipid lowering drug (in the case of Lipid), or the likelihood of them prescribing a prophlactic treatment in the case of Migrane. The third task was related to HRT (hormone replacement therapy) and not all doctors completed this task.

Findings from the study showed that the number of cues presented was significant in terms of prescribing decisions made by general practitioners. The more cues presented, especially for more complex

conditions (such as the Lipid task in this study), the easier the decision making process. The degree of insight that doctors had also yielded interesting results in that doctors tended to have limited insight. As the authors have noted "this finding is of considerable importance ... indicating that doctors have insight into what cues they do not make use of, but have poor intuitions about the cues they actually use. In other words, when a doctor says they are using a cue they may or may not be using it" (p.106).

On reviewing briefly the clinical judgement analysis as applied to the study of prescribing decisions of general practitioners, one can see that although it is of interest, it does seem of limited value largely due to a number of criticisms. The first of these draws on earlier points made relating to hypothetical cases presented to doctors. Harries et al. (1996) acknowledge this in relation to the goodness of fit between "real world" cases and those which are hypothetical. It is a failing of the present study that hypothetical cases were presented, hence the findings are limited. The second main failing of this model relates to their methodology. Although scientifically elaborate in the use of computer technology, it did involve quite a lot of time for doctors to complete in addition to it being largely experimental. In the real world setting of general practice, doctors have very different consultation styles, while also being constrained in terms of consultation times (DiCaccavo & Reid, 1995). Hence the value of the clinical judgement analysis is limited in its present context, largely due to its highly experimental nature, but it is of value in terms of highlighting the psychological and social processes at work in decision making in prescribing.

9.5.2 The Actor-Spectator Paradox Model of Prescribing.

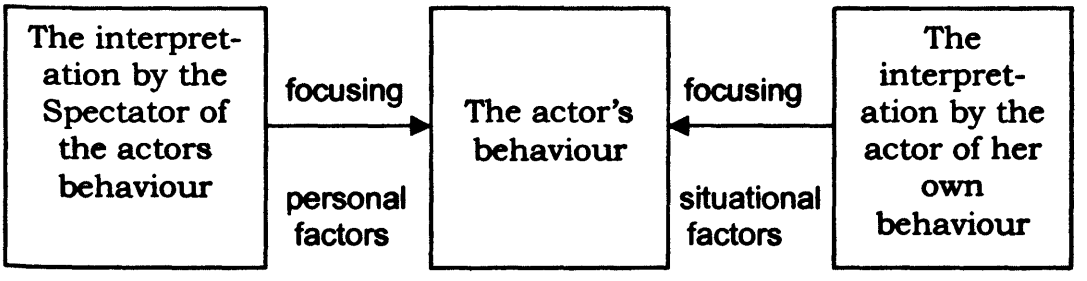
The actor-spectator paradox model of prescribing examines prescribing in terms of the relationship and communication between the prescriber and patient. Whereas traditionally prescribing was examined solely in terms of the prescriber's decision making process, this approach has

since been superseded with the era of shared decision making or patient centred approaches (Stephenson et al., 2000) in which the patient actively takes a role in the consultation.

The actor-spectator paradox as posited by Lilja et al. (1997) takes into consideration the cognitive systems employed by both doctor and patient within a medical encounter. In their model the authors examine the usefulness of this model in terms of psychotropic prescribing in general practice. Not only is there relatively little research on the area of psychotropic prescribing as applied to general practice, but this model is particularly useful for the present thesis, due to psychotropic prescribing being the core issue under examination.

The actor-spectator paradox has as its central concepts the issue of communication and cognitive processes in the medical consultation. In terms of cognitive processes, one must look to the metacognitive processes of those involved in the consultation. These metacognitive processes can be subdivided into two categories, each belonging to the same person – 1] the individuals thoughts about his/her own cognitions (internal metacognitions) and 2] the individuals thoughts about another persons cognitions (interpersonal metacognitions) (Lilja et al., p.1177). These are central to our understanding of this model as we examine the communication and cognitive processes of both the actor and the spectator in the consultation process. Figure 9.1 below outlines an overview of the Actor-Spectator paradox model taken from Schneider et al., 1979, and cited in Lilja et al. (1997) p.1179.

Figure 9.1 A figure depicting an overview of the Actor-Spectator Paradox model of Prescribing



Lilja et al. (1997) applied the actor spectator paradox model of prescribing to the study of psychotropic prescribing amongst general practitioners where patients were suffering from what the authors termed "common psychological symptoms such as nervousness, anxiety, sleeplessness and depression" (p.1176). Not only is psychotropic prescribing controversial within the field of learning disability, but it has also generated much interest and concern amongst the general population (Hemminki, 1977; Renaud et al., 1980; Cooperstock et al., 1983 and Smith, 1985). In particular there has been much debate around the prescribing of Benzodiazepines, with numerous arguments both in favour and against such widespread prescribing of these drugs. The debate is based on the relationship between mind and brain, with one argument being materialistic in nature (parallelism between mind and brain is assumed) and the interactionist perspective (whereby the mind and brain are seen as distinct interacting entities).

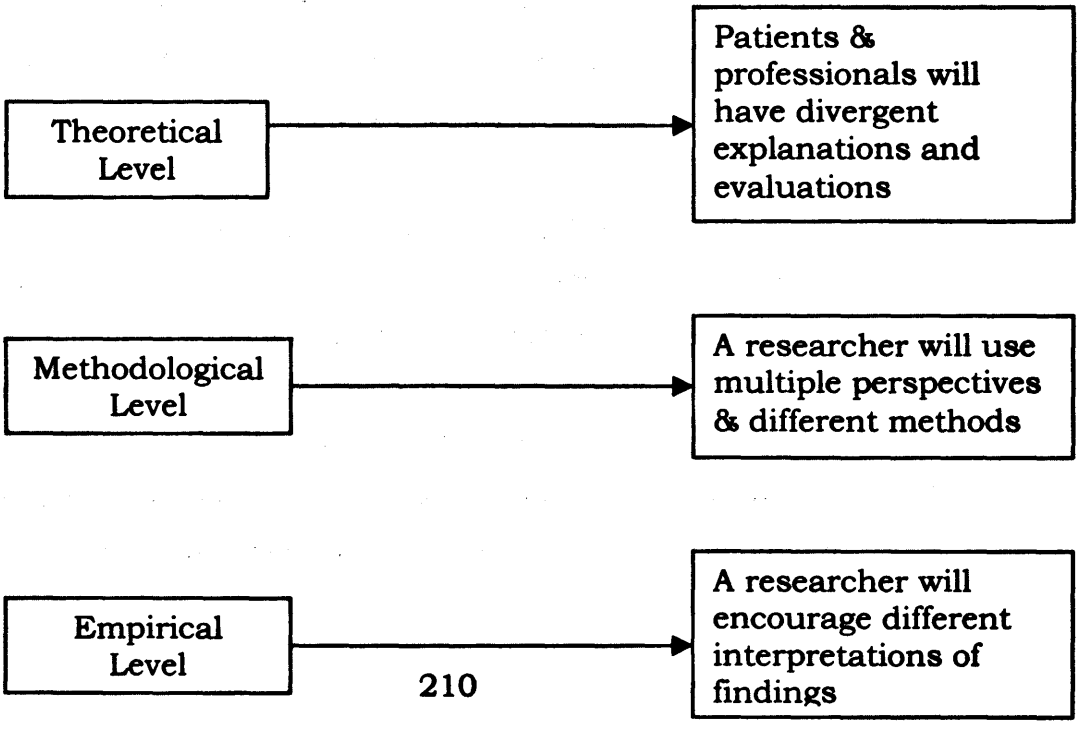
Larsson & Lilja (1992) applied the actor spectator paradox to psychotropic prescribing in order to determine its usefulness. In their studies the authors showed pre-recorded video-vignettes to a sample of both patients and health care professionals and asked them to recommend ways of dealing with the problems shown. In this respect the doctors and general public who were involved in the study acted as spectators in the study. Findings from the study showed that doctors viewed the video-patient as having a more serious problem than did the general public, more doctors recommended use of psychotropics than did the general public and finally the attitudes of doctors and the general public varied considerably in their views towards psychotropic drugs, with both doctors and members of the public viewing psychotropic prescribing as positive and negative.

The implications of adopting the actor-spectator paradox of prescribing in general practice may be summarised as follows:

1. If practitioners were to adopt this model, it would place emphasis on those issues which could be empirically studied – side effects associated with particular classes of psychotropics.
2. The general public could focus on value judgements pertaining to psychotropic prescribing, rather than holding the attitude that non-prescriptive methods of treatment are sufficient in themselves to deal with complex problems.
3. Empirical evidence is required for both practitioners and the public in order to form the basis of their attitudes and opinions on psychotropic prescribing.
4. The issue of dependency on certain psychotropic drugs (i.e. Benzodiazepines) is viewed differently by practitioners in comparison to patients. While patients view dependency in terms of difficulty in stopping taking a drug, practitioners view dependency in terms of pre-defined criteria (as outlined in DSM for example).

Given these considerations, Lilja et al. (1997) develop their model of prescribing as follows:

Figure 9.2 A figure depicting the Actor-Spectator Paradox as applied to the decision processes in psychotropic prescribing in General Practice.



Overall the Actor-Spectator Paradox model of prescribing offers us a unique insight into the communication process between prescriber and patient. Presently no other model offers the reader the insight into this phenomenon as applied to the process of prescribing. One of the most useful applications of this model is to the researcher and how they go about investigating the prescribing process. In essence the emphasis of research to date has been placed solely on the prescribers perspective and to a lesser degree on the patients perspective. Hence future research (certainly within general practice) should examine the discrepancies between the cognitive systems employed by both parties involved in this complex interaction and evaluate how this impacts on the communication between prescriber and patient.

9.6 Specific Studies in General Practice – Their Usefulness in Studying Prescribing in the Learning Disabled Population.

Throughout the present chapter the author has drawn on research undertaken in general practice, which has investigated issues around the prescribing process and the variables involved – be these pharmacological variables or variables of a social nature. It is necessary for the purposes of the present thesis to outline the rationale behind such studies as Part Two of this thesis attempts to use the literature outlined earlier to gain an understanding of prescribing for the learning disabled population. The last section of this chapter will examine a number of recent studies of particular interest to the present thesis due to similarities in the methodologies used by both.

The research of Bradley (1991, 1992a, b, c) is of particular interest to the present thesis. Bradley (1992c) outlines a methodology which has proved useful for a more in-depth understanding of the decision making processes involved in prescribing in general practice. As a rationale Bradley (1992,a) states "any attempt to influence the prescribing behaviour of doctors ought to be based on a thorough understanding of how prescribing decisions are actually made" (p.294). In order to

understand the decision processes in prescribing, Bradley has utilised a methodology known as the "critical incident technique", a technique originally developed by Flanagan (1954). Although the critical incident technique will not be explained in detail in the present chapter, the author will examine the usefulness of this technique in the following chapter, which outlines the methodology used (and rationale for same) in Part Two of this thesis.

Bradley (1992a, b) undertook to investigate those factors which were influential in the decision of whether or not to prescribe in general practice. Focussed Interviews were conducted with a total of seventy four doctors (five in training) in which the focus of the interview was to gather information regarding discomfort around prescribing decisions. The analysis conducted was based on the critical incident technique and involved a panel of experts in order to generate categories obtained from the interview material. Bradley (1992a) states "incidents are deemed to be critical when the purpose of the action and the outcome of the incident are reasonably clear and relevant to the phenomenon under study ... a key feature of this method is that the categories are derived purely from the data and not on the basis of preconceived theories" (p. 294).

Upon analysis of the data, information was obtained about factors which affected doctors in whether or not to prescribe (Bradley, 1992b) and about those incidents which caused discomfort when prescribing was initiated (Bradley, 1992a). Findings from the study indicated that discomfort arose most frequently when prescribing took place primarily for respiratory disorders, skin problems and psychiatric conditions and this discomfort arose across all drug types including cardiovascular drugs, antibiotics, non-steroid anti-inflammatory drugs and the psychotropics (Bradley, 1992b). Patient age and ethnic origin also tended to cause some level of discomfort, as doctors felt uncomfortable prescribing for elderly patients and especially for children. Other patient variables, which resulted in discomfort, were the social class of the patient, patients with a good knowledge of medical matters, how well

known the patient was to the doctor – with frequent attendees' causing more discomfort than others.

Doctor factors which resulted in discomfort tended to arise around the issue of drugs used – with the most common source of discomfort relating to side effects and then cost of the drug, and possible adverse side effects. Interestingly compliance was well done the list as only 4.3% of doctors cited this as a source of concern. Other factors of interest included doctor's expectations of themselves (in that they found it hard to refuse giving a prescription), they felt a need to do something or give something and there was also an issue of the prescription serving to "get rid of the patient". The issue of being unable to form a diagnosis arose in discomfort for a considerable number of doctors in the study.
Findings from the studies of Bradley (1992a, b) have indicated the usefulness of the qualitative approach to the study of prescribing decisions in general practice. Not only do these studies point to the influential factors in decisions regarding whether to prescribe or not, they also provide a useful insight into the reasons that doctors feel uncomfortable when issuing a prescription. Interestingly a considerable amount of this discomfort arises from the point of view of patient variables (hence the earlier discussion) in addition to variables associated with the drugs prescribed (largely pharmacologically driven concerns). These studies have again pointed to the influence that non-pharmacological factors play in the prescribing process. As Bradley (1992b) has stated "while all analyses of prescribing data have disclosed evidence of drug usage that is pharmacologically illogical it is still improbable that doctors are being deliberately irrational. The problem for the doctor is that the criteria of 'rational' prescribing must be balanced against considerations of the patients obvious suffering and the need to maintain a good doctor-patient relationship" (p.457).

Other studies which have made use of qualitative methods as a means for understanding prescribing in general practice are the studies of Dybwad et al. (1996), Sleath et al. (1997) and Allery et al. (1997).

However these studies, unlike the research of Bradley, are specifically associated with either a specific drug type – Benzodiazepines and minor opiates in the study of Bjorner et al. (1996), or with changes in clinical practice as discussed by the study of Allery et al. (1997). In this respect they are beyond they scope of the present chapter, but they do emphasise the usefulness of qualitative techniques in the study of the process of prescribing and changes associated in prescribing techniques.

9.7 Chapter Conclusions & Implications for the Present Thesis.

The present chapter sought to examine the existing literature in respect to prescribing decisions and factors affecting prescribing in general practice. Although this literature in one respect may be seen as being somewhat removed from the present thesis, it is central to our understanding of the factors which affect prescribing and the decision-making processes involved.

In order to account for the findings from Part One of this thesis and to further explore the prescribing behaviours of Consultant Psychiatrists in learning disability, it is necessary to draw on the findings from prescribing patterns in general practice and relate such findings to the present thesis. Much of the research undertaken in general practice affords this study the opportunity to use existing methodologies in an attempt to understand the rationale in prescribing for persons with learning disability.

The present chapter has examined issues around appropriateness and rational prescribing. Ever since the development of a definition of rational prescribing by Parish (1973) and its elaboration and re-definition by Barber (1995), general practitioners have had a framework on which to base their prescribing. If prescribers are unsure of what constitutes appropriate or rational prescribing, they can assess their behaviours in terms of these guidelines. The remainder of this chapter was dedicated to examining decision-making processes that are involved in the process

of prescribing, namely whether or not to treat the condition with a prescription, issues around the drug selection process and other more long-term decisions regarding introduction of newer drugs or drug reduction. In addition the author examined two models of decision processes – the Clinical Judgement Analysis (Harries et al., 1996) and the Actor-Spectator Paradox Model (Lilja et al., 1997) in an attempt to ascertain the usefulness as applied to the present study.

The final issue examined in this chapter relates to studies of specific importance in relation to the present thesis. It examined the work of Bradley (1992a,b,c) and how the research methodology used by Bradley may be incorporated to the study of prescribing within the field of learning disability. The qualitative method known as the critical incident technique proved useful in the research of Bradley (1992a) and it is this technique which is utilised in Part Two of this thesis, in an attempt to gain understanding of the prescribing behaviours of consultant psychiatrists in learning disability.

CHAPTER TEN

RATIONALE FOR METHODOLOGY

10.1 Chapter Introduction

The role of qualitative research methods has grown considerably over the past two to three decades and such methods are employed frequently by healthcare researchers, be these Sociologists, Psychologists or members of the Medical profession. The present chapter will examine the growing impetus of research that has been investigated by means of qualitative research methods and how qualitative methods have been employed successfully by healthcare professions.

Part One of this thesis employed strictly quantitative methods as a means of determining factors associated with psychotropic prescribing in the learning disabled population. This first phase of the thesis proved useful in that it offered the author the opportunity to compare drug prevalence figures gathered within this study to similar studies conducted within the UK, Europe and the US. However the major problem lay in how to account for the findings obtained in Part One of this thesis. Reviewing the literature on psychopathology proved useful to the author in that pursuing the avenue of research which would investigate the links between psychopathology and psychotropic prescribing would prove of little use in understanding the reasons behind prescribing. Quite clearly there are links between psychopathology and prescribing but they offer little in gaining an understanding of why such high figures of prescribing took place.

As a result of examining the literature on psychopathology and learning disability and trying to account for the drug prevalence findings obtained in this thesis, the author turned his attention to qualitative methods and how such techniques may prove beneficial in the current project. In addition to turning his attention to qualitative methods, the author also reviewed the literature outside of learning disability in an attempt to see whether a literature existed on prescribing, and if so, what techniques were employed

as a means of study and understanding this phenomenon. The results proved useful on both counts as firstly qualitative methods have been employed in the study of prescribing and secondly an extensive literature exists which examines prescribing in General Practice. In chapter eight the author has reviewed the literature on prescribing in General Practice and its usefulness in developing a methodology which will firstly allow the researcher to research this most complex phenomenon and secondly by employing a similar methodology to that used in General Practice, it will allow a greater understanding of prescribing in learning disability and aid in further research in this field.

The remainder of this chapter is devoted to a discussion, critical evaluation and rationale why qualitative research methods have been used in the present thesis, by outlining the principle components of qualitative techniques and a specific discussion of the technique of Grounded Theory (Glaser & Srauss, 1967). Part Two of this thesis has employed the technique of Grounded Theory in analyzing the findings obtained from the study. To conclude this chapter the author will outline and discuss a unique qualitative research tool known as The Critical Incident Technique developed by Flanagan (1954) and subsequently used in healthcare research more recently by Bradley (1992a,b, c).

10.2 Underlying Principles of Qualitative Research

Within the field of Psychology, the use of qualitative techniques can be said to be somewhat novel largely due to their relatively short use, in comparison for example to the field of social Anthropology which has routinely employed such methods for a considerable length of time. Despite the growing interest in qualitative techniques since the 1960's, it is not until quite recently that such techniques have begun to impact on the field of psychology (Richardson, 1996) and more widely healthcare research. Richardson

(1996) quotes from the UK governments Economic and Social Research Council (1992) which declares its intention to devote work on all research methodologies, by stating "giving equal attention to qualitative and quantitative methods and seeking to promote appropriate methodological development in all social science disciplines" (p.28 cited in Richardson, p.3).

Over the last number of years it can be said that a paradigm shift has occurred by many Psychologists working and researching in the field of healthcare. There has essentially been some discontent that traditional approaches to research have failed to shed an understanding on some of the many complex phenomenon under study. Such traditional approaches based on laboratory studies and strict experimental design have been severely criticized based on their narrowness (Smith et al., 1995). Many of the more traditional experimental-type studies, although methodologically rigorous and scientifically valid, failed to account for "real-world" experiences and in this respect could be said to be "flawed" on ecological validity grounds.

In this respect the discipline of psychology has expanded into a more real world setting where ecological validity is of the utmost importance. More broadly within the domain of healthcare research such research has expanded considerably and now focuses on areas, which were difficult to study prior to qualitative techniques. The area of prescribing could be said to be one such area where quantitative techniques have offered little in the way of understanding of this phenomenon. Other examples, which have benefited from qualitative techniques, include the study of asthma (Adams et al., 1997) and cardiac problems (Ruston et al., 1998).

On the issue of a paradigm shift occurring within how psychological research is conducted, Smith (1995) makes the following statement: "in order to be able to conceive of itself as truly embarked on a post-positivist

paradigm, psychology needs to find new methods, methods which are more appropriate to the questions it now wants to ask and to the settings in which it wants to ask them" (p.4). Taking this quote at face value and practical level, one has to develop a methodology which will be effective in gathering the type of data which the researcher feels will be of benefit and answer the questions that one is positing, within the real-world setting that the behaviour occurs in. This is the task of qualitative research methods.

10.3 Qualitative Research – What Does it Involve?

Whereas traditional quantitative research methods involve the use of experimental design and statistical analysis of numerical or quantitative data, qualitative research methods do not involve any of the above procedures. Strauss & Corbin (1990) define qualitative research as "any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification" (p.17).

Typically quantitative research methods involve the use of numerical data gathered from psychometric means such as a psychometric test or checklist. Such psychometric assessments involve the use of pre-defined criteria into which the researcher is consumed if one decides to follow this route. Hence a study is conducted which involves the use of an assessment tool, data is gathered within the confines of the criteria of the assessment and the researcher bases their conclusions on the basis of data that has been gathered and analyzed. Although such research may be scientifically rigorous and empirically validated, many other issues may underlie the results obtained from such an approach. Because the participants are completing a psychometric assessment tool, they are merely answering the questions that are laid in front of them. Participants may have many comments to make on the related areas, but because of the research design employed they are not given the opportunity to discuss their comments.

Qualitative research techniques on the other hand do not employ a set of pre-defined criteria into which the researcher is attempting to place data. A study typically involves the researcher asking a series of questions related to the topic of interest. Such questions emerge from the researchers area of interest, previous work undertaken on the topic and areas, which have not been explored previously. Invariably such questions are open-ended and the participant is offered the opportunity to speak freely and openly about his/her opinions on the topic being researched. For example for the purposes of the present study, the author was interested in the area of psychotropic prescribing for persons with learning disability. While the data gathered in part one of the thesis was quantitative in nature, employing a quantitative methodology would have offered little in the way of an understanding of the factors which influence prescribing. On this basis, and due to the fact that the author did not find a suitable quantitative methodology to employ, a qualitative methodology needed to be incorporated into the study.

In incorporating a qualitative methodology, the author was interested in a number of avenues of scientific enquiry related to psychotropic prescribing. On the basis of this, a number of questions were developed in order to account for the findings from part one. These questions were developed into five open-ended questions rather than a list of twenty closed questions – which would not have yielded valid answers, due to their construction and due to the sensitive nature of the research topic.

As a means of undertaking qualitative research and gathering data, qualitative methods incorporate a range of techniques. These techniques include observational methods, interviews, documentation, the use of video and books. For the purpose of the present thesis, data gathering took place by means of a Prescribing Checklist (adapted from the Critical Incident Technique) and a focused interview with prescribers.

A question which is asked by many researchers new to qualitative research is why use qualitative techniques when a large array of quantitative techniques are available? The answer to this question is simple and brief and for those involved in the study of complex areas of healthcare research, there is no doubt but employing qualitative techniques has proved of immense benefit largely due to their being no suitable quantitative techniques available. Essentially as Strauss & Corbin (1990) have put it, the answer to this question is related to the nature of the topic under research. While many researchers come from a background of social anthropology, which routinely employs qualitative methods, many researchers come from disciplines such as medicine and psychology, which do not routinely use such techniques. Despite this however, such disciplines do study complex phenomenon and there is a need to employ qualitative techniques to research areas in which quantitative techniques have failed to address. As Strauss & Corbin (1990) have stated: "qualitative methods can be used to uncover and understand what lies behind any phenomenon about which little is yet known. It can be used to gain novel and fresh slants on things about which quite a bit is already known. Also qualitative methods can give the intricate details of phenomena that are difficult to convey with quantitative methods" (p.19).

10.4 Introducing Grounded Theory as a Qualitative Research Tool

There are a number of qualitative research methods employed by healthcare researchers. These include protocol analysis, ethnography, discourse analysis and constructionist approaches and finally grounded theory. Depending on ones discipline and the topic under study any of the above approaches may be used in qualitative research. For the purposes of the present section the author will present an overview of an approach known as grounded theory, due to its usefulness in analyzing the present set of results and formulating theory based on these findings.

A brief historical background of the development of grounded theory is the best possible starting point.

Grounded theory emerged within the 1960's and was developed by Glaser and Strauss (1965, 1967) who were two sociologists. As was mentioned earlier in this chapter qualitative methods have been used extensively by disciplines such as sociology and anthropology. However the principle methods employed by such disciplines included ethnographic fieldwork and case studies (Charmaz, 1995). Despite such methods being employed by these disciplines, the quantitative method of research was gaining dominance over such qualitative techniques and essentially qualitative techniques were used as a means of strengthening quantitative research tools. In addition at the time, as Charmaz (1995) notes, despite quantitative research being undertaken, little was happening in the way of theory construction.

On the basis of the backgrounds of these two authors, and in particular Anselm Strauss, five major contributions can be said to have been influential in the development of grounded theory. These five developments taken from Strauss & Corbin (1990) are as follows:

1. The need to get out of the laboratory setting and into the field setting if one wants to understand the topic under investigation.
2. The importance of theory, which needs to be grounded in reality in the development of a discipline or the topic under study.
3. The nature of one's experience and undergoing as continually evolving.
4. The importance of the role of the person in shaping the world around them.
5. Emphasizing the role of change and process and the complexity of life.
6. The inter-relationship between conditions, meaning and action.

The above five points are central to gaining an understanding of grounded theory and the underlying principles which are involved. In developing their grounded theory methodology, Glaser and Strauss (1967) emphasized the role of specific analytic procedures to be employed while undertaking such research. Up until this point many qualitative researchers relied upon fieldwork or experience and mentoring in informing their qualitative practices. The authors challenged such notions by offering researchers a set of written guidelines for undertaking qualitative research. Such an approach could be said to be based on the theoretical background of Glaser who trained in quantitative techniques and on the background and contributions of Strauss.

One of the main points of interest to the present author, and one which Glaser & Strauss (1967) emphasize in their original theory is the fact that grounded theory can be used by numerous disciplines. Hence grounded theory is not discipline dependent and so it covers a range of phenomenon studied by differing disciplines. For the purposes of healthcare research and the present topic of research, this is positive step towards gaining understanding and developing theory.

10.5 Characteristics & stages involved in the grounded theory approach

Charmaz (1995) defines grounded theory methods as "a logically consistent set of data collection and analytic procedures aimed to develop theory. Grounded theory methods consist of a set of inductive strategies for analyzing data" (pp.27-28). In essence the principle features or characteristics of grounded theory are that it is grounded in the data and theoretical in nature – in that a theory must be developed from the data which is more than just a descriptive account of what the data represents (Chamberlain, 1999). The data analysis and collection phase of the study go hand in hand, so that as one is collecting data, one is also analyzing it so

as to develop further avenues of research and expand the research topic under study. In terms of the core characteristics of grounded theory as developed by Glaser & Strauss (1967) & Strauss & Corbin (1994), these are outlined by Charmaz (1995) as follows, and include the following points:

1. Simultaneous involvement in data collection and analysis phases of research.
2. Creation of analytic codes and categories developed from data, not from preconceived hypotheses.
3. The development of middle-range theories to explain behaviour and processes.
4. Memo-making, that is, writing analytic notes to explicate and fill out categories, the crucial intermediate step between coding data and writing first drafts of papers.
5. Theoretical sampling – sampling for theory construction, and finally,
6. Delay of the literature review (p.28)

In collecting data, the researcher refers to point five above – theoretical sampling. For the purposes of the grounded theory approach the researcher is not interested in population representativeness, rather they are interested in how theoretically representative the topic under discussion are to the construct being studied. For example in the present study, the issues discussed in the interview material are very relevant to psychotropic prescribing in the learning disabled but because this is such a clinically defined area, there are a relatively small number of participants involved in the study, largely due to its discrete nature. Hence due to the nature of the topic under study, the present author was not interested in population representativeness, as it would not be applicable in this case.

In terms of the data collection phase of the study, this can be undertaken by a number of different techniques as discussed earlier – observation,

interview etc. For the purposes of the present study the author made use of a Prescribing Checklist (which served to gather critical incident of prescribing) and a focused interview with prescribers. In analyzing the data, Chamberlain (1999) distinguishes between three levels of coding – open coding, axial coding and selective coding (p.185). Once data has been collected (in whatever form) and transcribed (for the purposes of interview material), open coding takes place. This is the first phase of analysis and it involves the researcher identify codes or overall categories on the data. In essence it means the data is broken up and chopped into little pieces – each piece being a code or category. The next phase of analysis is termed axial, secondary or focused coding. This procedure involves investigating other data or interview material, which confirms or elaborates on the existing codes identified in the first phase of analysis or to identify relationships between codes. This phase of the analysis also serves to determine if the codes used are suitable or if they should be replaced with alternatives.

By using the method of constant comparison of data, the researcher is enabled to redefine or check the usefulness of codes and categories. As Charmaz (1995) states "a major contribution of grounded theory methods is that they provide rigorous procedures for researchers to check, refine and develop their ideas and intuitions about the data" (p.28). Once axial coding has been undertaken, this allows the researcher to engage in the final phase of analysis known as selective coding or the development of core categories. In this stage of analysis, the author is attempting to verify that the theoretical account generated to date is "saturated" and includes all concepts generated earlier. By this stage, by means of constant comparison, the researcher should be in a position to generate core codes, which will lead to the development of a theory around the topic under study. The use of memo's and diagrammatic representation of the research topic aid greatly in the development of theory – the use of memo's will be seen in chapter 11, while in the final chapter of this thesis, the author will outline a

theory of prescribing, grounded in the data gathered from the interview material. The author will now examine briefly the issue of reliability and validity in the grounded theory approach.

10.6 Assessing validity in qualitative research

To quote Smith (1996), "qualitative research should be judged against criteria appropriate to that approach. In other words, qualitative research should not be evaluated in terms of the canons of validity that have evolved for the assessment of quantitative research, since these have different epistemological priorities and commitments" (pp.191-192).

There is the tendency for researchers who predominantly use quantitative techniques to be critical of qualitative techniques. This is understandable due to the fact that qualitative techniques are very different to quantitative techniques and based on different philosophical understandings. What we mean here is that many researchers are still within the old paradigm of research being solely quantitative – the furthering of science involves far more than quantitative research methods. If one takes the view that science is about confirming disconfirming hypotheses, then clearly qualitative research methods do not fall within this realm, as the process of qualitative techniques is not about disconfirming hypotheses.

In an attempt to develop a framework around validity in qualitative research, Smith (1996) posits five possible criteria or "suggestions" for assessing validity, which are as follows: 1] Internal coherence, 2] presentation of evidence, 3] independent audit, 4] triangulation and finally 5] member validation. Smith argues that if the researcher applies these criteria to the topic under study and the methodology employed, one *may* have the means to assess the validity of the study. Smith notes that at the time, the criteria presented are in their infancy and subject to further evaluation. Despite this

however, the present author feels that these criteria offer a useful critique of the methodology employed.

Internal coherence is concerned with the study positing a coherent argument – if the study fails to take into account variation amongst participants or aspects of the study difficult to identify, then it may be said to have poor internal coherence. On the other hand if the study represents a good global view of all aspects of the study and is coherent in its rationale, internal coherence may be said to be good.

Presentation of evidence refers to the researcher having ample raw data to support the argument and theory being formulated. In this criterion, the reader of the study should be presented with ample evidence (raw data) so as to "interrogate" the data themselves and take an integral part in interpretation. The researcher in this case should present ample evidence to support the theory being formulated, rather than merely presenting third-party reports or anecdotal evidence.

Independent audit: this refers to all data and notes or memos being subject to an audit as it were, by someone other than the researcher. If one were to adopt this strategy, then it would involve an independent person reading all information regarding the study and determining if the final conclusions were appropriate and credible for the data collected. Independent audit as Smith (1996) states "is not attempting to suppress alternative readings or necessarily to reach a consensus; it is attempting to validate one particular reading" (p.193).

Triangulation as a criterion involves the use of differing methodologies as a means of attempting to gain a similar result. For example one may use two different methodologies in order to study a phenomenon. If the two methodologies yield similar results then these results could be said to be

valid, whereas if different results emerged, one would have to call the methodology used into question. Triangulation when used appropriately will add richer information in addition to strengthening the study.

The final criterion Smith discusses is that of member validation. This involves seeking more democratic research practices, where the researcher takes the findings back to his/her participants to discuss and comment on the researchers interpretation of the data. Needless to say there are problems involved as it may not necessarily be a democratic process, and the participants may not be in agreement with the interpretations of the author.

To conclude this section on validity of qualitative approaches, what has been presented is an overview of possible ways of examining validity when using qualitative techniques. As yet there are no defined criteria or ground-rules for examining validity when using such an approach. In essence, this could be said to be the main criticism of qualitative techniques. However if one takes the view of Smith (1996) that a paradigm shift has occurred by means of the techniques used to undertake research within the discipline of psychology, such criticism is overshadowed by the proven benefits of qualitative research. One will now turn the focus of attention to the qualitative research methods employed in the present study.

10.7 Qualitative research methods & the present study

Due to the complex and sensitive nature of the topic under study, the present author employed qualitative techniques in order to study the decision-making processes of consultant psychiatrists prescribing for persons with learning disability. From reviewing the literature on decision making and prescribing in general practice, the author was faced with a dilemma in that no suitable quantitative techniques have been developed to

date which would assist the author in gaining an understanding of this complex phenomenon. As a result of this, and from the research undertaken in the area within general practice, the author has opted to research the area by employing qualitative techniques as a means of gaining and understanding and building a theory of prescribing. The techniques used are the Critical Incident Technique (Flanagan, 1954) and as a means of analyzing the data and theory building, the author uses grounded theory (Glaser & Strauss, 1967). The author will now examine the usefulness of the Critical Incident Technique in this area of research.

10.8 The Critical Incident Technique

The critical incident technique was developed by psychologist John Flanagan during the second world war. The critical incident technique can be said to have developed from research undertaken in the aviation psychology programme of the United States Army air forces during the time of the Second World War. The development of the critical incident technique began with research into the reasons why pilots were failing to learn to fly and from their elimination from flight school. In analyzing the reasons for these pilots failure to learn to fly, numerous reasons were given which were based on stereotypes and clichés. Flanagan found this of immense interest but noted that there was a need to develop a systematic means of gathering information regarding such "incidents", be they factual or otherwise. Follow-up studies collected specific data regarding incidents which occurred for pilots be these failed bombing missions (Flanagan, 1947) or disorientation while flying (Wickert, 1947). With a number of research studies now completed, the critical incident technique was developed further and given its present title (Flanagan, 1954).

Since its official emergence in 1954, the critical incident technique has been used widely in healthcare research (Hubbard et al., 1965; Hayes et al.,

1979; Calman and Donaldson, 1991, Bradley, 1992a, b, c, and Allery et al., 1997 amongst others). A critical incident may be defined as follows: "by an incident is meant any observable human activity that is sufficiently complete in itself to permit inferences and predictions to be made about the person performing the act. To be critical, an incident must occur in a situation where the purpose or intent of the act seems fairly clear to the observer and where its consequences are sufficiently definite to leave little doubt concerning its effects" (Flanagan, 1954, p.327).

Despite this definition being over forty-five years since its development, its relevance in the present day has not diminished in any way. In fact if one applies it to the present study, the critical incidents of prescribing which were gathered from prescribers could be defined within this framework. An incident of prescribing is an observable human activity, which is subject to inference and prediction. In order for an incident of prescribing to be critical, the incident of prescribing must take place in a specific situation (the consultation) where the intent or purpose of the prescribing is clear to the observer, with clear consequences for the client. Hence this framework acts as a definition of a critical incident of prescribing for the purposes of the present study.

One of the principal advantages of the critical incident technique is its adaptive nature, which allows the researcher to collect data in the form of critical incidents for the topic under study. In this sense it is not a rigid methodology with fixed ideas and rules. Flanagan himself emphasizes this notion, when he states, "it is clear that the critical incident technique is essentially a procedure for gathering certain important facts concerning behaviour in defined situations. It should be emphasized that the critical incident technique does not consist of a single rigid set of rules governing such data collection. Rather it should be thought of as a flexible set of

principles which must be modified and adapted to meet the specific situation at hand" (p.335).

The critical incident technique has three principle characteristics and is said to be based on the following underlying assumptions: Firstly it is based on factual accounts of real events which take place which have clear consequences. Secondly, the interview, which is conducted, is focussed on specific reasons for actions and behaviours. Finally, the incidents, which are collected, are categorised using inductive judgements rather than placing any predefined criteria or theories upon the data (Bradley, 1992c, p.99).

These are the essential components and criteria for an understanding of the critical incident technique. This procedure proved very useful in gathering data in the present study. The author, through the use of the critical incident technique gathered critical incidents of psychotropic prescribing for persons with learning disability. These incidents rather than being collected solely by interview were collected initially by means of a Prescribing Checklist (a brief checklist devised by the author) and followed up and expanded upon by means of a focussed interview with the author. In utilising the critical incident technique, it afforded the author to gather rich data on a highly sensitive topic and to further expand on the collected incidents by means of interview. A more detailed discussion of the methodology and procedure employed will be discussed in the following chapter – chapter ten.

10.9 Chapter conclusions

To conclude, the present chapter sought to give an overview of the usefulness of qualitative research within the healthcare setting, and how such techniques were applied to the present study. By giving an overview of the principles of qualitative research, the author noted how essentially a

paradigm shift has begun to take place within the discipline of psychology, and indeed within healthcare research, as qualitative techniques are being extensively within the last two to three decades as a highly useful research tool. The second focus of attention within the present chapter was to examine the usefulness and applications of grounded theory (Glaser & Strauss, 1967) and the critical incident technique as developed by Flanagan (1954). These two techniques were used in the present thesis and they proved highly beneficial to the author in researching the area of psychotropic prescribing in the learning disabled population due to their flexibility and adaptability to all areas of research, in particular healthcare research. As the final rationale for using qualitative research methods in the present study, the author will take a quote from Green and Britten (1998), in which the authors emphasize the usefulness and value of such methods in this type of research. The authors state, "qualitative research can investigate practitioners' and patients' attitudes, beliefs, and preferences, and the whole question of how evidence is turned into practice. The value of qualitative methods lies in their ability to pursue systematically the kinds of research questions that are not easily answerable by experimental methods" (p.1230). It is due to such reasons that the present author employed qualitative techniques in the study of psychotropic prescribing for persons with learning disability.

CHAPTER ELEVEN

METHODOLOGY

11.1 Learning Disability Services: The Irish Perspective

Learning Disability Services in the Republic of Ireland have grown considerably over the past number of decades. The vast majority of these services are of a voluntary nature and are run by a religious Order. Typical examples are the Brothers of Charity Services, The Daughters of Charity Services and the Sisters of Charity of Jesus and Mary. The Brothers of Charity and Daughters of Charity are the two largest Service providers within the Republic of Ireland at present.

Within all services for persons with learning disability, a multi-Disciplinary team is in existence. These teams generally consist of Psychology, Social Work and Psychiatry as the core disciplines. Other disciplines such as Speech and Language Therapy, Physiotherapy and Community Nursing may be in existence in some services but whether they are seen as part of the Multi-Disciplinary Team or part of the wider Multi-Disciplinary Services is a matter of Organisational Service structure and policy. These teams vary considerably in number and discipline orientation across services and indeed across regions. For example in terms of Psychiatric and Medical input, some services have only one Consultant Psychiatrist in conjunction with one Registrar covering a population base in excess of six hundred.

For the purposes of the present thesis, the author was interested in a range of issues relating to the prescribing of psychotropic and psychoactive medications for persons with learning disability. Hence access to those persons undertaking prescribing was the central feature of Part Two of this thesis.

11.2 Participants

The core topic of interest in Part Two of this thesis relates to issues regarding the prescribing of Psychotropic and Psychoactive medications for

persons with learning disability. Although Part One of the thesis concentrated on patterns of prescribing for persons with learning disability within the Brothers of Charity Mid-West Region, it was felt by the researcher that a broader perspective was required in order to account for the wide variation in prescribing witnessed in Part One. In this respect the author required access to those persons who are "actively" prescribing for persons with learning disability within the Republic of Ireland.

Within Services for persons with learning disability in Ireland, prescribing of psychotropic and psychoactive medications is undertaken by Registrars (Junior and Senior) and primarily by Consultant Psychiatrists. From observing the drug charts, by means of which data was collected for Part One of this thesis, it was observed that the majority of prescribing is undertaken by Consultant Psychiatrists, with Registrars responsible to a far lesser degree for prescribing, and General Practitioners also involved (usually for those living in community facilities). Hence it was decided to gather the views of Consultant Psychiatrists throughout the Republic of Ireland on a range of issues regarding prescribing for persons with learning disability. For the purposes of the present study it was decided not to involve Registrars or General Practitioners for the following reasons:

- *Consultant Psychiatrists are involved in decision-making regarding service users (i.e. at case conference level) at a greater frequency than registrars.*

- *Within the majority of learning disability services within the Republic, "rotating schemes" are in operation for registrars, whereby they are on placement for a period of twelve months duration. In this respect registrars are essentially gaining experience in learning disability and their level of familiarity with services and service users is limited.*

- *Where registrars are faced with potential discomfort around prescribing decisions or complex issues arise, due to the nature of their training placement, they will consult with their senior Consultant Psychiatrist.*

- *Hence, the final decision regarding prescribing will rest with the Consultant Psychiatrist, placing emphasis on their experience in prescribing.*

- *In the case of General Practitioners who may prescribe for persons with learning disability, their role in the prescribing process is more clearly defined, as they tend to prescribe for conditions such as asthma and skin conditions, rather than prescribing psychotropic or psychoactive medications. Where they do prescribe a psychotropic medication, it is generally in consultation and in conjunction with the Consultant Psychiatrist.*

On this basis, the author sought the list of Consultant Psychiatrists who were members of the Royal College of Psychiatry while also being members of the Learning Disability Section. It should be noted that while all practicing Consultant Psychiatrists are members of the Royal College of Psychiatry, it is only those that are actively working in the field of learning disability that are members of the Learning Disability Section. In addition a number of Consultant Psychiatrists may be prescribing for persons with learning disability who are not in learning disability services (i.e. a number of persons with mild learning disability may be in psychiatric care and not in a learning disability service per se). These consultants are not members of the Learning Disability Section.

The author contacted the secretary of the Learning Disability Section of the Royal College of Psychiatry and outlined the rationale for the proposed study. A full list of the names (including addresses and phone numbers) of those Consultant Psychiatrists who are members of the Section was forwarded to the author. In total there were twenty-four Consultant Psychiatrists who were members of the Learning Disability Section within the Republic of Ireland.

Participants in the present study were eight Consultant Psychiatrists who were members of the Learning Disability Section of the Royal College of

Psychiatry. One of the prerequisites of the study was that any participants were required to be "active prescribers" for persons with learning disability. By this it is meant, they had to be employed within the field of learning disability and prescribing on a regular basis. As will be seen in the Procedure Section, the first task in the study was to complete Prescribing Checklists (Appendix B) – hence if prescribers were not "actively" prescribing, they were automatically excluded from the study.

On the basis of this prerequisite, four names were automatically excluded from the list, based on telephone conversations with the Consultant Psychiatrists. These consultants were retired (one), the nature of their work was largely managerial and research orientated (one), they were employed as Clinical Director and hence were not actively prescribing (one) and finally one consultant was on long-term sick leave due to illness. In this respect the population base on which the present study was based, consisted of twenty Consultant Psychiatrists in Learning Disability.

Of the eight consultants who partook in the study, five were female (62.5%) and three were male (37.5%). An age range was not obtained for the purposes of the present study, rather a "prescriber profile" was sought, where each consultant indicated on the Prescribing Checklist how long they had been prescribing (in general terms and specifically within learning disability), and whether they were presently prescribing primarily for adults with learning disability, children with learning disability or a combination of both. In terms of those involved in the present study, three female prescribers were "job sharing", one female prescriber was allocated to two different services (a split post), while the remaining four were full-time in the service where they worked. Table 11.1 below outlines the prescriber profile for the present study.

Table 11.1: A Profile of Prescribers involved in the Present Study.

	MALE			*FEMALE*	
Gender	*3*			*5*	
	0-5yrs	*6-10yrs*	*11-15yrs*	*16-20yrs*	*>20yrs*
Length prescribing	*0*	*1*	*2*	*0*	*5*
Do you prescribe mainly for:	*Adults with Learning Disability*	*Children with Learning Disability*	*Combination of Children & Adults*		
	5	*0*	*3*		

11.3 Materials.

Materials for the present study consisted of a Prescribing Checklist (see Appendix B), A Focussed or Semi-Structured Interview (see Appendix C), a Sankyo tape recording device with internal microphone and a set of TDK 90 minute recording tapes. Upon completion of the interviewing, data was transferred (by means of transcribing) onto a PC using Microsoft Word 2000 ©. A copy of ATLASti Version 4.1 © (Muhr, 1997) – a qualitative software package was used for the purposes of data management and analysis (PC version) upon completion of transcribing the interviews.

11.4 Constructing the Interview Schedule.

For the purposes of the present study the author has used a semi-structured or focussed interview schedule. While in most qualitative research projects the term "semi-structured interview" is used, Bradley (1992a) prefers the term "focussed interview" as it reflects the focused nature of the researcher to the topic at hand. In the case of used a semi-structured or focussed interview, respondents are not given a set of possible answers as in a structured interview, rather the respondents are free to answer in whatever manner they choose. In this respect the semi-structured interview is a far

"looser" process in terms of the researcher asking broad questions and the respondent answering them in a free-flowing manner. As Smith (1995) states "with semi-structured interviews, the investigator will have a set of questions on an interview schedule but the interview will be guided by the schedule rather than be dictated by it" (p.12). This was an important aspect for both the present thesis and also for the researcher who was new to qualitative research methods.

Smith (1995) also outlines a number of procedures for producing the interview schedule. These procedures were kept in mind at all times while the present interview schedule was being designed. The following stages outline the development of the present "Prescribing Interview Schedule":

- As part one of the thesis had been fully completed and analysed, the author needed to produce an interview schedule, which would both attempt to answer the questions posed from part one of the study (i.e. how does one account for the wide variation in prescribing for persons with learning disability), while doing so in an ethical and "unchallenging" way (the author who is a Psychologist would be interviewing members of a discipline other than his own (the medical profession), therefore caution was urged and questions needed to be posed in a "politically correct" manner). The five core issues which required answering were related to: typical incidents which result in prescribing, common presentations which give rise to prescribing, complex factors in prescribing, links between challenging behaviour and prescribing and finally discomfort arising from prescribing.

- An initial list of approximately twenty questions was generated. However upon review, many of the questions included were either value-laden or they were extremely sensitive (in that respondents would feel them far too sensitive and difficult to answer). These twenty questions were then

loosely categorised into five core issues, which the author felt would probe the area under investigation and yield interesting material for the purposes of the study.

- Once the core categories emerged, five "open-ended" questions were generated. Once this task had been completed, these questions then needed to be put in sequential order, with the initial questions being more general while the final questions were somewhat more sensitive in nature – in particular the issues of discomfort around prescribing decisions was a particularly delicate or sensitive area for prescribers.

- It could be said upon reviewing the present interview schedule, all the questions generated were somewhat sensitive - in that the author was essentially questioning each prescriber about their prescribing practice. However, it was felt by the author that such questions were required in order to generate meaningful discussion material, while also gathering data which would account for the findings of part one of the thesis. In this respect a number of probes and prompts were designed for each of the five core questions – these were a series of "mini-questions" in themselves, which would be asked when it was felt that a response was either sluggish, not enough information was obtained from the broader question, or where the respondent questioned the interviewer, or was unsure of the question being asked. Typical examples of such prompts were "could you tell me a little more about that", "that's interesting, could you describe another case where this happened" and "does this [a particular incident] happen frequently".

11.5 Research Design.

The design of the present study is descriptive in nature. The literature to date from the perspective of general practice has shown the value of

qualitative techniques in the study of prescribing decision-making (Bradley, 1991, 1992a,b, c). At present there is no empirical or psychometric technique, which may be used to assess or gain an understanding of such a complicated phenomenon as prescribing. In this respect the author chose to use qualitative techniques in an attempt to gain an insight into the prescribing behaviours of Consultant Psychiatrists in learning disability. The study used the technique of Grounded Theory methodology (Glaser & Strauss, 1967). The Interview Schedule, which was utilised, afforded the author to gain rich data from the prescribers into complex, controversial issues, which would have otherwise been difficult to gather by means of more traditional approaches. In addition, due to its interactive nature in all aspects including data collection and analysis, it gave the author the opportunity to generate theoretical models of prescribing based on data obtained through the interview technique.

11.6 Procedure.

The present study involved three distinct phases. These included:

1] Targeting Consultant Psychiatrists.
2] Consultant Psychiatrists completing the Prescribing Checklist, and finally,
3] Interviewing the Consultant Psychiatrists

Targeting the participants was undertaken by means of the author making contact with the secretary of the Learning Disability Section of the Royal College of Psychiatry, who herself is a Consultant Psychiatrist. A brief meeting took place in early October 1999 in which the author outlined the purposes of the study and the reasons for obtaining the list. At the time of the initial meeting, the secretary was aware that the author was a PhD student and was researching in the field of learning disability.

Within approximately two weeks of the initial meeting a list was forwarded to the author, which included the names, addresses and phone numbers of all those Consultant Psychiatrists who were members of the Learning Disability Section. The author then made contact with all names on the list by means of an initial cover letter, which outlined brief details regarding the author, the rationale behind the proposed study and what the study would involve. – completion of Prescribing Checklists in conjunction with a twenty to thirty minute recorded interview with the author on issues relating to prescribing and learning disability. A copy of the letter is attached in Appendix D. The letter concluded that within the following ten to fourteen days the author would make contact with each individual consultant by telephone to further explain the study while also answering any queries that consultants had regarding the study. Cover letters were sent via registered mail (in late November) so as to guarantee delivery.

Prior to the fourteen days expiring, there were a number of queries from consultants interested in the study. Any queries were duly answered and the rationale for the study was further outlined. Textbox 11.1 below outlines some of the positive comments made regarding the study:

Textbox 11.1: Initial Comments from Consultant Psychiatrists Interested in Partaking in the Study (transcribed directly via phone conversation).

- *I think it makes for a really interesting study ... prescribing definitely needs to be looked at.*
- *Yeah of course I'd like to be involved ... sure it's only an interview, no problem, it should be good.*
- *Yes – definitely count me in, no problems at all. Just make contact with me after the Christmas holiday and we'll arrange a time to meet.*
- *I think we should be involved at this end ... my colleagues in (location x- are going to be involved ... I was just talking to them this morning, so yes I would like to be involved.*

Within the fourteen days, the author made contact with the majority of consultants on the list (approximately twenty out of the twenty four). For those who were not contact prior to Christmas 1999, contact was made in early January 2000. The author failed to make contact with two consultants, despite numerous phone-calls and two cover letters being sent at various times.

Of the twenty-four consultants on the list, twenty were deemed eligible for the study due the prerequisite mentioned in the Participants section (consultants had to be "active" prescribers within the field of learning disability). Based on the information included in the initial cover letter and a follow-up phone-call, approximately fifteen to sixteen (70%) of the remaining twenty consultants were interested in, and agreed to partake in the study. Those consultants who had expressed interest in partaking in the study were sent copies of the Prescribing Checklist – this was a brief checklist designed by the author for the purposes of the present study. It included brief sections to be completed by the prescriber on service user demographic data, information about the service users presenting symptoms/behaviours, situational factors of significance, the resulting prescription(s) and finally some information about the prescriber themselves ("prescriber profile").

Consultants were asked over the course of a five-day period, to complete a separate Prescribing Checklist for every third service user for which any form of medication is prescribed. A specific time period was not allocated to the consultants involved – by this it is meant that due to other commitments, consultants were free to choose any five-day period in which to undertake this phase of the study. It was felt that if consultants were specifically directed to complete the Prescribing Checklists within a specified week, it may result in a poor response rate. Consultants were asked not to send the completed Prescribing Checklists via post, due to the sensitive nature of the

material recorded, rather they were asked to keep the checklists until the time of interview with the author and they would be collected at this point.

Once consultants had completed this phase of the study, contact was made once again via telephone by the author. In general the consultants had asked the author to ring back within four to six weeks as they felt this was an appropriate time-span in which to complete the Prescribing Checklists. Despite sixteen consultants being interested in the study, nine participants completed the Prescribing Checklists and wished to be interviewed.

The final phase of the study involved the author meeting face to face with the individual Consultant Psychiatrists who wished to be interviewed. All interviews were conducted in the consultant's place of work. Prior to conducting each interview, the author introduced himself in full, outlined the purposes of the study (in brief) while establishing a rapport with the consultant to be interviewed. Once each consultant was briefed in full, they were asked if they had any questions prior to the interview being recorded. If any questions were asked, these were answered in full (any questions asked were generally related to how long the interview was scheduled for, and were not regarding specific details of the study). The first of these interviews was held in Mid-February while the final interview was conducted in early June. Prior to the study being initiated, a focussed/semi-structured interview schedule was developed by the author. The aim of the interview schedule was to ask consultants about specific issues of relevance to prescribing for persons with learning disability. The complete interview schedule (including prompts) is attached in Appendix C. The principle issues covered in each interview were based on the following five questions - (for question one, consultants were asked to refer to their completed Prescribing Checklists when answering):

1. *Can you describe a recent case in which you prescribed medication?*

2. *From your experience in the field of learning disability, what are the common presentations which give rise to prescribing?*

3. *What factors do you feel influence the complexity of prescribing?*

4. *What issues do you feel are important in relation to prescribing and challenging behaviour?*

5. *Can you describe a case in which you felt "uncomfortable" about prescribing?*

Each interview took approximately thirty to forty minutes to conduct. All nine interviews were recorded in full with the permission of all participants. Prior to completion of the interview, while still being recorded, consultants were asked if there were any "other" issues which they felt were of importance to the study. This was an open-ended question designed to give consultants the freedom to raise any issues they felt were of significance or which they may have forgotten to mention earlier in the interview. Most consultants in the study raised novel topics or re-iterated some of the significant points made earlier in the interview. Once the interview was completed, the recording device was stopped and each consultant was thanked for his or her contribution to the study and complete confidentiality was assured. In general an informal conversation then arose regarding the research prior to the departure of the author. Completed Prescribing Checklists were collected by the author at this point.

11.7 Some Ethical Considerations.

Part Two of this thesis has a number of ethical considerations, which are of importance when taking the findings of this thesis into consideration. These ethical considerations may be seen as primary and secondary ethical dilemmas faced. Each will be discussed in turn.

Primary ethical considerations take into consideration the highly sensitive topic being researched – in this case prescribing for persons with learning disability. The participants in Part Two of this thesis were Consultant Psychiatrists within the field of learning disability. Throughout the interview they gave the author in-depth information about their prescribing practices, their own viewpoints on aspects of their work and most importantly they discussed individual cases where they were prescribing medication. These areas are highly sensitive and warrant extreme confidentiality. The following primary ethical procedures were put in place, both prior to the study commencing and upon its completion.

- Prior to the study commencing, each consultant was ensured complete confidentiality – both in terms of their own identity and also regarding the identity of any cases discussed.
- The Learning Disability Section of the Royal College of Psychiatrists was aware that the study was taking place, and broadly what the aims of the study were.

- Prior to each consultant being involved in the study, they were informed in full what the study involved (completion of Prescribing Checklists and an interview). Each consultant was informed by means of written letter and telephone conversation.

- Consultants were informed in advance that the interviews would be recorded in full and then transcribed by means of computer.

- Regarding participation in the study, due to its sensitive nature, each consultant made his or her own decision to participate or not. A collective decision from the Learning Disability Section was not sought (despite some consultants wishes for this approach to be used).

- Upon completion of Prescribing Checklists, each consultant was asked not to send any information by post. All Prescribing Checklists were collected by the author in person upon completion of each interview.

- Once each interview was completed, it was transcribed within a two-week period. Once fully transcribed, each individual tape of the interview was destroyed. Consultants were made aware of the fact that tapes would be destroyed upon transcribing. The author was the sole person which undertook all parts of the study (including transcription). At no point was secretarial support sought.

- Upon completion of each interview, the consultants were given full contact details for the author's place of work. This included address, phone and fax numbers and e-mail address, for the purposes of contacting the author if any queries regarding the study arose.

CHAPTER TWELVE

DATA ANALYSIS, PRESENTATION AND DISCUSSION

12.1 Core Issues Analysed and Discussed.

For the purposes of the present chapter, the author will display the core topics analysed in conjunction with a discussion of the issues raised by each. While many authors present their analyses and discussion independently, it was felt by the author that presenting data analyses and discussion together would make for a far more coherent overview of the topic under research. It also served to avoid an overlap of issues to be analysed and discussed.

As can be seen from Chapter ten, there were five core issues under study in Part Two of this thesis. These core issues were as follows, and the present chapter will adhere to the order of presentation as outlined below:

1. *Critical Incidents of Psychotropic Prescribing.*
2. *Common Presentations which give rise to prescribing.*
3. *Factors influencing the complexity of prescribing.*
4. *Links between prescribing and challenging behaviour.*
5. *Uncomfortable prescribing decisions.*

For each core issue under study, line-by-line coding took place followed by focused coding. In terms of data presentation in the present chapter, the author will attempt to provide as coherent a perspective as possible for each core issue, given that throughout the analysis a certain degree of overlap is present. This overlap represented participants raising similar issues in different stages of the interview, each being of relevance to the particular core issue under discussion. In order to decrease this possible overlap, the author will attempt to analyse and present the core issue giving line by line cores where appropriate in conjunction with focused codes followed by direct quotes from participants. Data presented and analysed in this manner follows logically the technique of Grounded Theory (Glaser & Strauss, 1967). Finally where relevant the author has generated conceptual models of prescribing which have been "grounded" in the interview

material. Such models are of importance in that they provide the reader with a diagrammatic overview of how prescribing takes place in terms of the prescribing practices of the consultants under study.

12.2 Critical Incidents of Prescribing.

For the purposes of this section the author will provide the reader with a series of tables (tables 12.1.1 to 12.1.7) which present an overview of the critical incidents of prescribing collected from consultants upon completion of the Prescribing Checklists. There were three main topics of interest gathered from these critical incidents. These related to service user demographic information (age, gender, level of learning disability and living environment), presenting symptoms which played a part in prescribing (medical/physical symptoms, behavioural symptoms and situational factors), and finally resulting medication prescribed (main drug category prescribed (anxiolytic, antipsychotic etc). Despite no critical incidents of prescribing for children being given, such incidents of prescribing represented the core issue under investigation – prescribing for adults with learning disability. As can be seen from the Medication Prescribing Checklist (Appendix B), prescribers had the opportunity to record information pertaining to children's cases. However none were collected and it avoided the issue of accounting for developmental level in the broader realm of prescribing. However information was gathered from some prescribers throughout the interview on issues pertaining to prescribing for children. Such issues will be discussed later in the chapter. In addition it must be noted that not all prescribers completed prescribing checklists and so the present section is based on a total of twenty-two critical incidents gathered from seven consultants.

Table 12.1.1 Critical incidents of prescribing gathered from Dr. A.

Demographic Information					*Presenting Symptoms*			
Case	*Gender*	*Age Range*	*LD*	*Living Envir.*	*Medical/ Physical*	*Behav.*	*Sit./ Other*	*Meds. Prescribed*
1	Male	18-30	Sev	Comm	-	4,8, Other	-	Anxiolytic Antipsychotic
2	Male	31-40	Sev	Res	-	4	2	Anxiolytic Antipsychotic Antidepressant

Table 12.1.2 Critical incidents of prescribing gathered from Dr. B.

Demographic Information					*Presenting Symptoms*			
Case	*Gender*	*Age Range*	*LD*	*Living Envir.*	*Medical/ Physical*	*Behav.*	*Sit./ Other*	*Meds. Prescribed*
3	Male	41-50	Sev	Res	-	1,3,8	2	Antipsychotic anticonvulsant
4	Male	31-40	Mod	Res	6	3,8	-	Anticonvulsant (x2)
5	Female	51-60	Mild	Comm.	-	3,5	-	Antipsychotic Antidepressant
6	Male	31-40	Sev	Res	-	1,3, other	-	Antipsychotic (x2)
7	Female	18-30	Mod	Comm	6	1,2,3, other	-	Anticonvulsant (x2)

Table 12.1.3 Critical incidents of prescribing gathered from Dr. D.

Demographic Information					*Presenting Symptoms*			
Case	*Gender*	*Age Range*	*LD*	*Living Envir.*	*Medical/ Physical*	*Behav.*	*Sit./ Other*	*Meds. Prescribed*
8	Female	18-30	Mild	Home	-	Other	-	Antipsychotic
9	Female	31-40	Mod	Comm	-	5,6, Other	-	Antipsychotic Antidepressant

Table 12.1.4 Critical incidents of prescribing gathered from Dr. E.

Demographic Information					*Presenting Symptoms*			
Case	*Gender*	*Age Range*	*LD*	*Living Envir.*	*Medical/ Physical*	*Behav.*	*Sit./ Other*	*Meds. Prescribed*
10	Male	18-30	Sev	Res	2,6	1,2,3, 4,8,9	3	antipsychotic
11	Female	31-40	Sev	Res	4	1,2,3, 4,6,8,9	4	anxiolytic
12	Female	31-40	Mod	Res	2,8	1,4	1,4	Anxiolytic Antipsychotic
13	Male	41-50	Mod	Res	2,6,9	5,6,9	-	anxiolytic antidepressant
14	Male	41-50	Sev	Res	7,8,9	4,8	-	Anxiolytic Antipsychotic

Table 12.1.5 Critical incidents of prescribing gathered from Dr. F.

Demographic Information					*Presenting Symptoms*			
Case	*Gender*	*Age Range*	*LD*	*Living Envir.*	*Medical/ Physical*	*Behav.*	*Sit./ Other*	*Meds. Prescribed*
15	Female	31-40	Sev	Res	6	1,3,4, other	2	Antipsychotic Antidepressant
16	Male	31-40	Sev	Res	9	1,2,8,9, other	2	Anxiolytic Antipsychotic Anticonvulsant

Table 12.1.6 Critical incidents of prescribing gathered from Dr. G.

Demographic Information					*Presenting Symptoms*			
Case	*Gender*	*Age Range*	*LD*	*Living Envir.*	*Medical/ Physical*	*Behav.*	*Sit./ Other*	*Meds. Prescribed*
17	Male	31-40	Mod	Home	-	1,6	1	Antipsychotic
18	Male	41-50	Mod	Res	5	1,3	3	Antipsychotic
19	Male	18-30	Sev	Res	-	3,4,5	2	Antipsychotic Antidepressant Anticonvulsant
20	Male	31-40	Mild	Res	5	3,6, Other	1	Anxiolytic
21	Male	18-30	Mod	Comm	-	3,6,8, Other	Other	Antidepressant Stimulant

Table 12.1.7 Critical incidents of prescribing gathered from Dr. H.

Demographic Information					*Presenting Symptoms*			
Case	*Gender*	*Age Range*	*LD*	*Living Envir.*	*Medical/ Physical*	*Behav.*	*Sit./ Other*	*Meds. Prescribed*
22	Female	31-40	Mod	Home	-	Other	-	Antipsychotic

Legend for Tables 12.1.1 to 12.1.7 (categories as per prescribing checklist in Appendix B).

Medical/Physical Conditions	*Legend*	*Behavioural*	*Legend*	*Situational/ Other*	*Legend*
Viral infection	*1*	*Hitting/kicking staff/peers*	*1*	*Recent change of environment*	*1*
Respiratory disorder	*2*	*Damage to property*	*2*	*Shortage/change of staff*	*2*
Sexual disorder	*3*	*Screaming/shouting*	*3*	*Medication requested by staff*	*3*
Pain disorder	*4*	*Self-injurious behaviour*	*4*	*Client expectation*	*4*
Cardiovascular disorder	*5*	*Depression*	*5*		
Neurological disorder	*6*	*Anxiety*	*6*		
Skin disorder	*7*	*Withdrawal*	*7*		
Allergic disorder	*8*	*Hysterical/hyperactive*	*8*		
Gastrointestinal disorder	*9*	*Sleep problems*	*9*		
Nutritional disorder	*10*				

Not only did the Prescribing Checklist serve to gather critical incidents of prescribing for persons with learning disability, it also served as a tool for consultants in answering question one of the interview schedule, which related to a recent case of prescribing where medication was issued. When answering this initial question, consultants were asked to refer to the completed checklists and give an overview of a recent case, which resulted in prescribing. Textbox 12.1

below gives an example of one consultant talking about a recent case, which resulted in a prescription.

Textbox 12.1 **Extract from one consultants interview (Dr. A) regarding question 1: Can you describe a recent case in which you prescribed medication for a person with learning disability.**

Dr. A: *Right, one of the cases which I would have been prescribing for quite recently was somebody who was a male adult, who is functioning in the severe range of learning disability and his problem would have been self-injurious behaviour. He would have been tried already over a number of years on behaviour modification methods, and this had been unsuccessful. So he was actually on a combination of antipsychotic and anxiolytic drugs, and he was noted to be drowsy by staff so the last time I reviewed him I reduced his drugs. He has benefited from the reduction in terms of his drowsiness but his self-injurious behaviour has not changed.*

For the purposes of the above quotation, which related to question one a total of six line-by-line codes were generated, which resulted in two focused codes being employed. Textbox 12.2 below will give an example of the interview extract, the line-by-line codes employed and finally the focused codes, which emerged from the data. From this point onwards, the author, only where relevant will give examples of line-by-line codes as the number of line by line codes per interview ranged from a minimum of sixty-eight to one hundred and ten codes. For the purposes of the present analysis, a detailed analysis of all line by line codes would be far too time consuming and would be far beyond the scope of the present research project. Rather, the author will examine in detail focused codes which emerged from the data and discuss these in detail. Due to the sensitive nature of the topic under discussion, prescribers only gave permission for the author to quote from their interviews in the present chapter. However they did not wish for their interviews (in full) to be cited or included in the appendices as it may identify the prescriber in question. Hence, they are not included in the appendices of this thesis.

Textbox 12.2 Extract taken from Dr. A's interview including line by line coding and resulting focused coding which emerged.

Interview Transcript	Line-by-line coding	Focused coding
Dr. A: Right, one of the cases which I would have been prescribing for quite recently was somebody who was a male adult, who is functioning in the severe range of learning disability and his problem would have been self-injurious behaviour. He would have been tried already over a number of years on behaviour modification methods, and this had been unsuccessful. So he was actually on a combination of antipsychotic and anxiolytic drugs, and he was noted to be drowsy by staff so the last time I reviewed him I reduced his drugs. He has benefited from the reduction in terms of his drowsiness but his self-injurious behaviour has not changed.	**Demographic data preceding "diagnosis"** **Problem area identified** **Failure of behavioural approach resulting in prescribing** **Polypharmacy being routinely prescribed** **Reduction in drugs due to side effects** **Reduction benefiting side effects but not behaviour**	**Drug reduction relating to side effects not condition**

The focused codes, which emerged above are solely related to the extract taken from the interview. It depicts how line-by-line codes emerge from the data itself and how in turn broader categories emerge. At all times the author is striving for codes which are readily apparent in the data and not simply placing "labels" or pre-defined criteria on the interview material. The next step in the analysis of the first core issue is to examine all the focused codes, which emerged from interview material pertaining to the critical incidents of prescribing.

Table 12.2 Core Issue 1: recent case in which you prescribed medication (critical incidents of prescribing) – Emergent Focused Codes & Categories.

Core Issue 1: Recent case in which you prescribed medication

Emergent Focused Codes:

1. **Demographic data impacting prescribing**
2. **Constant striving for a diagnostic label**
3. **Prescribing rationalized by presence of a "diagnostic label"**

12.2.1 Demographic Data impacting prescribing

Despite demographic data being included as a heading and section in the Medication Prescribing Checklist, all eight consultants made reference to the level of learning disability when discussing recent cases of prescribing. Upon transcribing, analysing and coding the interview material, the author felt that consultants tended to find the presence of a label such as "severe learning disability" a useful aid in prescribing. It tended to give prescribers a free hand to prescribe at will, just because there was a label present. It is interesting to note that from Table 12.1 above almost all cases of prescribing recorded were for service users within the moderate to severe level of learning disability. Only two cases out of the twenty-four were of mild learning disability. In this respect prescribers made note during the interview that the majority of their service users had a severe or profound level of learning disability and that

this in itself made them more susceptible to conditions such as challenging or disturbed behaviour.

One prescriber (Dr E.) at the very outset of the interview, prior to discussing any case makes the following statement:

> *Dr E: Well most of our residents here are within the severe to profound level of learning disability and over 60% have an overlying behavioural or psychotic condition so that there is a high degree of co-morbidity. So most patients I would prescribe for would have been disturbed – by that I would mean that they would be disturbed by means of a condition manifesting itself like self injurious behaviour or externally directed aggression or hyperactive purposeless behaviour, disruptive behaviour or they may have had a mood disorder, hypomanic disorder or they may of had a depression – an overlying depression or they may have had an overlying psychotic disorder such as schizophrenia or whatever.*

The prescriber in this respect is setting the scene for the author in that he goes on to discuss a number of cases where he prescribes on the basis of purely behavioural indicators, while constantly making reference to "diagnostic labels" such as "psychosis", "manic disorder". He describes one of his cases as follows:

> *Dr E: Now the first person – she is a female, between 18 and 30 years of age, severely learning disabled and residential. An associated respiratory disorder – asthma, neurological disorder – epilepsy and skin disorder – he had schoriasis. The behavioural aspect was really – I ticked off hitting and kicking staff or peers, damage to property, screaming and shouting, self-injurious behaviour, hyperactive and skin problems.*

The resulting medication, which is prescribed, in this case is an Antipsychotic and she is put on both a routine dose while also being prescribed a prn dose.

One female prescriber makes reference to level of learning disability as a means of trying to apply a diagnostic label. She makes note that a service user is in the mild range of learning disability (although not sure) and due to this fact she is verbal and can talk about her condition.

> *Dr H: Well she would have actually thought that people were talking about her and it was while she was preparing for her 21st birthday – that was really it, she felt that others were talking about her. She said that they are laughing at me.*

Now it wasn't me that took the original case – there was no agitation, she had also said that somebody put poison or drugs into her food, so that was another thing and she said that people in the centre were trying to harm her and were talking about her, and that was the first time that it came on acutely, and it has responded and she is an articulate lady and she is probably low mild.

In this respect from the evidence produced, prescribers constantly make reference to level of learning disability while making decisions about whether or not to prescribe. This may work in a positive fashion if the person is within the upper ranges of learning disability, however if they are in the lower ranges and are non-verbal, this certainly does have an impact on prescribing.

12.2.2 Constant striving for a diagnostic label

This is a key issue within the present thesis as all prescribers in the study constantly make reference to a "diagnostic label" prior to issuing a prescription. In a sense it can be said from reviewing all interview transcripts that there is a striving to find a diagnostic label for the purposes of rationalizing the treatment method employed. This not only relates to the issuing of a psychotropic drug but it also relates to non-pharmacological approaches. The author will now give some typical examples:

Dr B: Lets see, it would be a male in his 30's, with moderate learning disability, presenting with a long history of hyperactivity and intermittent aggression towards objects and screaming and shouting. His learning disability is of unknown origin and he also has some physical problems for which he is on gastrointestinal drugs.

In the example above the prescriber makes reference to two labels – hyperactivity and intermittent aggression. Further on in the interview the prescriber further elaborates on the issue of hyperactivity and how it relates to prescribing and the management of this service user:

Dr B: It takes a lot of staff input because he is on the move all the time, especially around mealtimes and that's the time when he can be destructive at objects and to things around him and he is also at risk himself from a tea drinking point of view as he will take a pot of hot tea and try and drink it if he could get the chance. Am, we have looked at him in various paradigms of mental illness because he seemed to have some characteristics of manic illness

but really when one goes back to his history he seems to have a constitutional hyperactivity. He would have a broad diagnosis of pervasive developmental disorder and the management problem is due to his hyperactivity and the aggression is secondary to his hyperactivity [ ] He is on major tranquillizer and that really hasn't made a great deal of difference to him. We have tried him on mood stabilizers, sodium Valproate, we tried him on lithium, and once again that hasn't made a great deal of difference to him. That' s about it, we're contemplating what we should do next and I suppose looking at the literature there is some evidence that Nalporoxone which is an opiate blocking agent may be helpful in children with pervasive developmental disorder and hyperactivity so we're just reviewing his health from the point of view of trying that.

As will be further elaborated on in the next section, the presence of a diagnostic label in itself seems to justify the prescription of psychotropic medication. Note how the "paradigm of mental illness" is now drawn into the interview in conjunction with pervasive developmental disorder. Another male prescriber who discusses a male service user with hallucinations and delusions again discusses the paradigm of mental illness. The author notes once again the emphasis on the use of labels and the need for a diagnosis:

Dr G: Am this next one is a middle aged man, he would be in his mid thirties and he is again, in fact he is within the mild range, low mild range of learning disability. He is on the medical side of things, he would have a minor cardiac problem, but it doesn't require any interventions – medication wise. On his behaviours, I would have ticked screaming and shouting, and anxiety. But the most prominent symptoms that he has in fact are, he has delusions and hallucinations. He has fixed delusions about people getting at him basically, and hallucinations – he would hear voices in his head on an ongoing basis.

This prescriber again places emphasis on the notion of behavioural indicators pointing to the presence of an underlying psychopathology. Interestingly the prescriber goes on to note that medication has not been effective in this clients but it is used in order to control the symptoms:

Dr G: I have known him over the years and I have had him on various medications and the diagnosis here would be schizophrenia. We don't – he has never responded to them (the medications) very well. So the medication has been more to control his symptoms for the moment rather than treating, well we certainly have not successfully treated his direct delusions and hallucinations.

Despite pharmacological interventions not being effective, the prescriber makes reference to the presence of hallucinations and delusions in conjunction with anxiety as a means of later justifying his prescribing.

The following case discussed with a female prescriber (Dr H) makes reference to a number of labels and conditions for which the prescriber seems unsure of what exactly is going on. She makes reference to numerous "diagnostic labels" without any apparent justification or presenting evidence.

> *Dr H: ... but the problem was that she was very anxious, she was ill at ease in her mental state. She had low mood, she was crying, she was irritable, her energy was up but her sleep was down and they felt that it was coming on over the last year and there was a query about auditory hallucinations.*

From this extract one can see again the constant striving for a diagnostic label. If a label does not seem to be forthcoming, all possibilities are thrown out in an attempt to find a suitable diagnosis. In such cases prescribers made reference to the complexities of some conditions in which it was difficult to apply a label readily. In this respect it could be said to be and "either–or" type of diagnosis. Signifying uncertainty on the part of the prescriber.

> *Dr H: I have written here query schizo-affective ... [ ] ... So this is a lady who either has a very severe depression that is psychotic but she wasn't actually saying anything, and she was laughing so you would wonder if she is schizoaffective. So she is on both and I was quite happy that she was depressed, and there is a family history of schizoaffective, both schizophrenia and affective disorder.*

12.2.3 Prescribing rationalized by presence of a diagnostic label.

As can be seen from the above section, prescribers in a sense "have a need" to find a diagnostic label that they can place on a cluster of behaviours. We can see this occurring in everyday practice whereby classification systems such as DSM-IV and ICD-10 are in constant use and aid in the process of labelling. Interestingly however, throughout all eight interviews no reference was made to any form of psychometric tool in aiding diagnosis. A possible explanation of this could be accounted for by the fact that the consultants under study felt themselves to be "experts" in the area of diagnosis and thus did not rely on psychometric aids.

Once a diagnosis had been placed on the client, it seemed to serve as a justification for the resultant prescribing. In this respect, if I place a diagnosis of depression on this person, I have then rationalized my method of treatment in that I will prescribe an antidepressant. A number of examples of this can be seen from each of the interviews conducted.

> *Dr A: The second case I think is quite similar. [ ] ... Again it is someone who has lived here for quite a long time and he is in his late thirties and he actually was self injuring also. He has quite significant self-injury – he is blind and there is an obsessional quality to it and he was on a drug that has an anti-obsessional characteristic to it and is also an antidepressant.*

In this example the prescriber has placed a diagnosis of self-injurious behaviour on the client. The rationale behind pharmacological treatment is in terms of firstly the diagnosis made (self-injury) and secondly in order to further rationalize the treatment, the drug prescribed has "anti-obsessional" properties in conjunction with being an antidepressant. In this respect the prescriber feels she has rationalized fully the prescribing of this psychotropic drug for the clients condition.

In the case of the male with hallucinations and delusions discussed above, again the rationale for his pharmacological treatment lies in the diagnostic label applied to him. The prescriber rationalizes the treatment regime as follows:

> *Dr G: I just put here delusions and hallucinations are ongoing, he would be anxious as a result of these delusions and then at times, he would respond to these voices by screaming and shouting as well as threatening. [ ] The most recent change of medication has been more as an anxiolytic medication which is Diazepam which he was on 5mgs three times a day, but I decreased it to 4mgs three times a day. [ ] He is on a variety of different medications for his psychosis – he is on Clopixol 400mgs weekly, he is on Respiridol 4mgs twice a day, so he on a lot of neuroleptic medication. And then in addition to that he is on Prozac 20mgs and Cogentin for the possible side effects from the neuroleptics.*

Not only does the prescriber rationalize the issuing of a change in this mans anxiolytic medication but he also rationalizes the administration of multiple drugs (polypharmacy) through the presence of labels such as psychosis, hallucinations and delusions and the severity of his agitated behaviour.

Other examples include the diagnosis of obsessional-compulsive disorder and depression in a woman with Downs Syndrome. Again the prescriber (Dr D) rationalizes the treatment in terms of the underlying diagnostic label.

> *Dr D: [ ] ... her presenting behaviour would have been some obsessional – obsessive compulsive behaviour. That was really what it was and I felt it was secondary to depression because in the past she had been depressed and she has had sleep disturbance and appetite disturbance with it. On this occasion she had the obsessive-compulsive behaviour without those. So I prescribed Seroxat (Piroxetene [prescriber unsure of the drugs chemical name]) – it doesn't really matter. It is an antidepressant – an SSRI.*

Finally on the issue of prescribing being rationalized by the presence of a diagnostic label, one prescriber (Dr H) clearly states the importance of finding a diagnosis and relating this to treatment. She states:

> *Dr H: [ ] ... literature would say that you cannot diagnose schizophrenia in an IQ of less than 50. but you can pick up signs that suggest that the person is hallucinating. Or they may come out with something very strange which would suggest that they are deluded about something and in that case, if there does not appear to be any affective component – if they are eating well, if they are sleeping well, they are still interested in things despite, as long as these other strange things do not interfere, I would put a diagnosis of schizophrenia on them and give them a trial of antipsychotic.*

Likewise in the case of "depression", the prescriber (Dr C) notes the importance of the behavioural indicators leading to a diagnosis, which in turn rationalizes the prescribing of an antidepressant. Note the added complexity of patients who are elderly and who may be diagnosed with depression. This issue will be discussed later in the chapter.

> *Dr C: Then if there is, depending on how able the person is, if there is clear signs that they are depressed, in other words, if there is a loss of interest in things, if there is a loss of weight, or increase in weight, less sleeping or increased sleeping, and general crying or they have basically lost interest in things, or they have slowed down or whatever. Again depending on their profile, if they are very elderly, and again you have to rule out organic in all of this. You presume that they have been checked over physically and that there is nothing physical wrong with them, that is the first step in making a diagnosis. And then in that case you are probably talking about a depression.*

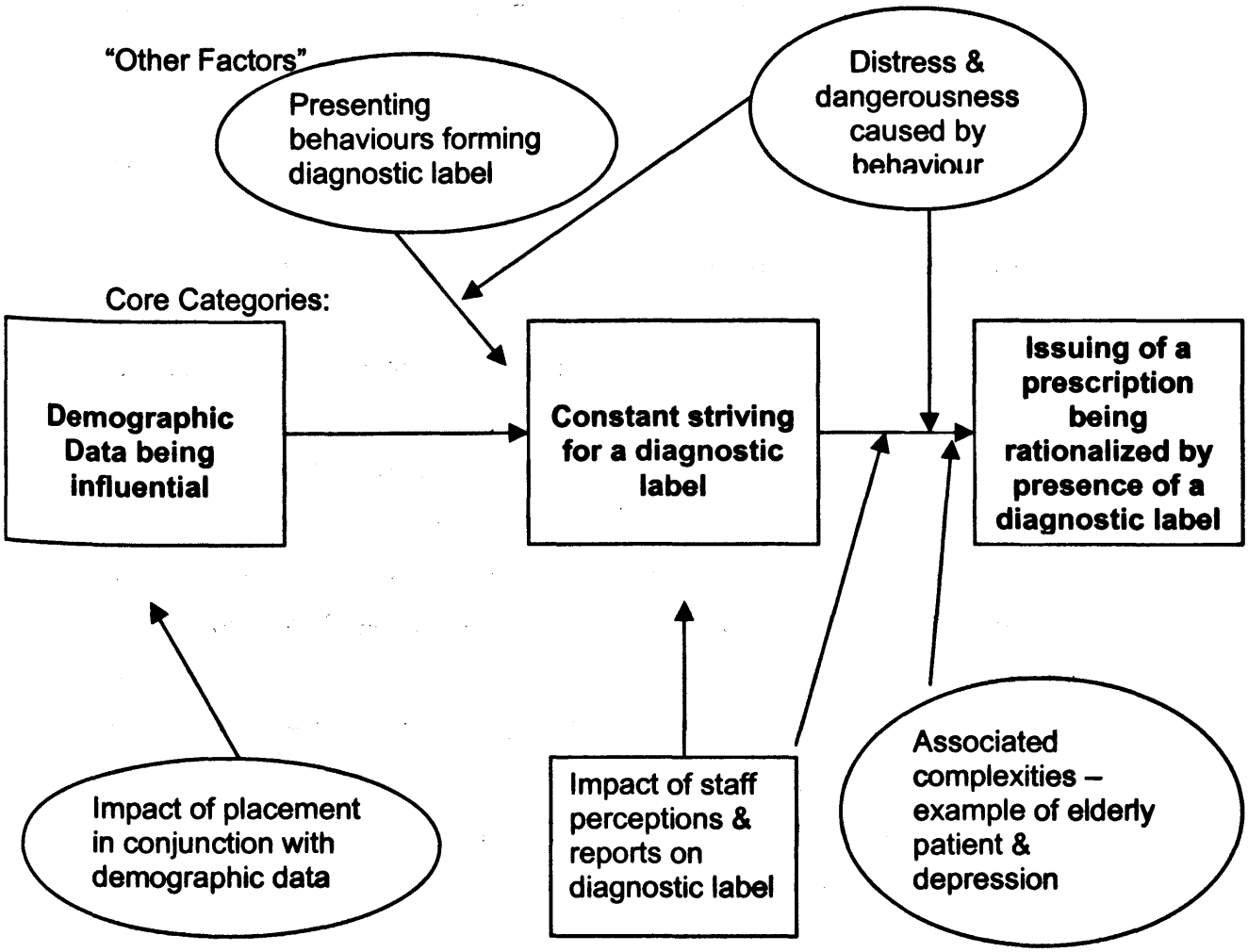
12.2.4 Concluding Remarks regarding Critical Incidents of Prescribing – Formulation of a Conceptual Framework of Prescribing.

Although only twenty-two critical incidents of prescribing were collected in the present study, they generated quite a number of issues regarding prescribing for persons with learning disability. The first section of the current chapter has been devoted to examining the initial criteria used to both formulate a diagnosis which in turn formulates or justifies the treatment rationale. It was difficult to discuss the emergent categories within this section as they essentially were somewhat derived from predefined criteria set out in the Medication Prescribing Checklist. Despite predefined criteria existing in the checklist, the author feels that rich and useful data was gathered by means of completed checklists in conjunction with interview material based on the checklists. Hence from this analysis, three core categories of interest emerged - how demographic data impacts on prescribing, constant striving for a diagnostic label on the part of prescribers and then in turn how prescribing is rationalized by presence of a diagnostic label. Each has been discussed in turn with relevant examples taken from interviews.

What has emerged from a discussion of these categories is a conceptual framework outlining part of the rationale behind the prescribing of psychotropic medication. However these three core categories only give us partial evidence into the decision-making processes of consultant psychiatrists in learning disability. A number of other factors come into being, many of which are yet to be discussed in the present chapter. With this in mind it is possible to generate an initial conceptual framework which gives us an understanding of prescribing in its broadest context. What were presented in Tables 12.1.1-12.1.7 above are actual cases of prescribing taken from a typical five day period. In this sense they are "real world" examples of prescribing and the factors which were taken into consideration when these prescriptions were being made. The conceptual framework outlined below provides a diagrammatic

representation of the core categories in conjunction with other factors of interest (to be discussed at a later point in the chapter).

Figure 12.1 Generation of an Initial Conceptual Framework of Prescribing including core categories and other factors of interest.



As can be seen from this initial framework many factors impact on the core categories which can lead to substantial changes in prescribing. For example as will be discussed in the sections that follow, reliance on third part information from direct-care staff may indeed have an impact on the diagnostic label, which is placed upon the individual. The issue of

placement is a factor, which is significant in terms of prescribing as the findings from Part One of this thesis have shown. Hence if a service user is in residential care, they have a greater probability of being placed on psychotropic medication than do those service users in community facilities. Finally the other factor of importance included within this framework is the issue of dangerousness or distress caused by the individual. This factor although not discussed in the present section was raised by a number of consultants due to its impact on prescribing. It will be discussed in the next section of the present chapter devoted to examining common presentations, which give rise to prescribing.

12.3 Common Presentations which Give rise to Prescribing.

The next core issue to be analysed and discussed relates to common presentations which give rise to prescribing. Whereas the first core issue was solely related to the prescribers practice and involved real world cases which resulted in prescribing, the following core issues were largely theoretical and the author was attempting to gain an understanding of the other complex factors that are involved in prescribing decision-making. The present section builds upon the issues discussed in the first sections of this chapter. Prescribers still made reference to the three categories mentioned above and throughout there was still the sense that at all times prescribers were either striving for a diagnosis and once this was obtained prescribing was rationalized and justified according to the diagnostic label placed upon the person. The author will now discuss the core categories which have emerged from interview material relating to this second section.

Table 12.3 Core Issue 2: Common Presentations which give rise to prescribing – Emergent Focused Codes and Categories.

Core Issue 2: Common Presentations which give rise to Prescribing.

Emergent Focused Codes & Categories.

1. **Psychiatric Diagnosis**
2. **Challenging behaviour/behaviour problems**
3. **Prescribing based on dangerousness & level of distress - "theory to practice hypothesis of prescribing"**
4. **Diagnosis based on third party reports**

12.3.1 Psychiatric Diagnosis.

This core category follows on from the issues raised in the first section of the present chapter. In this respect all consultants asked this question during the interview brought up issues pertaining to "psychiatric diagnosis" or "an underlying psychiatric diagnosis". On the basis of this, it helped to further strengthen the prescriber's rationale for issuing a prescription. Hence if I have a diagnostic label then this justifies my resultant prescribing.

It is interesting to note that almost all the prescribers involved in the present study were very clear-cut in answering this question. They felt it was an "either-or" situation. Two prescribers make reference to this immediately once the question is asked:

> *Dr D: but I mean really if you are talking about the formal mental illness which is schizophrenia or affective disorder or this disturbed behaviour – these are the main ones.*

> *Dr G: I think they come into two main categories – those with clear obvious psychiatric illness (which I mentioned above) – maybe like schizophrenia, where the person is clearly psychotic and where they may be depressed. The other group would be those with more or coming under the term challenging behaviour.*

Either the person had a psychiatric diagnosis or a behaviour disturbance. As will be discussed in the latter part of this section, many consultants felt that the term "psychiatric diagnosis" was a broad term used to incorporate the issue of challenging behaviour. Hence some prescribers saw the challenging behaviour itself as a psychiatric diagnosis.

Specifically on the issue of psychiatric diagnosis, the service user generally presents with signs of "problematic behaviour", which immediately result in prescribers attempting to find a diagnostic label. An example of this is given below.

> *Dr C: It's rare that someone starts with disturbed behaviour and if they do then you are really looking for a diagnosis. Usually it can be a depression or it can be a psychosis*

Within this example, the prescriber is saying that essentially she feels if someone is presenting with disturbed behaviour, then there must be an underlying psychiatric condition. Hence the striving to find an appropriate diagnostic label as again outlined below.

> *Dr E: I suppose I would also prescribe for adults who would have a bi-polar disorder, and who have a schizophrenic illness.*

One prescriber makes reference to the historical perspectives of prescribing for the learning disabled population. Again this prescriber (female) makes use of labels and attempts to justify prescribing from a historical perspective where perhaps "someone got it (the diagnosis) wrong" and thus this accounts for the high frequency of prescribing of Antipsychotics.

> *Dr B: One of the difficulties with the learning disabled population is when they present with behaviour problems it is not always easy to identify the psychiatric disorder if there is one. I think that is a big problem and I think that is why a number of people in the past were prescribed Antipsychotics and then left on them and then people assumed that they had a schizophrenic illness or something and then kept them on the medication.*

Finally on the issue of psychiatric diagnosis, one prescriber goes on to relate psychiatric diagnosis to the underlying brain damage that the person with learning disability has. In this respect, the perspective of the prescriber is very biological in nature relating any conditions to the underlying brain injury, which may not be an accurate reflection of the cause of a condition. In addition he makes reference to the need for more secure environments while also relating the condition (or diagnosis) to the prescribing or "need for more medication".

> *Dr B: And also I think there will be a few people who are going to present with extreme behavioural problems who will need medication and more secure environments, the same as there are in our general population. It may be a higher amount because of the amount of brain damage. We do know that most things like personality disorders, psychosis are related to brain damage and so are obviously a complication of brain damage, by virtue of the fact that is why they are here.*

MEMO BOX 12.1 – THE AUTHORS THOUGHTS ON PSYCHIATRIC DIAGNOSIS.

Quite clearly the consultants feel that challenging behaviour falls under the umbrella of "psychiatric diagnosis". My reasons for stating this are two-fold. Firstly although they clearly define the two categories, they devote far less to a discussion of psychiatric diagnosis per se, than they do to challenging behaviour. At all times they refer to the difficulties associated with finding this diagnosis – although they do label, they do so from the point of view of behavioural indicators – it's like the clustering effect. Just because this number of behaviours are present, I will label the persons as being [ ]. Secondly, they tend to refer to the complexities in finding this diagnosis, things like the person being non-verbal or the behaviours being difficult to classify. Its as though they see the person as having challenging behaviour, but this disruptive behaviour just points to a psychiatric diagnosis. The interview material makes for really interesting listening – on one hand there are two categories for which medication is prescribed but really when it comes to it, there is only one – challenging behaviour. The use of labels in a sense helps to justify this. I will further

analyse this later in the section when I refer to the "theory to practice" hypothesis" of prescribing, which will involve other complex issues.

The next core issue to be analysed and discussed is the issue of challenging behaviour as a common presentation which gives rise to prescribing.

12.3.2 Challenging Behaviour/behaviour problems.

As mentioned above in the Memo box, the author felt that although prescribers felt psychiatric diagnosis was a common presentation which gave rise to prescribing, essentially challenging behaviour or behaviour problems are the most common reason why psychotropic medication is being prescribed. Prescribers tended to "gloss over" the issue of psychiatric diagnosis and certainly they did not discuss it as frequently as the issue of challenging behaviour. Although the present section, devoted to the discussion of the core category of challenging behaviour/behaviour problems a range of terms were used to describe it. Prescribers tended to primarily use the term challenging behaviour or behaviour problems, but terms such as difficult behaviour, problematic behaviour and behaviour that challenges the system were also used. The present section will analyse and discuss the findings obtained relating to this core category.

At the outset one prescriber makes reference to the historical perspective where people with learning disability were prescribed medication purely for the purposes of challenging behaviour, and how he feels things have changed (in respect of the "underlying condition") more recently on this issue.

> *Dr B: I think historically, and as we know, people with learning disability tended to get put on major tranquillizers for aggression and aggression in inverted commas. I think what we're now hopefully taking a more in-depth look at why people are presenting with behavioural problems and the assessment looks at what's causing it and hopefully determining what's causing it with medication rather than treating it with just signs that are presenting.*

As an aside to this analysis, although still forming part of it is the issue of the terminology used by different prescribers. Note above the use of the term "major tranquillizer". Essentially this term has since been replaced with the term antipsychotic, which the majority of prescribers used throughout the interview. It is interesting to note however that some prescribers still refer to the older terminology, despite such terminology being out of date.

On the positive side of things, the above prescriber makes reference to attempting to ascertain what is causing the challenging behaviour. This is positive in that he does not believe in treating symptoms, but it may mean that again he is striving to find a diagnostic label, which will rationalize the resultant prescribing behaviour.

Again another prescriber (Dr A) talks about prescribing psychotropic medication for those who either have challenging behaviour which may be part of a psychiatric diagnosis or for those who she feels do not have a psychiatric diagnosis. In this respect she states:

> *Dr A: The second group then I suppose where psychotropic medication may be used is probably in the whole area of managing behaviour difficulties. Now that can be two groups – that can be where there can be an association with a psychiatric illness anyway, and you are talking about acute management there. And then there is the other group who have different features of behaviour which is seen as challenging. And it really depends on what that is for the individual.*

Again we see the relationship between challenging behaviour and psychiatric diagnosis once more. At this point it seems as if prescribers tend to have two classification systems in their own heads – those persons with learning disability who have challenging behaviour which may be associated with a psychiatric diagnosis and those for which a relationship between psychiatric diagnosis is poorly understood. This classification framework would tie in with the earlier discussion on "striving for a diagnostic label" in that prescribers are more comfortable prescribing psychotropic medication where a diagnostic label does exist, whereas if the relationship between challenging behaviour and psychiatric is poorly

understood and thus a label is not placed on the person, this results in some discomfort for the prescriber. In this respect the author terms it the "theory to practice" hypothesis of prescribing whereby in theory prescribers are not happy prescribing just for "purely" challenging behaviour, but in practice they do prescribe for challenging behaviour. This will be discussed in the next section.

Other prescribers make reference to challenging behaviour as a common reason for prescribing as follows, emphasizing the difficulties encountered.

> *Dr A: Self-injurious behaviour is a hard one to call at times, as to whether it does reflect an underlying psychiatric condition, or with any of the behaviours, I suppose it's hard.*

The extract taken from an interview outlined below clearly outlines that this prescriber (male) prescribes medication solely in terms of challenging behaviour – based on its dangerousness.

> *Dr D: The other group would be those with more or coming under the term challenging behaviour, severe behaviour disorder where it is not clear why the person is behaviour like they are but what is definite is that they are a danger to themselves or to others and there would be a significant number of people that I see where medication and I would have to choose medication in those circumstances.*

The same prescriber outlines that at times he comes away "unhappy" when he has to prescribe for challenging behaviour in the absence of an underlying psychiatric diagnosis, while to conclude he rationalizes the prescribing in terms of it seeming beneficial.

> *Dr D: Sometimes with the challenging behaviour group it is difficult to know is there an underlying condition – in one of the cases that I mentioned, the man had severe autistic disturbed behaviour, he was depressed and he was injuring himself and the medication did seem to have some benefits – he did gain some benefits from it. There is a bit of trial and error but I would say that even in some cases where there is no obvious psychiatric diagnosis, you don't come away particularly happy but whether it is their agitation or they are acting out behaviours, you are treating maybe the symptoms, rather than an illness as such. And it seems to benefit them.*

Finally one female prescriber (Dr A) classifies behavioural problems as being the primary or most common reason for her prescribing, in particular self-injurious behaviour. Note the issue of dangerousness or distress being influential in terms of prescribing, although it is not clearly stated here.

> *Dr A: I suppose the commonest would be behavioural problems and they would be in the residential population here. Aggressive behaviour be it self inflicted – self-injurious behaviour or towards other staff members. I think that would probably be the main one.*

Finally on this issue a male prescriber (Dr E) again makes reference to challenging behaviour (primarily self-injurious behaviour) as being a common presentation which results in prescribing. Not only does this prescriber mention self-injurious behaviour per se, but he also makes reference to the behaviour as a being a manifestation of a possible underlying condition, further emphasizing the points made earlier.

> *Dr E: Well now speaking for this place here, the most common problems which give rise to prescribing are really disturbed behaviour – be it self directed or externally directed. These are the two most common and they seem to be very prevalent. And there is a high degree of co-morbidity and it manifests itself as disturbed behaviour.*

To conclude the present section it is interesting to note the interaction-effect between the concepts of psychiatric diagnosis and challenging behaviour. Where the challenging behaviour may be related to a psychiatric diagnosis, it again tends to justify the prescribing behaviour, whereas if the challenging behaviour is not viewed within the "paradigm of mental illness", it tends to leave prescribers feeling unhappy about issuing a prescription, largely due to the absence of a label other than "challenging behaviour".

12.3.3 Prescribing based on dangerousness & level of distress - "theory to practice hypothesis of prescribing"

It was largely due to the preceding core category "challenging behaviour" than the present core category emerged. From the discussion above, it

can be seen that prescribers routinely prescribe for challenging behaviour, even in the absence of an underlying psychiatric diagnosis. However not only is the presence of the label of challenging behaviour of significance, it is strongly related to the type of challenging behaviour displayed by the individual and most importantly it is related to the dangerousness (for the individual or for other individuals) or level of distress displayed by the individual. The present section will elaborate on these issues further.

The prescriber below clearly outlines his rationale for putting a service user on medication – it is because the person has challenging behaviour which is of such significance that they are a danger to themselves or to others. Hence the emphasis on level of dangerousness displayed.

> *Dr G: [ ] ... but what is definite is that they are a danger to themselves or to others and there would be a significant number of people that I see where medication and I would have to choose medication in those circumstances. In some cases you require a fairly small dose of the medication, maybe you need very little, but it can be just enough to work to help.*

The extract taken from the prescribers interview below, outlines part of her decision-making process in terms of balancing the risk between prescribing and not prescribing, resulting in injury to either the service user or those around him.

> *Dr A: Balancing that with the risk to the individual and to others around them, so I look at it in terms of are they going to injure themselves, whether they show aggression towards objects, or aggression towards others, in the context of the level of learning disability that they have and what their environment is.*

Within this extract the prescriber also makes reference to the importance of environmental factors within the process of prescribing. She goes on to state a number of interesting points in relation to the environment and other factors discussed already such as placement within the services and level of learning disability.

> *Dr C: The environment can play a huge part. The individuals we look after do not choose to live with who they live with if they are particularly disabled, when they are a little bit less disabled, they are more likely to explain to people that they don't like a or b, those that are sharing the house with them and they may move, particularly in a community setting. But certainly in the residential setting,*

where people are more disabled, its harder for them to make choices and some individuals are stronger willed than others and make their feelings known, maybe by being aggressive. So you have to take that into account and in saying that, medications may be used.

The issue of service users being non-verbal or their lack of ability to communicate will be further discussed under core issue number 3 – factors affecting the complexity of prescribing.

The issue of level of dangerousness, be it internal or external is further emphasized by another prescriber below. She states (and I extract three distinct quotes from her interview material):

Dr D: So with regard to factors which influence my prescribing certainly I think the degree of distress the actual patient is in and the actual staff are experiencing as a result of the behaviour problems as well. I do feel influenced by staff's responses to behaviour and what they feedback to me.

The following quote introduces the prescribers "sense of responsibility" into the prescribing equation, in that if a person is injured or the client is self-injuring, the prescriber feels a sense of responsibility in conjunction with the "need to do something". These are clearly stated as influential factors in prescribing.

Dr D: But I would say that with regard to challenging behaviour as I may have said earlier, [ ] ... injuring a staff would be one of the reasons that I would prescribe – injury to another staff member, or self-injury – those two. I see these as factors which would definitely influence me to prescribe.

Dr D: So I think I do feel responsible when, I have a sense of responsibility for staff and for patients when injury comes into it. The level of dangerousness is the key here – dangerousness.

From the evidence produced to date, one can see a type of transformation occurring in respect to the common presentations which give rise to prescribing. In the opening pages of this chapter, the author discusses the prescribers constant striving for a diagnostic label in order to rationalize prescribing. In this respect prescribers were attempting to keep within the realm of objectivity and scientific practice. If they were able to diagnose a particular condition and place a label on a service user

because they were presenting with a number of symptoms which pointed to a diagnosis, then in a sense this was rational and objective and was well within the realm of the medical model.

However what the author has just presented here is evidence to the contrary grounded in what prescribers themselves have said. In essence for a number of prescribers one of the key issues in whether they are to prescribe or not is the issue of level of dangerousness displayed by the person – be this internally directed aggression (SIB) or externally directed aggression towards others. The author terms this the "theory to practice hypothesis of prescribing", where two differing perspectives emerge, those of a theoretical nature and those relating to practice. Rather than discussing these issues in the current section, the author will provide some further evidence throughout other sections of the present chapter relating to other core categories and further discuss them in the concluding section of the present chapter.

12.3.4 Diagnosis based on third party reports

From reviewing Chapters two and three of the present thesis, one can see that due to the many difficulties associated with the learning disabled population, quite frequently diagnosis are formed around third party information. The major problem with diagnoses being based on third party information is that very often the information received is inaccurate and unreliable. The present section sought to examine these issues in relation to prescribers involved in the present study.

From the material analysed and discussed to date in the present chapter, there is an emphasis on diagnosis in an attempt to rationalize prescribing. In respect of diagnoses being formed however, prescribers in the present study clearly outline the subjective elements associated from basing diagnoses on third party reports, while also outlining that their diagnostic labels formed were reliant on these third party reports. One prescriber (Dr A) states:

Dr A: Issues around the complexity of diagnosing mental health problems can be a complexity – you are very reliant on an historian at times and the best historians are often family. But sometimes it can take somebody else outside the family to recognize something, certainly in the community attendees.

She further elaborates on this point, emphasizing the role of the primary carer in aiding the diagnostic process, when the service user is unable to report on how they are feeling.

Dr A: You are very reliant depending on their ability level on the people that care for them to give you the information, apart from members of the clinical team which might be involved. And if you are dealing with the community, you have to link in very much with primary carer.

The following prescriber (Dr F) places emphasis on the role of the carer in observing any changes in their behaviour in conjunction with offering information to the prescriber about the pattern of behaviour observed by the carer.

Dr F: You are relying on knowing the people quite well or talking with people who know them quite well, who see another change in how they actually are.

Dr F: Getting information from third party reports is very helpful and it is usually very genuine. Ideally if the staff know the person very well, then that's the important thing – if they have known them over time, so they know them well enough to actually see a change.

Although this prescriber is noting that information received from direct carers is genuine, she does not question whether or not the information obtained is accurate and reliable. In this respect the formation of a diagnosis may be based on inaccurate information.

One prescriber takes the information from staff as being reliable and bases her diagnosis of depression largely based on the fact that staff have said this lady is depressed

Dr F: but from reports from staff, they are mainly saying that she is depressed.

Interestingly one female prescriber (Dr H) makes a strong statement about the issue under study and feels that if the client is non-verbal and

unable to tell the prescriber how she is feeling, then it is a very imprecise science.

> *Dr H: [ ] ...we use the interview and the very person we need to interview we cant. So it is all speculation unless the person is mild and has good articulation and comprehension. Other than that if they are non-verbal or if they are poor verbal abilities, it is all speculation and conjecture. You are dependent on the carers telling you and that is imprecise and very difficult.*

Interestingly this prescriber feels that diagnoses based on third party information are quite imprecise. If she is unsure of a diagnosis she makes reference to giving a trial of a drug and if there is no improvement she will cease to prescribe this drug.

> *Dr H: I see them [staff reports] as being imprecise, and as I keep saying I give a trial of something and if it doesn't work ... [ ] ... So I am very very cautious about it because I actually like to actually give a drug and know why I am giving it, and know that there is an improvement, and if there is no improvement, there is no point.*

Most prescribers however do not seem to be as cautious in taking third party reports from staff for granted. Likewise they acknowledge the difficulties associated with diagnosis when clients are non-verbal and rely on nursing reports in conjunction with their own observations.

> *Dr F: It is hard to diagnose when the person cannot communicate clearly and a lot of the time a lot of them – the patients cannot verbalize, but they will – it's a matter of monitoring their behaviour pattern and trying to decide as best you can from nursing reports plus your own observations and what exactly is the whole problem, if you can get to that. And then prescribe as appropriate you know.*

Finally one prescriber (Dr C) makes note that direct-care staff are the "best observers" of clients behaviours and she values the information/observations received from staff. An extract emphasizing this point is taken from her interview.

> *Dr C: Well somebody who looks depressed, that is the first thing and staff are the best monitor of this because they will tell you about this – someone is not sleeping well – maybe a first sign, maybe they are not interested if they are in a workshop, they are not interested in television, like a general lack of interest –*

only on a more difficult scale than an ordinary person who can tell you I'm this, this and this ... It is observation on the part of staff mainly.

12.3.5 Concluding Remarks regarding common presentations which give rise to prescribing

To conclude this section, one can see the issues that prescribers feel are common presentations which give rise to prescribing. Although prescribers themselves feel these can be generated into two distinct categories – psychiatric diagnosis and challenging behaviour, there is more going on that just the presence or striving for a diagnosis. While prescribers do strive to find an appropriate diagnostic label in order to justify their prescribing, evidence points to the fact that the diagnoses made are most certainly over-reliant on information received from third party reports. Although some prescribers make reference to observing nurses reports and undertaking their own observations, such observations commonly take place within the consultation session and not within the person's real-world or "home" environment (be this in a residential or community house).

The fact that most prescribers in the study made reference to dangerousness and level of distress as the key factor which influenced their decision to prescribe raises some caution. Not only do prescribers base their decision to prescribe on dangerousness or distress, but also this is most often conveyed to them by means of staff reports. Quite clearly what one staff may consider or perceive as dangerous behaviour may be perceived completely differently by another staff member. Hence justifying prescribing based on what staff report to the prescriber is a dangerous practice and is subject to numerous ethical considerations. As one prescriber (Dr C) has stated in relation to getting a different picture from different staff:

Dr C: ... [ ] Maybe getting one story from one staff and another story from another would make it very difficult for as until you know the staff awfully well and you can balance that up between the two of them, it is very difficult. You get two different pictures.

As a result of the present discussion, prescribing from the perspective of the prescribers themselves is very often a trial and error process and is subject to a wide range of elements outside those of a strictly pharmacological nature.

12.4 Factors Influencing the Complexity of Prescribing.

Factors influencing the complexity of prescribing was the third core issue of interest in Part Two of this thesis. Although what has been presented to date in the current chapter has included many of the complex issues in prescribing as outlined by prescribers themselves, this section focuses on the specific issues which prescribers felt were complex in relation to psychotropic prescribing. Even though quite a number of issues emerged as complexities, these were categorized into four main categories which will now be analysed and discussed.

Table 12.4 Core Issue 3: Factors influencing the Complexity of Prescribing – Emergent focused codes and categories.

Core Issue 3: Factors influencing the complexity of prescribing.

Emergent Focused Codes & Categories.

1. **Whether or not to prescribe psychotropic medication – a trial & error approach.**
2. **Drug profile & side effects – the risk benefit ratio.**
3. **Ruling out physical/underlying causes.**
4. **Expectation element on the part of others (staff & family) – the magic bullet.**

12.4.1 Whether or not to prescribe psychotropic medication – a trial & error approach.

In the last section the author makes reference to the "theory to practice hypothesis of prescribing", where in theory prescribers were saying they were unhappy prescribing for challenging behaviour but in practice they

were actively prescribing for challenging behaviour where there was no presence of an underlying "psychiatric diagnosis". The present section is somewhat similar in that prescribers feel the process of prescribing rather than being an objective science is more to do with trial and error, hoping that the prescription will be of some benefit to the client. A number of prescribers make reference to this "trial and error approach" to prescribing.

> *Dr G: Well there is always the complexity of deciding whether it is worth while putting somebody on medication or not and a lot of the time it is a trial and error approach and for instance I saw someone recently and she was ADHD I felt this was the diagnosis with her, but the use of Ritalin for her did not have any benefits for her.*

In this case the prescriber is again guided by the fact that a diagnosis of Attention Deficit Disorder with Hyperactivity is present. Although he does not state whether this is a child or adult, children are frequently prescribed Ritalin for the purposes of controlling ADHD, but in this case it has proved of little benefit. He goes on to further this point by stating.

> *Dr G: And then you are looking at, what in any other medication would be of benefit for her, so there is the complexity of which medication to use sometimes – should you use that or should you use major tranquillizers or antidepressants – SSRI's may sometimes be beneficial. So on the diagnosis it can be varied as to what medications might be beneficial*

Many other prescribers have the same perspectives regarding the trial and error approach to prescribing and how this in itself can lead to discomfort in prescribing.

> *Dr D: There is a bit of trial and error but I would say that even in some cases where there is no obvious psychiatric diagnosis, you don't come away particularly happy.*

The prescriber below (Dr D) makes reference to using or "trying" multiple drugs in an attempt to find the one of most benefit. In these cases it is the prescribing of a series of medications which can lead to polypharmacy, if

the initial drug is not withdrawn upon commencement of the add-on medications.

> *Dr D: I suppose in a number of cases here, you are often trying a whole series of different medications and that can be hard particularly for the families and for staff.*

On the issue of medication being ineffective for some conditions, one prescriber reiterates this point in relation to prescribing for self-injurious behaviour, noting the complexity of the length of time it may take to withdraw medication.

> *Dr D: ... let me see, well for severe self injury I mean sometimes medication is ineffective anyway, so you make the decision sometimes that you just don't use it, you might try it but you don't keep people on it, because it doesn't work but it takes a while to take people off it. Sometimes that can take a while as well, years in some cases.*

As was mentioned above, prescribing multiple medications in an attempt to ascertain which is most effective or beneficial may increase the likelihood that polypharmacy will result. This is a common cause of concern for those clients with epilepsy and a number of prescribers make reference to epilepsy as a complex condition in prescribing. One prescriber makes reference to epilepsy as a "triple handicap" – epilepsy in association with the presence of a dual diagnosis. The prescriber outlines the difficulties which emerge when prescribing for the person with epilepsy.

> *Dr G: [ ] I have mentioned brain damage, which leading on to that of course is that a lot of the patients I see have more that a dual diagnosis, they have a triple diagnosis in that they have epilepsy as well. So that leads to complexities in several ways. One is the epilepsy will affect mood and behaviour, Secondly the epileptic drugs will affect mood and behaviour and thirdly the drugs that we use to treat anxiety, depression, mania will also affect the epileptic. So you can get into a cycle of one thing leading to another ...*

Specifically on the issue of whether or not to prescribe, a female prescriber (Dr D) states in one of her critical incidents that she has

increased a dosage of Lamictal (an anticonvulsant) in an attempt to see if the increased dosage will "make a difference".

> *I increased his Lamictal. He had been on 75mg twice a day and I increased that to 100mg in the morning and then 75mg in the evening because he is having continuous seizures so I want to get him up to 100mgs just to see if that will make a difference.*

Another female prescriber (Dr C) makes reference to getting two varying reports from staff and how this can lead to a trail and error approach, resulting in this prescriber relying on her own judgement of whether to commence medication or not and a "hoping for the best" type of approach.

> *Dr C: [ ] ... but it does happen and you would kind of wonder should I wait another fortnight before medication or does this person really need it, so you go by your own judgement at the end regardless and just hope for the best that you are right.*

Finally on this point another female prescriber (Dr H) makes reference to medication being a "muddle" as people with learning disability are tried on numerous medications without any awareness of which one is of benefit.

> *Dr H: Again you try them with the neuroleptics, now more recently people have started using Lamictal, and the use the antiepileptics like Valproate and Tegretol and they are thrown in, [ ] ... So it is a muddle as far as I am concerned – medication.*

In this respect prescribers feel that not only is the decision to prescribe imprecise and largely a trial and error approach, but once prescribers have initiated psychotropic prescribing, the choice of drug and dosage may change in a purely ad hoc manner in an attempt to see if the medication is being of benefit. This is indeed a complexity. The following section will examine further the issue of drug profile and side effects as a continuing complexity.

MEMO BOX 12.2 – FROM OBJECTIVITY TO SUBJECTIVITY ...

Now I feel we are really getting down to basics. The first two core issues were a little difficult to analyse in that prescribers were being very theoretical. I form a diagnosis and I treat. Simple as that. However now that the questions have become a little more abstract and prescribers feel they have a "therapeutic alliance" with the author, they are opening up. The fact alone that they are telling a Psychologist that prescribing is difficult, not always scientific and based on conjecture tells a picture in itself. There is no doubt but the data being gathered is extremely rich and novel. At the start I didn't feel they were going to open up this much. Long may it continue.

12.4.2 Drug Profile & side effects – risk-benefit ratio.

This section relates to the more pharmacological aspects of prescribing. Now that prescribers have made the decision to prescribe a number of issues emerge which relate to the core category of drug profile & side effects – risk-benefit ratio. This core issue is far more grounded in the pharmacological aspects of prescribing than some of the other core categories which have been discussed but they still raise quite a number of interesting factors.

One male prescriber (Dr G) during the interview speaks of the limitations of prescribing certain psychotropic medications due to their profile and the severe consequences which may follow if the medication is not reviewed properly.

> *Dr G: ... [ ] ... side effect profile – one has to be very careful to see especially with medications such as Lithium, where there is a certain level that you try to attain and do not go any higher because it can be very dangerous, could result in death.*

This prescriber goes on to mention the complexity of clients who are non-verbal not being able to communicate how they are tolerating their medication.

> *Dr G: Yes, I think one of the difficulties in prescribing for the severely mentally handicapped is their inability to firstly tell you how they are tolerating their medication [and] ... If they cannot communicate the side effects, if they are suffering side effects, then I would rather not prescribe that particular medication. So that's one of the complexities.*

The complexity of drug profile is a difficulty not only if the person is non-verbal but also if they are verbal, the client may not be able to tell the prescriber how they are feeling or if how they are feeling is related to the medication prescribed. Another prescriber makes reference to the difficulty of persons with learning disability tolerating their psychotropic medication and urges caution when she herself is prescribing.

> *Dr F: I suppose just one thing to mention I think is the fact that people with learning disability who are being prescribed psychotropic medications they tend to be more sensitive to the adverse side effects and so on and what it means really is that it takes quite a bit of time and attention because of that and to be aware of that. That their tolerance is not as good as others and they are more inclined to have idiosyncratic reactions to them. They are more vulnerable to medications really so its really important to look at it hard.*

One prescriber (Dr H) makes note of a recent case (prior to her being appointed to the service) which resulted in death, which the prescriber felt was related to medication.

> *Dr H: And the other thing of course is that definitely was an influential factor is that there was a death – now thankfully it was before I came but it was in or around the time that I took over. And they were all scared witless that it was due to the drug and it probably was, but that is neither here nor there. It was inconclusive and the lady died, a young woman, and as you know with all the neuroleptics, major tranquillizers, they slow the heart, they are dangerous drugs.*

This prescriber goes on to talk about the issue of "tweaking" medication – upping the dose and decreasing the dose when clients are on polypharmacy. This prescriber is quite unhappy with polypharmacy and the expectation from staff was that she was going to continue this practice. Due to drug profile, her own expectations and the increased risk

associated with this practice, the prescriber was reluctant to engage in this practice.

> *Dr H: ... and the expectation was that I would do what my predecessor would have done and that was to tweak the medication, but they are already on polypharmacy, so in other words they have got more disturbed, quick we will increase this or decrease.*

Specifically on the issue of side effects, one prescriber (Dr D) makes note of the complexity of side effects and their reduction with prescribing a low dose of medication.

> *Dr D: you have to always be aware in the case of people with learning disability that they are more prone one would have to say to the side effects of medications, more so even than those who do not have a learning disability. And so that is an important factor and I think certainly from my experience is that you do always start with a low dose no matter what you are trying, you always start like so, more so than you would in the general population. It is of no use getting to a high dose quicker, so you have to be patient with that and go for low doses in the use of the medications.*

It is interesting to note that this prescriber feels that initiating prescribing on a low dosage regime is a seemingly good practice. What he does not make reference to here is that although psychotropic medication may be commenced at a low dosage, it rarely stays this way and invariably the dosage increases.

Despite the problems and complexities encountered with drug profile and side effects, almost all the prescribers in the present study made reference to the newer drugs on the market being used in an atypical fashion. Although many of these medications may have psychotropic qualities associated with them, they are not licensed as psychotropic medications per se. Prescribers in the present study make reference to using the newer anticonvulsants (Lamictal) for example in treating conditions other than epilepsy.

> *Dr D: ... or else you can hopefully use some of the medications which are vital if the person has never received those to treat other problems such as mood disorder. And I think some of the newer epileptic drugs are showing a lot of hope here.*

Another prescriber (Dr E)refers to the anticonvulsant Carbamazepine, which he may use on occasions as a mood stabilizer where psychotropic medication has been ineffective or not used due to side effects.

> *Dr E: Well we would use the mood stabilizing agents such as Carbamazepine – it can be effective especially if there is mood swinging and it is bi-polar and we would tend to use those but as I was saying there are times when they may become acutely disturbed and Carbamazepine is for long term use – its not for acute disturbance, its to level out the mood*

Finally on the issue of drug profile, one female prescriber (Dr H) questions the issue of drugs becoming "broader in their profile" in that drugs are not become more selective, rather they are becoming broader and used for a wider array of conditions, for which she feels some discomfort.

> *Dr H: Sure even if you start looking at the antidepressants, it muses me personally that they started off the SSRI's saying they were so selective and that was their forte. Now all of a sudden you have the SNRI or something – which affects seratonin and noreadrenalin and because it includes noreadrenalin as well, it's better than the SSRI's. so you are back to the full circle.*

In respect to the core category of drug profile & side effects, the main issue of concern for prescribers is the issue of persons with learning disability having a poor ability to tolerate medication. The other source of concern for prescribers is if clients are non-verbal, they are unable to state how the medication is affecting them. Perhaps the greatest complexity and difficulty for prescribers is the possible side effects of medication on the people they prescribe for. Only two of the eight prescribers made reference to death or very serious side effects such as neuroleptic malignant syndrome as possible serious side effects. These issues will again be discussed in the final section on uncomfortable prescribing decisions.

12.4.3 Ruling out Physical/underlying causes

This was a core category which was of significance to almost all the prescribers in the present study. Prior to prescribing, prescribers deemed it as a necessity to rule out all possible physical and underlying causes. Physical causes although not specifically stated related to issues such as

Alzheimer's disease in elderly patients who prescribers felt may have been depressed and underlying causes were typically related to the presence of epilepsy, which may not have been picked up on. One prescriber (Dr E) at the outset noted that one lady with learning disability also had epilepsy and this was a significant variable in how this lady was treated.

> *Dr E: She has organic brain damage secondary to meningitis and she also suffers from epilepsy.*

The extract taken from a female prescriber below (Dr C) makes reference to ruling out physical causes as the first step in "diagnosis" as she states for elderly patients in particular.

> *Dr C: Again depending on their profile, if they are very elderly, and again you have to rule out organic in all of this. You presume that they have been checked over physically and that there is nothing physical wrong with them, that is the first step in making a diagnosis.*

One prescriber makes reference to ruling out physical or underlying causes first but adds that there is an added complexity when prescribing for these underlying or physical conditions.

> *Dr E: Other issues then would relate to individual cases where there might be associated disabilities, they might be sensory impairments, when you are prescribing any additional medications, it always causes a problem and also physical disease and we would have a lot of people with associated physical disease, so prescribing of any extra drugs is always going to cause more problems.*

The prescriber below (Dr B) gives an example of a client with self-injurious behaviour which is related to the underlying condition of an ear or chest infection. Because the client is low functioning, he has no way of communicating how he is feeling and so engages in self-injurious behaviour. The prescriber notes that if he were to have "rushed in" with medication, it would have been purely to treat the symptoms and not the underlying condition. Getting the balance is important for this prescriber.

> *Dr B: Another thing to is to always rule out the physical cause if somebody becomes this way. I have just seen a man there now who is self injurious and is very low functioning and his self injurious behaviour – nine out of ten times, it*

seems to be related to some kind of ear infection or chest problems or something like that. He does not obviously take to discomfort well and so he self injures, so the use of medication other than antibiotics would not be appropriate. You have to, there is a danger of rushing in and using inappropriate medication. So you have to balance it right and get the balance right.

In a similar fashion another prescriber (Dr E) makes reference to that problem of lack of mobility for some persons with learning disability in conjunction with physical illness and prescribing for these can have added complexities.

Dr E: And then of course a lot of the people we have, have problems around mobility and the presence of increased physical illness and thus medications on top of these can cause behavioural problems.

Finally on this issue the prescriber below (Dr E) makes reference to the association between physical illness and learning disability and a high mortality rate amongst these persons. He sees this as a complexity in his role as prescriber.

Dr E: ... we have one ward here which is for profoundly handicapped persons and they are people who have an associated physical disability such as quadriplegia or it could be any physical disorder and most of them are very very ill and they have a potentially high mortality rate.

MEMO BOX 12.3 – IMPORTANCE OF RULING OUT PHYSICAL & UNDERLYING CONDITIONS PRIOR TO PRESCRIBING.

Prior to moving on to the next section, I am glad that most prescribers in the study place emphasis on ruling out physical causes prior to prescribing. But on reflection, this would stem from their medical training. It is interesting that most of the prescribers brought this issue up under complexities – only one of the eight prescribers mentioned an underlying physical cause when they spoke about recent cases of prescribing. It could have been that physical causes were not an issue in these cases or the alternative is that it is a case of "theory to practice" once again. Prescribers may know that they should be looking for underlying causes in theory but in practice this may not be the case. It warrants further investigation ....

12.4.4 Expectation element on the part of others (staff & family).

Similar to the findings from General Practice, client and family expectations played a large part in the process of prescribing in the present study. All but two of the prescribers in the present thesis made reference to client and/or family expectations, be these expectations or pressure to prescribe or expectations that medication would not be withdrawn. Each will be discussed in turn.

The majority of the eight prescribers felt pressure from families or relatives to prescribe. Prescribers noted that families felt that prescribers possessed a "magic bullet" and that prescribing would solve all of the problems encountered by them. One prescriber (Dr B) notes this by saying:

> *Dr B: families will be looking for an instant cure for something that would respond better to a behavioural approach and it's very hard to get them to engage in a behavioural approach when they think of a magic bullet. So it's a matter of trying to bring a balanced approach to the individual that you're treating*

This prescriber also notes the opposite happening where families are very much against the issue of psychotropic medication, despite the prescriber outlining the rationale for medication use.

> *Dr B: The family issues around medication are huge because some families will not hear of medication even when you try to show how their logical approach of some one being on medication*

On the contrary two prescribers felt that staff or family expectations did not play a "major" role in the prescribing process. Interestingly these two prescribers were male and had been prescribing for over twenty years. Whether it was a matter that they themselves felt that they were not pressured into prescribing by staff or families or whether they did not attribute their prescribing on the basis of what staff said or observed is a complexity yet to be further analysed. Interestingly however one of the prescribers (Dr G) when discussing a recent case of prescribing noted

that it was staff that brought the case to his attention and it resulted in medication being prescribed. The extract below highlights this fact.

> *Dr G: The situational factors – medication specifically requested by staff members - it was the staff who brought it to my attention. This is a recurrent condition – this behavioural thing for that particular person. The resulting medication prescribed was an antipsychotic*

In this case the client was seen by the consultant based on the staff bringing the case to his attention. The "end-product" of this consultation was that the person was prescribed an antipsychotic. Later on in the interview the prescriber when asked about client, family or staff expectations, feels that although expectations are present, they do not represent "not a major problem". The text box below depicts an extract from this prescribers interview.

Text Box 12.3 Extract from Prescribers Interview (Dr E) – Expectations to Prescribe

	Extract From Interview
R = Reporter **P = Prescriber (Dr E)**	***R*** *You mentioned there Dr. about a client expectation, would you find that happens often ... from a client or from family or staff ...* ***P*** *Oh yes, mentally handicapped people in the community, the problem arises when they become adolescent and when they become big and strong and awkward and they go through that that phase and they very commonly, they can become quite disturbed and their parents cannot manage them because they are no longer children and the parents cannot really cope with them and you get requests for residential care or respite care or in some extreme cases the GP would refer them on, with the expectation that something would be prescribed to ameliorate their behaviour.* ***R*** *Would you see this as being quite a problem, these expectations ...* ***P*** *Ah not really, the matter of prescribing would be up to the consultant who see the person, obviously if there are other strategies, then we don't prescribe we use what is applicable, so its not really a major problem.*

In this case although the prescriber does not see pressure to prescribe as a major problem, he still comes in contact with it and it may indeed have an impact of his prescribing practice.

In a similar fashion, the other male prescriber mentioned above (Dr G) does not see pressure or expectations to prescribe as influencing his prescribing, rather he sees them as having an impact on containment of those with challenging behaviour. He does mention the issue of staff shortage in the wider context of treatment of persons with learning disability.

> *Dr G: Oh yes, and particularly recently, and that seems to be country wide now. We have a significant problem here with staff shortage and I don't think it has, funnily enough, added to the problem. There is always the feeling if you do have staff shortages, you find yourself using more medication to try and control or manage situations. I don't think really that that has happened and I don't accept that but there is always that worry that you are going to end up having to be more containment and having to use that.*

Rather than prescribing a routine dose of psychotropic medication, this prescriber sees the use of PRN medications as being more effective. Although in one sense he does not feel staff have an expectation of the prescriber to prescribe but on the other hand by writing the client up for PRN medication it is giving the staff leeway to prescribe in an ad hoc basis as they see fit.

> *Dr G: The other side and something that comes to mind for me is that the use of PRN medication is something that is very beneficial and to give the staff leeway to give medication to somebody when required within a 24 hour period to manage his behaviour if they become difficult, rather than having to put the person on ongoing medication. Sometimes we can put a number of people on this sort of medication and usually we put them on ongoing medication, but on a PRN basis.*

If one looks to long term PRN medication as a prescribing practice in itself, it may lead to staff becoming overly dependent on administering this form of medication whenever things "begin to get rough". Staff perceptions of when the client may need PRN medication will also vary

considerably which invariably will lead to more frequent prescribing, often without the knowledge of the prescriber themselves.

Finally the prescriber below (Dr D) describes how she feels both influenced to prescribe by means of staff reports and how they "handle" challenging behaviour within the residential setting, while in the community settings, it tends to be family members that place pressure on the prescriber.

> *Dr D: I do feel influenced by staff's responses to behaviour and what they feedback to me. In the residential population sometimes I feel there is pressure to prescribe as well and it is not always easy to be scientific about it in those situations. In the community it is usually family members*

However this pressure comes not only to prescribe medication but also not to withdraw medication in certain conditions.

> *Dr D: but in fact my experience has been that it is in withdrawing medication tends to be the bigger problem in the learning disabled than prescribing itself.*

The problem here tends to lie in the fact that it is not the withdrawal in itself that is the problem, it is related to the possible negative impacts if withdrawal is unsuccessful.

> *Dr D: sometimes there are fears that they are going to get worse and one of my rationale for withdrawing a drug is when their behaviour is no different on the drug [ ] ... But there is a response then from staff or from the family, well if you withdraw it, they are going to get worse.*

This prescriber goes on to discuss a recent case where there was resistance from staff and the GP to withdraw anticonvulsant medication. The fear on the part on the family and the GP was that if the medication was withdrawn or reduced, it would affect the clients' seizure frequency and would result in a recurrence of seizures. As a result of this pressure, the prescriber did not withdraw the medication.

> *Dr D: staff have a lot of problems around that [anticonvulsant withdrawal] – they have a lot of fears of seizures recurring if you withdraw. I have someone in the community at the moment who I am trying to withdraw, who I had planned to*

withdraw from, and I had huge resistance from staff, from the GP, so as a result, they are still on the same. So it is an added complexity.

From the perspective of prescribers, staff and family expectations or pressures to either prescribe or withdraw represent an added complexity to the process. Most prescribers felt it was a complexity, although two prescribers, while acknowledging its presence, did not feel it impacted on their prescribing behaviours. Client expectations and pressures, to a lesser degree have an impact on prescribing, that is for those who are verbal and have an understanding of why they are being prescribed medication.

12.4.5 Concluding remarks regarding factors influencing the complexity of prescribing.

From the above sections presented, one can see that a number of complexities have an impact on the prescribing behaviours of consultant psychiatrists. These complexities have ranged from decisions regarding whether they should prescribe or not, to more pharmacological considerations of drug profile and risk benefit ratio of psychotropic medication. In true "medical model" fashion, almost all prescribers felt that physical or underlying conditions such as epilepsy very often put prescribers in a dilemma and there is the need to rule out any physical causes prior to prescribing. It was interesting in itself that this category emerged as being a complexity due to many conditions having an organic basis. Finally the issue of expectations and pressure to prescribe was discussed. Prescribers presented numerous cases where they felt pressured to either prescribe or not to withdraw medication. The issue of withdrawal presented an interesting facet in that it tended to hinge on the issue of epilepsy, which is seen by prescribers as being a complexity in itself.

We will now turn out attention to the next core issue of interest – the links between challenging behaviour and prescribing.

12.5 Links between Prescribing and Challenging Behaviour.

Although the issue of challenging behaviour has been discussed in some detail under the core issue of common presentations which give rise to prescribing, all prescribers were asked their views on what they felt were the links between challenging behaviour and prescribing. Many of the core categories taken from the above sections also relate to the present section. Hence prescribers feel that prescribing is ultimately based on the level of distress displayed by the client plus the level of dangerousness exhibited and the treat to others based on dangerousness. Prescribers also feel that although they dislike prescribing for purely challenging behaviour in the absence of a diagnostic label, this happens quite frequently.

The main purpose of having such a question on the interview schedule as "what do feel are the links between prescribing and challenging behaviour" was to tease out any further issues that prescribers felt were of significance in terms of challenging behaviour. Now that prescribers were talking "openly" about issues such as prescribing being based on speculation and prescribing being a trail and error approach, it was hoped other issues of interest would emerge by asking such a question.

Prescribers in this instance still spoke about reliance on third party reports in the formulation of a diagnostic label and on issues regarding dangerousness and distress. However three new core categories did emerge which were not spoken about prior to asking this question.

Table 12.5 Core Issue 4: Links between Prescribing and Challenging Behaviour – Emergent Focused Codes & Categories.

Core Issue 4: Links between prescribing and challenging behaviour.

Emergent Focused Codes & Categories.

1. **Global role of multi-disciplinary team in prescribing.**
2. **Theory to practice hypothesis of prescribing – prevention and control.**
3. **Classification of challenging behaviour.**

12.5.1 Global role of multi-disciplinary team in prescribing.

Most prescribers in the study made reference to the role of the multi-disciplinary team. However the role of the multi-disciplinary team tended to be in its broadest context and related more to the collection of clinical information that it did to the actual process of prescribing. In this respect the author has termed this core category "the global role of the multi-disciplinary team".

One prescriber (Dr G) makes reference to the global role of the multi-disciplinary team placing emphasis on the role of the nurse in dealing with challenging behaviour. He notes that people tend to see the multi-disciplinary team in its narrowest context and not take on board all those members of the team.

> *Dr G: Yes I think that it is just crucial [the multi-disciplinary team] and we just have to do it and it goes beyond that and when people talk about multi-disciplinary teams too they can talk in a very narrow kind of way. By that I mean that they talk about the psychiatrists, psychologists and social worker, but I think that it should be much broader than that, particularly with the nurse. The nurse is well grounded and perhaps has the skills that one needs for interventions and we need to bring them on board much more than we do – they can tend to stay separate and I don't think that's good.*

This prescriber goes on to talk about the role of the multi-disciplinary team in dealing with other issues and not just with challenging behaviour. He believes it is not "an all or nothing approach".

> *Dr G: Well I just would repeat that I don't think that it is an all or nothing as – its either medication or use of behavioural intervention for challenging behaviour. I think that the combination is very important to use both in challenging behaviour – you certainly don't use medication on its own. But I would even apply that to not only challenging behaviour but to those with clear psychiatric illness as well and I think that often people have the view that just because someone has depression or schizophrenia or manic depression that medication is just the answer.*

Another prescriber (Dr B) mentions the issue of having a "balanced approach" in any treatment rationale for persons with learning disability.

> *Dr B: So it's a matter of trying to bring a balanced approach to the individual that you're treating and a multidisciplinary team approach as well to the situation.*

This prescriber feels that the discipline of psychology undertaking a functional analysis is similar to what the discipline of psychiatry undertakes, in that both are looking for the underlying causes of the behaviour as a rationale for treatment. Again this statement may signify the prescribers striving for a diagnostic label as a justification to prescribe.

> *Dr B: Well I think the kernel is a functional analysis - a proper psychologists functional analysis is the very formulation, but I think what psychiatrists do is related to the functional analysis and we are looking at what aspects of our area of expertise are causing the challenging behaviour – the challenging behaviour been seen as the sign of something – like a pain in the head is the sigh of the flu – thus challenging behaviour is the sign of something and we need to try and find out what it is.*

It could be said that in the true sense of the medical model, this prescriber is attempting to find a diagnostic label (perhaps under the paradigm of mental illness), which will explain this client's behaviour. By a psychologist undertaking a functional analysis, it serves as the collection of clinical information so as to place a label on the client.

Finally this prescriber states the authors assumption above and rationalizes psychotropic medication where the challenging behaviour,

which is now labelled in terms of a mental illness, has not been responsive to behavioural approaches, or which he feels will not be responsive to a behavioural approach.

> *Dr B: So medication should be used in challenging behaviour if you can delineate a reasonable reason for putting someone on medication – like there is anxiety, depression mania or else if there is something which should be worked on with a behavioural approach – maybe something is blocking it, so the person is too anxious to respond to a behavioural approach.*

In a similar fashion another prescriber (Dr E) makes reference to the "supplementary notion" of medication, used in conjunction with behavioural techniques.

> *Dr E: I think a lot of behavioural regimes which can be used for challenging behaviour – we have psychologists and behaviour therapists here working with challenging behaviour. Sometimes they may need a low dose of supplementary medication while they are going through these behavioural therapies.*

Other prescribers have made reference to the usefulness of the multi-disciplinary team to the prescribers, the clients and the people caring for those with challenging behaviour - hence its "global role".

> *Dr A: ... certainly for issues around challenging behaviour it is very helpful to work in the team. It's helpful for ourselves, its helpful for the client and its helpful for carers because we generally try and talk out of their own hymn book, and that's helpful too.*

One prescriber (Dr F) talks of getting "tunnel vision" if one doesn't have access and work with a multi-disciplinary team.

> *Dr F: I would I think it is terribly important because I think you can get tunnel vision if you just work on your own and you may become dependent on just drugs or if you are a psychologist may on behaviour therapy or something. But I think a mix, I think a lot of people and a team effort is very good.*

Finally to conclude this section on the global role of multi-disciplinary teams, all prescribers in the study felt that a team approach was necessary in assessing and treating persons with challenging behaviour. However the multi-disciplinary team was not closely related to the process

of prescribing, rather it tended to work in conjunction with prescribing of psychotropic medication.

12.5.2 Theory to Practice Hypothesis of Prescribing – Prevention & Control.

This next section covers the issue of the theory to practice hypothesis of prescribing and how prescribers see psychotropic medication in terms of either preventing challenging behaviour or trying to control it. Although some prescribers are adamant that they do not like to prescribe for challenging behaviour in the absence of an underlying psychiatric condition, other prescribers are now saying that they prescribe psychotropic medication as a means of prevention and control of challenging behaviour. Hence in theory they say they do not prescribe for challenging behaviour but in practice a different picture emerges.

One prescriber (Dr H) clearly states that she does not like to prescribe for challenging behaviour and feels that challenging behaviour should be dealt with by means of behavioural techniques

> *Dr H: I don't like prescribing for challenging behaviour. If at all possible it should be dealt with through trained staff and I think behaviour therapy is the answer there.*

On the issue of theory to practice, another female prescriber (Dr D) makes reference to initially viewing challenging behaviour as being treated by means of behavioural techniques, but then seeing the risks involved begins to intervene and prescribe psychotropic medication based on dangerousness of the behaviour displayed.

> *Dr D: I think when I came into learning disability [ ] ... I very much took the view that behavioural problems were to be managed and managed by behavioural therapy and as time went on I begun to realize that it didn't always work and that there were too many risks to be taken in terms of staff safety and clients safety not to prescribe. But I would say that with regard to challenging behaviour as I may have said earlier, I would look at other methods first of dealing with it and injuring a staff would be one of the reasons that I would prescribe – injury to*

another staff member, or self-injury – those two. I see these as factors which would definitely influence me to prescribe.

On observing the above extract one can see how this prescriber's perspective on challenging behaviour has changed since she has begun to work with persons with learning disability. Her theoretical perspective at one point was that challenging behaviour was treated by means of behavioural techniques but once the element of dangerousness or injury entered the equation, she felt responsible and thus began to prescribe on this premise.

Another prescriber (Dr F) makes reference to the issue of the threat of injury to others, and the difficulties in treating challenging behaviour where there is no "underlying psychiatric condition". In such cases prescribing may be complex and quite unclear.

Dr F: I think where challenging behaviour is a reflection of an underlying psychiatric condition, I think you are obviously treating the psychiatric condition and that can be fairly clear. I think that people with learning disability, if they have a psychiatric condition they deserve to be treated for it. I think where it is more difficult is where the challenging behaviour doesn't obviously reflect a psychiatric condition and yet the challenging behaviour in some way poses a threat to the person with learning disability themselves or to others.

On the issue of the use of psychotropic medication as "preventative method" and in calming the person, the above prescriber makes the following comments.

Dr F: With self-injurious behaviour, this is a sort of dilemma you get caught into – that you are really trying to prevent people from very often seriously injuring themselves.

sometimes the level of the self-injurious behaviour is so compelling that you do need to do something to just calm the person down to try and prevent it. I'm thinking of one other man who is in that same group of houses who has a lot of autistic features and his level of self injurious behaviour can be so high at times that in his own interest really you try and prevent it by using some kind of sedative to calm him down.

Finally one prescriber (Dr E) sees behavioural techniques as being very effective in treating challenging behaviour and sees these techniques as being used far more frequently than psychotropic medication.

> *Dr E: ... a lot of challenging behaviour here is, a great deal of it here is treated by means of behavioural regimes rather than by psychotropic medication.*

Interestingly prior to discussing his critical incidents of prescribing this prescriber made the following statement regarding the frequency of his psychotropic prescribing, stating:

> *Dr E: ... [ ] ...over 60% have an overlying behavioural or psychotic condition so that there is a high degree of co-morbidity. So most patients I would prescribe for would have been disturbed – by that I would mean that they would be disturbed by means of a condition manifesting itself like self-injurious behaviour or externally directed aggression.*

This prescriber then goes on to state that he feels it is best to try and prevent challenging behaviour rather than using psychotropic medication to control or "dampen down" the behaviour. Quite clearly these are conflicting views on the part of the prescriber, and conflicting prescribing practices also.

> *Dr E: Well challenging behaviour in the long term it is better to try and prevent challenging behaviour rather than using something to try and dampen it down ...*

Finally on this issue one psychiatrist (Dr B), although he does prescribe for "challenging behaviour" when there is an associated underlying condition, feels that psychiatrists are called in at the last moment in order to deal with a crisis and this in itself results in the prescribing of psychotropic medication.

> *Dr B: Often, I think there has been a habit in Ireland and maybe the U.K. of psychiatrists being called in at the last moment, when things are really bad and we have to do something whereas if the psychiatrists and the behaviour analysts were together at the start – looking at an integrated approach. So you don't really see that kind of thing happening. It should be but ...*

On this point the prescriber feels that a multi-disciplinary approach is required well in advance of a crisis situation occurring, which in itself may result in psychotropic medication being prescribed to a lesser degree.

To conclude the present section, prescribers in the study felt that although there was a need to "prevent" challenging behaviour – this was their theoretical perspective, in practice, prescribers were prescribing psychotropic medication in order to control or suppress the behaviour. If one looks to the literature regarding suppression of challenging behaviour, this is a practice which is very much frowned upon in present-day practice for persons with learning disability. We will now turn the focus of attention to the last core category, which examines how a number of prescribers have attempted to classify challenging behaviour.

12.5.3 Classification of Challenging Behaviour.

This was an interesting core category to emerge as it related to the prescribers views on challenging behaviour as being a "stand alone" classification in itself – unrelated to psychiatric diagnosis or whether they felt it was part of an underlying psychiatric diagnosis. Although the author has referred to this issue in earlier sections of the present chapter, a number of prescribers made reference to this issue when asked about the links between challenging behaviour and prescribing.

All but one of the prescribers in the present study felt a strong association between challenging behaviour and a psychiatric condition. Most often prescribers felt that where a client was presenting with challenging behaviour, it is in some way related to an underlying psychiatric condition. The prescriber below (Dr F) makes reference to this.

> *Dr F: I think where challenging behaviour is a reflection of an underlying psychiatric condition, I think you are obviously treating the psychiatric condition and that can be fairly clear. I think that people with learning disability, if they have a psychiatric condition they deserve to be treated for it. I think where it is more difficult is where the challenging behaviour doesn't obviously reflect a psychiatric condition*

In this case the prescriber feels that where a psychiatric diagnosis exists it results in a clearer approach toward prescribing, whereas if a psychiatric diagnosis is not present or a label is difficult to determine, it results in a level of discomfort or complexity for the prescriber.

The prescriber below (Dr G) sees the presence of challenging behaviour as a symptom of an underlying condition and classifies it in this way. Again prescribers are striving for a diagnosis and not examining the behaviour and the function it may be serving.

> *Dr G: Certainly in the area of challenging behaviour, it is behaviour, it is not an illness, it's a symptom of something, and that's the way I like to look at it.*

On the difficulties of ascertaining the relationship between challenging behaviour and psychiatric diagnosis, one prescriber, (Dr C) notes that it is a difficulty in that she feels a relationship exists but is not sure of what diagnostic label to place on the condition.

> *Dr C: But it is a difficult area – there can be associations between challenging behaviour and psychiatric disorders. It can be part of a depressive illness or it can be part of a schizophrenic illness or a psychotic illness.*

One prescriber (Dr H) who was quite outspoken on a number of points raised the issue of the term "challenging behaviour" and how she dislikes using this term. She also makes reference to psychiatry still dealing with syndromes and how this is an imprecise science and the difficulties associated with getting to the underlying condition.

> *Dr H: Challenging behaviour is not a diagnosis, all it is saying is that whatever behaviour is presented it is a challenge to the system. [ ] ... The other thing to say is that in psychiatry we are dealing with syndromes, no other area of medicine to my knowledge deals with syndromes, except genetics.*

> *Dr H: We are still caught in psychiatry, well they present with - they're hearing voices, but we don't know the origins and we are in a totally different ballgame and I think that people think that some of the time we are in the same ball game as our physician counterparts and that we can use medication as precisely.*

Finally on this issue, two distinct perspectives emerge from two prescribers on the issue challenging behaviour and how it may be classified or whether an association exists between challenging behaviour and psychiatric diagnosis.

On the one hand one male prescriber (Dr G) feels that the presence of challenging behaviour due to its impact on the individual and the service, it should be viewed as a psychiatric diagnosis in itself due to the intervention required in treating them.

> *Dr G: ... its hard to put a specific diagnosis down for them, in fact I would consider them within the psychiatric diagnosis if they have a severe challenging behaviour and they are requiring my attention on a regular basis. I would include that under the psychiatric disorder in that they need intervention of a major nature. I mean I don't like the term challenging behaviour*

In this case the prescriber feels that challenging behaviour should be classified as a psychiatric disorder based on intervention required. It is difficult to ascertain where such a viewpoint has emerged as many persons with learning disability who do not have challenging behaviour still require a substantial input in terms of time and staffing. This may be associated with discomfort around prescribing for challenging behaviour per se and the need for a label to be present in order to justify his prescribing practice.

A totally opposing viewpoint is offered by a prescriber (Dr C) who feels that challenging behaviour and psychiatric conditions are totally unrelated. She feels that challenging behaviour should be treated by means of strictly behavioural techniques and not by the use of psychotropic medication. She also states that she feels it is rare to see a "psychotic" condition in a person with learning disability.

> *Dr C: I feel behavioural disorders are not part of an underlying psychiatric diagnosis. I think it is rare that you get it – a psychotic illness in people with learning disability. Behaviour disturbance is largely behavioural and it can be treated as such – without drugs or very little anyway.*

This perspective is in stark contrast to the views held by most prescribers in the present study. Whereas most prescribers were striving to find an appropriate label to place on the client and the majority of times this label pointed towards a "psychosis" or "psychotic condition", this prescriber feels that such instances of labelling a person as psychotic are rare. In this respect she does not feel there is an association between challenging behaviour and "psychosis" although earlier in the interview she made reference to prescribing a range of psychotropic medication to persons with learning disability, including the Antipsychotics.

> *Dr C: [ ] ... yes you would use them here for very disturbed people and that could range from Melleril to I suppose Ativan maybe but that is only pre-med and that would lead to Valium. I would use this to relax them.*

From observing both these interview extracts we can see that although this prescriber feels that challenging behaviour is not part of an underlying psychiatric condition, she does prescribe the usual range of psychotropic medication to the learning disabled population. Hence providing further evidence for a theory to practice hypothesis of prescribing in itself.

12.5.4 Concluding remarks regarding links between prescribing and challenging behaviour.

The core categories which emerged from this section proved useful in our understanding of prescribing for persons with learning disability. On a strictly theoretical perspective, many prescribers feel there is a sense of inappropriateness about prescribing for challenging behaviour. In order to distance themselves from inappropriate prescribing, most prescribers look for an appropriate diagnostic label to place on the person, usually from the paradigm of mental illness. If such an "appropriate label" can be found, then the sense of inappropriate prescribing is no longer in existence and the resulting prescribing seems rational and appropriate. What the current core categories and evidence have shown is that there are many times when prescribers fail to place a diagnostic label on some clients with challenging behaviour and thus prescribers in such instances

are prescribing purely for the purposes of controlling or suppressing the behaviour in an attempt to alleviate injury and dangerousness, be it self directed or externally directed.

12.6 Uncomfortable Prescribing Decisions.

The final core issue under study relates to uncomfortable prescribing decisions that were discussed during the interview. Prescribers made reference to a number of dilemmas which resulted in "discomfort" when issuing a prescription or prior to prescribing during consultations. Broader theoretical issues also emerged. For the purposes of the present analysis and discussion, the author will refer to the four core categories, which emerged throughout analysis.

Table12.6 Core Issue 5: Uncomfortable Prescribing Decisions – Emergent Focused Codes and Categories.

Core Issue 5: Uncomfortable Prescribing Decisions.

Emergent Focused Codes & Categories.

1. **Discomfort arising from side effects and drug profile – polypharmacy.**
2. **Crisis intervention & resource implications.**
3. **Expectation/pressure element on the part of others.**
4. **Issues of consent.**

12.6.1 Discomfort arising from side effects and drug profile – polypharmacy.

Not only were drug profile and side effects significant issues in terms of factors influencing the complexity of prescribing, these issues also emerged as core categories within the present section. Prescribers felt discomfort around issues such as side effects of particular medications and how those clients prescribed such medication would tolerate same. Drug profile was also a consideration as in some cases due to the unwanted side effects of particular medications (in particular some

Antipsychotics), certain medications could not be prescribed and so an alternative psychotropic medication was required. One prescriber in particular (Dr E) makes reference to this issue in terms of neuroleptic malignant syndrome and how this caused discomfort on his part.

> *Dr E: Yes, I'm trying to think. Yes one comes to mind – two in fact come to mind. Two people who developed neuroleptic malignant syndrome and as you know it's a syndrome where you cannot prescribe phenothiazines or you cannot prescribe the major neuroleptics, which would include the phenothiazines. That poses a problem if that person who develops neuroleptic malignant syndrome, it's a side effect, it's a sensitivity reaction to a major neuroleptic, and its lifelong, it doesn't always but can remit but the danger is when you recommence neuroleptics, you are always afraid that they will redevelop it as it is a life threatening illness and people have died from it and they can go into renal failure, cardiovascular problems – it's a hazardous condition.*

In this case the prescriber has a sense of discomfort, which has arisen from the side effects of particular medication. It places the prescriber in a dilemma in that this condition has emerged from prescribing neuroleptic medication and if he were to recommence such medication it could have serious implications for the individuals.

This in turn has the "knock-on" implication for these individuals in that it places the prescriber in the difficult situation of deciding which medication is suitable (other than the neuroleptics for example) for the individual. In this case it resulted in the prescriber prescribing the anticonvulsant Carbamazepine, largely based on the psychotropic properties of this drug. As a practice, although the prescriber was in somewhat of a dilemma, it must be questioned on ethical grounds, as this drug although it has psychotropic properties it is not routinely prescribed where neuroleptic medication is not warranted.

> *Dr E: Well we would use the mood stabilizing agents such as Carbamazepine – it can be effective especially if there is mood swinging and it is bi-polar and we would tend to use those but as I was saying there are times when they may become acutely disturbed and Carbamazepine is for long-term use.*

Most prescribers throughout the interview made reference to their dislike of polypharmacy. The majority of prescribers in the study felt that one drug should be prescribed where necessary and in the case of two or

more drugs being prescribed, they would question this as a practice. Where cases were presented to prescribers where the individual was on polypharmacy, this presented with some discomfort and difficulty, particularly in attempting to withdraw this medication.

> *Dr D: Yes I prefer one drug and that is another area. I try to use the minimum dose of the most effective drug, the safest drug and most effective drug in a particular situation. If someone is on medication already this can be a difficulty withdrawing generally speaking.*

As a matter of individual prescribing practice, the above prescriber makes the following statement when a new medication is being tried.

> *Dr D: I would add-on a drug and then withdraw the other drug and this would be the way I would do it. If I start them on a newer antidepressant, I would withdraw the other gradually.*

As mentioned earlier as a complexity, the issue of epilepsy (as an underlying condition) also results in some discomfort when medication is being prescribed - as there is the tendency to prescribe polypharmacy as a means of controlling seizures (which may often be irrational). The prescriber below (Dr D) notes how she has "not had the courage to withdraw" due to implications for seizure pattern.

> *Dr D: In the area of epilepsy it is more complicated and this is an area I would feel is maybe less educated in because I am not a neurologist I am a psychiatrist. None the less I know I would treat a lot of them, but the newer antiepileptics like Lamictal – in fact it has been shown to be effective as monotherapy but I have not as yet used it as in the population that I work with, who have been on a number of anticonvulsants over a number of years, I have not had the courage really to withdraw, I might have withdrawn one of the others but I usually use two – I have them on two anticonvulsants. It often has the added complication that if you withdraw it will affect their seizure frequency – it often does.*

Another prescriber (Dr H) has discomfort around the issue of "inherited polypharmacy" – where she is new to a service and clients are already on a combination of psychotropic medications, for which there is a poor rationale.

> *Dr H: In relation to the place I have inherited, I am uncomfortable around that because I am trying to rationalize the medication and I am bringing it down but it*

is during a stage – and if it goes wrong then I am waiting for that and [ ] ... I am very uncomfortable with what I have inherited and I have refused to tweak the medication and what has resulted is that people have had to go into hospital, because I have refused to go any higher.

This situation of "inherited polypharmacy" has left this prescriber to withdraw medication, due to there being a poor rationale on the part of the previous prescriber. There is some pressure to "tweak" medication but the prescriber feels discomfort around this practice and will not give way to such pressure.

Finally on the issue of atypical sensitivity to side effects (which was discussed earlier) one prescriber (Dr F) feels this is an area which gives rise to discomfort on the part of prescribers.

Dr F: [ ] ... people with learning disability who are being prescribed psychotropic medications they tend to be more sensitive to the adverse side effects and so on and what it means really is that it takes quite a bit of time and attention because of that and to be aware of that. That their tolerance is not as good as others and they are more inclined to have idiosyncratic reactions to them. They are more vulnerable to medications really so its really important to look at it hard.

Again similar to the issues raised relating to complex issues in prescribing, prescribers felt these complexities were often issues which arose in discomfort. Getting the "right balance" between the person and the drug is a complex issue in itself and warrants much caution on the part of the prescriber. If prescribers get this balance incorrect or the person with learning disability has a poor tolerance of a particular drug, prescribers are uncomfortable about prescribing such a drug. The dilemma is then raised as to whether the drug needs to be withdrawn and replaced with a "safer" and "more effective" drug or whether the person continues with this medication with the possibility of serious side effects developing into a condition as neuroleptic malignant syndrome, as was discussed by one of the prescribers in the study.

The next issue to be discussed is that of crisis intervention and resource implications as a source of discomfort to prescribers.

12.6.2 Crisis intervention & resource implications.

The issue of crisis intervention and resource implications in the prescribing process was mentioned by a number of prescribers in the present study. Although these two issues are somewhat distinct, throughout the interview material prescribers made reference to these issues as a combination of factors. Largely due to limitations in staffing and overall resource implications, a sense of pressure was placed on prescribers which they felt was related to "crisis intervention prescribing" which arose in a significant amount of discomfort. One prescriber (Dr F) makes reference to the fact that the potential is always there for discomfort relating to crisis intervention.

> *Dr F: Well I think the potential for that is always there. I suppose what makes me uncomfortable is hen there is a lot of pressure coming to sort out a situation which you feel maybe much better managed in terms of having appropriate or better staffing levels or different environment.*

In this example the prescriber feels that a crisis situation has occurred and it may have been handled at an earlier stage by means of behavioural or alternative approaches. She goes on to talk about the resource implications when undertaking behavioural assessment (functional analysis) or intervention.

> *Dr F: Or where maybe a more sort of thorough behavioural analysis or something may be helpful but we may not just have the resources for that or I suppose it is like any other sort of work, it is when you feel that the pressures are coming on you to do something and it isn't specifically and the answer doesn't specifically lie in the area of medication.*

In relation to discomfort arising from crisis intervention this prescriber goes on to mention that such situations may occur at specific times during the year – especially at holiday times when staff are away and resources are not as plentiful as usual.

> *Dr F: So it can happen in specific situations and maybe at specific times. Like holiday times for other people tend to not to be great times.*

One prescriber (Dr D) made reference to a case she felt uncomfortable about when the client was resident in a community house. The prescriber was called in to give inter-muscular medication due to the seriousness of the behaviour. As mentioned earlier many cases of prescribing are based around the issue of dangerousness and this was a typical case of crisis intervention essentially based on level of dangerousness.

> *Dr D: I think I am just remembering a case which comes to mind, but it has been in the past two weeks or so, but that was a difficult situation. It was someone with a learning disability who has a personality disorder and has had chronic behavioural problems now living in a community house and used to be living in residential care here and obviously there were a lot of issues around the community house being able to deal with the challenging behaviour and the lack of the facility here to re-admit and in a situation like that where the behavioural methods that were employed were not working there was continuous aggressive behaviour towards staff members, and I certainly felt under pressure and in that instance I did prescribe an inter-muscular, which I had a lot of difficulties with. Certainly the inter-muscular medication I would have a lot of difficulties with.*

In this sense the prescriber administered inter-muscular medication but with a significant amount of guilt and discomfort.

> *Dr D: So I would have a lot of guilt about that at the time largely due to the fact that I generally don't prescribe inter-muscular medication*

On the issue of depot medication another prescriber (Dr G) notes that he dislikes prescribing depot medication and as part of his practice does not routinely prescribe this form of medication as he feels it is not good practice and very often such emergency cases can be dealt with be means of behavioural interventions such as seclusion.

> *Dr G: ... [ ] ...we do not, and it has been many many years since I have given inter-muscular medication for emergency management, not for depot medication – somebody becoming highly disturbed, I think we rarely, it is very rare that somebody cannot be either placed in a seclusion area or where you are able to deal with them from a behavioural approach or by way of medication but we don't do that. That's only highly disturbed people.*

Another prescriber (Dr A) clearly states her dislike for depot medication and where depot medication is prescribed, a very balanced approach must be taken.

Dr A: The other area where I tend not to use too much in terms of prescribing is depot medication, basically because of the issues around consent, so there would be very few people on injections, but again that is a very individual thing and you have to balance it, but in general I would put very few people on depot medication.

Interestingly this prescriber makes reference to the issue of consent when prescribing medication. Only two prescribers made reference to issues of consent through the interview. This issue will be dealt with in the final section on uncomfortable prescribing decisions. We will now turn our attention to discomfort relating to expectations and pressure to prescribe.

12.6.3 Expectation/pressure element on the part of others.

In a similar fashion to factors influencing the complexity of prescribing, the issue of expectations and pressure to prescribe was a source of discomfort for prescribers in the present study. In was interesting to note that this category emerged as a core category in these two core issues under study. Almost all prescribers in the study made reference to this issue as a source of discomfort. One prescriber (Dr D) makes specific reference to pressure coming from staff in the residential services to prescribe and this may result in prescribing becoming "unscientific".

Dr D: I do feel influenced by staff's responses to behaviour and what they feedback to me. In the residential population sometimes I feel there is pressure to prescribe as well and it is not always easy to be scientific about it in those situations.

This prescriber also makes reference to a case where parents placed pressure on the prescriber to change the medication for their child. These parents came equipped with information which they received from the Internet on the types of medications prescribed and the prescriber in this case was extremely uncomfortable with the pressure which was placed upon her to change the medication.

Dr D: I have actually felt under pressure by parents there to prescribe and I felt very uncomfortable in one situation where pressure was put on me to change the medication to move onto another and then another by the parents and I was faced with a dilemma. I felt uncomfortable and they got their information from

the Internet so they knew all the drugs that could be used and I felt professionally undermined by their attitude coming in and sort of making the suggestion that this drug should be used. So that would be the other area which can generate an uncomfortable decision.

In this case the prescriber felt very uncomfortable with the situation that arose and notes how she felt "professionally undermined" by a family who wanted medication changed.

As mentioned earlier the case of the prescriber who felt pressure to "tweak" medication feels this is a very uncomfortable area that many prescribers are subjected to. Her rationale when faced with such uncomfortable decisions is rather than tweaking the medication, she will prescribe PRN medication as a means of overcoming this situation. However as mentioned earlier this is a questionable practice as it may result in PRN medication being prescribed routinely and as a long-term solution.

Dr H: That has been difficult, but as I say maybe at the beginning I would have tweaked it up or down a bit, but how I would do that is put them on prn and then re-manage it. But enough was enough and I said that I cannot be doing this any more, so we have begun to start talking about it and they are on board now – but there was an issue.

Interestingly one male prescriber (Dr G) notes that he does not feel any uncomfortable prescribing decisions but he does feel that junior doctors and registrars may feel uncomfortable about some prescribing decisions largely based on their inexperience in handling pressure from staff.

Dr G: No I cannot say that I have found that – perhaps the registrars do find it or run into that or a junior doctor coming into the system – he or she may be approached by the nurse and there is this problem and they want to treat it immediately.

Although this prescriber has not felt any discomfort around prescribing decisions for some time, his policy regarding pressure or expectations to prescribe from staff is to avoid rushing in to deal with the situation immediately by means of prescribing. Most importantly he states that a record should be kept of behavioural observations and if medication has to be prescribed it should be prescribed in small doses.

Dr G: No not for myself but I certainly know that registrars have been approached and they do face a dilemma sometimes, and I would always say to them, in fact it is one of the first things I say to them that do not rush in to give medication – keep behavioural recording beforehand and if you are going to give medication, give it in small doses initially.

It is interesting to note that while prescribers in the study made reference to expectations and pressure from others as a source of discomfort, not all prescribers felt that it was applicable to themselves personally. The comments from the last prescriber above emphasize this point stating that although he does not feel uncomfortable around any prescribing decisions, his junior doctors or registrars may feel pressure to prescribe. A possible explanation for this lies in the fact that all prescribers in the present study were very experienced and had been prescribing for a number of years. In this respect the level of experience could be said to counteract the effect of pressure and expectations from others to initiate psychotropic prescribing.

12.6.4 Issues of Consent.

Of the eight prescribers involved in the present study, only one prescriber (Dr A) made reference to the issue of consent when prescribing for persons with learning disability. The issue of informed consent is receiving increased interest in recent times in Ireland for persons with learning disability as the new Mental Health Act is soon to be introduced and there is no doubt but it will have implications for persons with learning disability, especially those with mental health problems and those who are being prescribed psychotropic medications. Currently in many services – both residential and community, prescribing of psychotropic medication takes place without informed consent taking place. Although the person with learning disability in many cases may not have the ability to understand the implications of treatment, consent should be sought from the client's guardian or family member. In this respect in many cases clinical practice falls short in respect to theoretical perspectives on consent. This could be seen as another example of the theory to practice

hypothesis of prescribing where consent should be sought prior to the prescribing of any medication but in practice it does not always take place.

It was interesting to note that only one prescriber felt uncomfortable around the issue of consent when prescribing psychotropic medication. This female prescriber (Dr A) noted that the issue of consent was her main source of discomfort in its broadest sense.

> *Dr A: I suppose it is always difficult prescribing for someone who cannot give their consent, I suppose that is the main issue.*

Later in the interview this prescriber makes reference to the issue of depot medication as discussed earlier in terms of crisis intervention, but presently in relation to consent and the dilemma of trying to find a balanced approach to prescribing. She states:

> *Dr A: The other area where I tend not to use too much in terms of prescribing is depot medication, basically because of the issues around consent, so there would be very few people on injections, but again that is a very individual thing and you have to balance it, but in general I would put very few people on depot medication.*

Despite this prescriber feeling uncomfortable around the issue of consent, as a means of "over-coming" this discomfort, rather than seeking consent for those she is prescribing for, she seeks approval from her colleagues as a means of justifying her prescribing behaviour and adhering to a "best practice" model of prescribing. In this respect she makes reference to getting a second opinion from a colleague or expert in the field.

> *Dr A: You do what is best practice – I would tend for some cases to actually get a second opinion, because I am single handed, so any particular areas where I feel uncomfortable, I get somebody else to look at the person – somebody who would be an expert in this sort of area.*

Clearly in this case the prescriber is faced with a dilemma which she resolves by asking a colleague or expert in the field for a second opinion rather than firstly seeking consent from either the client themselves (if

possible) or from a family member or guardian and then getting a second opinion regarding the type of medication to be prescribed. Although only one single case is presented here based on a single prescriber, it would be interesting to gather information on psychotropic medications prescribed over a set period of time and how many of these were issued without the prescriber seeking consent. In such cases where consent is not sought, this clearly warrants caution as the legal implications of such prescribing may be called into question. However for the purposes of the present thesis, the evidence to further elaborate on this issue is lacking and there is certainly the need for further research on the issue of consent, rights of the persons with learning disability and the information which is given to them on the risks associated with psychotropic medication prior to the prescribing of same.

12.6.5 Concluding Remarks regarding uncomfortable Prescribing decisions.

When asked about uncomfortable prescribing decisions all but one of the prescribers stated incidents whereby they felt uncomfortable when issuing a psychotropic medication. From the four core categories which emerged, only two of these categories could be said to be strictly "pharmacological". That is to say issues such as drug profile, side effects and the issuing of depot medication could be said to be pharmacological in nature. The other categories such as expectation from others and issues of consent are broader social variables which although arose in some level of discomfort for prescribers are essentially non-pharmacological. Most of the prescribers within the present study at some point felt uncomfortable in relation to one or more of the four core categories. Where a prescriber stated that he did not feel uncomfortable prescribing psychotropic medication, he did note that some junior doctors or registrars may feel discomfort due to expectations from others or from staff pressure. The fact that this prescriber noted such an example may indicate that the level of experience in prescribing psychotropic

medication for persons with learning disability may have an impact on the types of situations which result in discomfort for prescribers.

12.7 Chapter Conclusions.

Unlike the study of Bradley (1992a) which examined uncomfortable prescribing decisions among General Practitioners, the present study had a number of avenues of interest. Not only did the author examine issues around discomfort which resulted in prescribing for persons with learning disability, rich and valuable data was obtained on a number of issues regarding psychotropic prescribing for this population. By means of utilizing a methodology known as the Critical Incident Technique, the author was able to gather "real world" and everyday examples of psychotropic prescribing and the range of factors which influence such prescribing. Further questioning enabled the author to gather data on issues which are highly emotive and controversial and under review by many services to the present day (Coughlan, 2000a).

What is presented in the current chapter is an in-depth analysis of the findings from the present study. The author, through use of grounded theory, has developed focused codes and core categories for each of the principle topics under study. Through the use of grounded theory all core categories which have emerged are grounded within the interview data which was generated from the eight interviews undertaken. The main advantage of such an approach is that the author becomes immersed in the data and all resulting core categories are not merely a set of pre-conceived categories which are applied to the data. From reviewing the literature on prescribing for persons with learning disability and the literature from General Practice, such an approach is quite novel and certainly within the learning disability field is one of the first studies of its kind.

Throughout the presentation and analyses of results in the present chapter, the author also embarked on a discussion of the relevance of

these findings. By means of constant comparison and evaluation (key elements of the grounded theory approach) the author was able to further question and elaborate on issues discussed by prescribers in the present study. However comparison of results generates some difficulties for the author as no such similar approaches have been utilised within the field of learning disability to date. However it is hoped that the present study will act as a catalyst for further research of its kind, while in addition generating interest in the advantages of using qualitative research methods in healthcare research and specifically within the field of learning disability.

Although the present chapter served multiple functions in that I have presented analyses of results and a discussion of same, it is necessary to conclude this thesis with a chapter which will examine the practical implications of the present study in addition to limitations of previous research and directions for future research of this kind.

The final chapter of this thesis is entitled *General Discussion and Conclusions – Implications of the Present Study.* This final chapter discusses the broader implications of the present study and how it serves to address the topic under study – prescribing for persons with learning disability.

CHAPTER THIRTEEN

GENERAL DISCUSSION AND CONCLUSIONS – IMPLICATIONS OF THE PRESENT STUDY

13.1 Chapter Introduction

Prescribing of psychotropic and psychoactive medications for persons with learning disability has had an emotive and controversial history and this continues to the present day with many clients being prescribed multiple medications for a variety of conditions. These conditions include the presence of an underlying mental illness in a proportion of clients, additional handicapping conditions such as epilepsy or autism, or perhaps more controversially challenging behaviour in the absence of an underlying psychopathology. The author uses the term "controversial" in that there are no clear guidelines regarding prescribing of psychotropic medications for persons with learning disability who display challenging behaviour, yet medications such as the Antipsychotics are routinely used for the purposes of behaviour control.

In addition to prescribing being undertaken for clients who display challenging behaviour in the absence of stringent guidelines, such medications are prescribed with a high frequency, especially in clients living in larger residential-type facilities in comparison to those living in smaller community-type facilities. The rationale for such prescribing is poorly understood and despite the vast array of studies undertaken on prevalence of prescribing, such studies have tended to focus solely on prevalence and have offered little in the way of an understanding as to the reasons *why* such prescribing takes place.

In an attempt to gain an understanding of the process of prescribing for persons with learning disability, the present author undertook to examine the rates of psychotropic medication prescribed within the Brothers of Charity Services, Mid-West region. This drug prevalence study examined the rates of prescribing of all psychotropic medications for persons with learning disability in both residential and community settings and it acted as the first

phase of the present thesis. The second phase of this thesis has deviated somewhat from the published research to date. Rather than attempting to account for the findings from part one of the study by means of examining the associations between prescribing and psychopathology, the present author has employed a novel methodology in attempting to understand the process of prescribing, the factors affecting prescribing and the rationale why such medications are prescribed in the fashion they are for this population. Hence as the title of this thesis shows, the author investigates and reports on both quantitative and qualitative perspectives of prescribing within the learning disabled population.

The final chapter of this thesis is devoted to a discussion and concluding remarks regarding the implications of the present thesis. The author is faced with the dilemma of discussing the present piece of research within the confines of the field of learning disability and prescribing, where traditionally the literature has been of a quantitative nature and has not expanded beyond this point. Part one of this thesis fits "neatly" within the realm of published literature on the topic at hand, due to its quantitative framework. The author suggests that this is the principle strength of the study and its adds to our understanding of the demographic variables which impact upon prescribing. Part two of this thesis however presents a more formidable challenge to the author in terms of a discussion of its implications due to the novel means by which the author undertook the study. This is the first study of its kind, which uses qualitative techniques in order to gain a meaningful understanding of psychotropic prescribing within this population. Hence the difficulty arises of how to relate the present findings to previous research, as there have been no efforts of a similar nature to conduct this type of research. What the present chapter will attempt to undertake is a discussion of the usefulness of the methodologies employed, how they relate to the existing literature and how they may be incorporated and expanded upon in future research in this area.

13.2 Prevalence of pharmacotherapy – the need to question?

Throughout the writings of the present thesis the author has attempted to give a detailed overview of the current status of pharmacotherapy within the field of learning disability. Chapter one of this thesis gives an overview of the relevant issues in the field of learning disability and perhaps the principle theme of the chapter is one of the complexity of the condition of learning disability. Despite there being unified definitions of what constitutes learning disability (AAMR, 1992, WHO, 1992) and the fact that in these definitions the importance of adaptive behaviours are highlighted, one must view this condition in its broadest sense for each individual. This is of importance, not only in terms of assessment and diagnosis, but also in terms of treatment. Hence the core issue under study within this thesis is the issue of treatment, and in particular, treatment with psychotropic and psychoactive medications.

Chapter two specifically deals with the issue of pharmacotherapy in learning disability and the author presents an overview of recent research within this highly specialized area. Not only is this a highly specialized area, but as stated in the opening paragraph of the current chapter, it is an emotive and controversial one. In researching this area from a psychological perspective, one is at a unique advantage in terms of the way one wishes to study the area. The field of psychology has traditionally been a distinct discipline and has much to offer the field of learning disability, not only in terms of diagnosis but also in terms of treatment methods employed. The use (and advantages) of behavioural techniques within this field have long been recognized and more recently cognitive approaches are proving beneficial. In this respect, the discipline of psychology has not studied the phenomenon of prescribing behaviours among doctors and psychiatrists within the learning disability field. Hence the present thesis offers a unique scientific, objective perspective of prescribing in the learning disabled population from a discipline other than psychiatry.

In attempting to provide a rationale for the studies employed within this thesis, the author feels there is the need to question the underlying principles of pharmacotherapy, not only in terms of the prevalence of prescribing but also in terms of the rationale for their use. Gadow (1999) puts forward a series of questions regarding drug therapy in children and adolescents. These questions are as relevant for the field of learning disability as they are for the general population. In relation to psychotropic prescribing Gadow asks "how common is the medical prescription of such drugs at the moment? Is it too little or too much? Does clinical application precede scientific verification of safety and efficacy? Are recommendations for patient management generally followed in everyday clinical settings?" (p.51).

If one turns one's attention to the present thesis, similar questions are being asked. Although the first phase of this thesis is concentrated on drug prevalence, the objective of the exercise is much more than simply "head counting". To date no published figures are available for psychotropic and psychoactive medications within Irish residential or community services for persons with learning disability. This was the first aim of part one of this thesis – to examine patterns of prescribing within an Irish context and compare them to the existing published studies to date. The second aim was to examine a range of demographic variables and determine whether they were of significance in terms of prescribing for this population. Not only did study one examine patterns of prescribing for an entire population base of residential clients, it also served to study an entire population base of community clients within this same region in Ireland. Hence the present study has overcome many of the limitations of published drug prevalence studies to date – the problem of lack of breadth (Spreat et al., 1997), problems inherent in the sampling procedures employed and the range of medications studied (study one investigated all drug categories affecting the CNS and not just psychotropic medication).

From the published research to date, one fact is clear and this is highlighted by almost all studies of prevalence – "people with mental retardation constitute one of the most heavily medicated segments of our population" (Gadow, 1999, p.56). Hence if one asks the question whether persons with learning disability are being over-medicated, the answer is a most definite yes. Within part one of this thesis, this question has been posed once again. The author feels that the figures obtained from the study speak for themselves. Of the residential population studied, 81% of clients were administered some form of psychotropic or psychoactive medication, with the corresponding figure being 33% for clients in the community. If one turns to the residential figure again, antipsychotic prescribing amounted to 73%. Quite clearly this is a high figure, within present day circumstances and the author urges caution in prescribing to such a high degree. Rather than examining the entirety of results once again, the reader is referred to chapters four and five for a detailed analyses and discussion on the findings of the study. However one of the principle conclusions from part one of this thesis is that a] psychotropic and psychoactive medications are prescribed frequently and at a high rate to the population under study, b] multiple medications are prescribed for a sizeable number of clients – both polypharmacy and co-pharmacy, and c] the rationale for such medications is poorly understood, with medications not being matched to specific diagnoses or symptoms.

In attempting to account for such findings, one must again begin to ask questions. Now that one has produced evidence to support the notion that persons with learning disability are prescribed medication to a high degree, how does one gather information pertaining to why such medications are prescribed. One question which is often posed is: are there medications being reviewed and monitored appropriately? The answer to this question is difficult and clearly beyond the scope of the present thesis. However from the published literature on litigation and legislation in this area, it is clear that

psychotropic and psychoactive medications are very often not being monitored effectively in many states and countries (Schouten & Duckworth, 1999). Part two of this thesis did pose many questions. However the questions posed were not specifically regarding whether medications were being prescribed appropriately or not, or whether monitoring procedures were being employed, they related specifically to decision-making processes, factors which affect prescribing and determinants of prescribing for persons with learning disability.

The author will now turn the focus of attention to part two of this thesis and how it has attempted to account for the findings obtained in part one.

13.3 Accounting for the findings – do qualitative techniques fulfil this role?

Attempting to account for the findings from part one of this thesis is by no means an easy task and it is probably beyond the scope of the second part of this thesis to account for these findings in full. However despite its limitations, part two of this thesis offers a unique picture of the prescribing behaviours of a number of prescribers, whose role is prescribing for persons with learning disability.

From reviewing the literature on pharmacotherapy in learning disability and on prescribing within general practice, the author felt there was a need to put in place a methodology, which would serve two principle functions. The first of these functions was to answer many of the questions which remained from completing the first phase of this research project and which could not be answered from the findings obtained. The second function was to gain a deeper understanding of the decision-making processes which are employed by prescribers prior to issuing a prescription and what factors might influence these decisions.

From reviewing the literature on prescribing (from both the perspectives of general practice and learning disability), one factor is common to both. Prescribing is a complex phenomenon and is based on the knowledge of the practitioner, the symptoms displayed by the patient and a host of social factors, many of which are not easily identifiable nor subject to scientific study. In the words of Werry (1999) "the act of prescribing a drug is a complex human transaction set in a social field at a particular historical time and subject to a variety of unseen influences. If one believes that Home Sapiens is at least in part a rational being, knowledge of these factors may lead to better prescribing by practitioners and more informed participation by consumers in the process" (p.11). If one examines the factors involved in prescribing, considerably less is written about the social influences in the prescribing process, than for example demographic factors. The primary reason for the lack of research in this area is due to the inherent difficulties in studying the social processes at work in prescribing. By utilizing a qualitative methodology, the present author was able to objectively study some of the social processes at work when prescribing for the learning disabled population.

Utilising a qualitative approach to the study of prescribing in learning disability has proved more useful in gaining an understanding of the processes at work and determinants of prescribing than it has in attempting to account for the findings from the present drug prevalence study. Despite this however, from the responses obtained from the prescribers in the present study, they do, in particular, go a long way in accounting for the high rate of antipsychotic prescribing. From part two of this study prescribers tended to rationalize their prescribing in terms of the diagnoses they formulated. From chapter twelve one can see that a diagnosis is the cornerstone on which any later treatment regime is implemented. If the diagnosis falls within the paradigm of mental illness, prescribers in the present study tended to rationalize and justify their prescribing on this basis.

On the other hand, if the label of "challenging behaviour" was placed on the person, prescribers were not as content prescribing for this condition. Despite this however, and based on the critical incidents of prescribing gathered, many prescribers do prescribe solely for the purposes of challenging behaviour, even in the absence of an underlying psychopathology. In the formulation of a model of prescribing as discussed in chapter twelve, this is what the author terms the "theory to practice hypothesis of prescribing" – where in theory prescribers say they do not prescribe for challenging behaviour, but in clinical practice, and on the basis of evidence produced in this second study, they do prescribe for the control or suppression of challenging behaviour.

Another example of this can be seen in terms of polypharmacy or indeed copharmacy. From part one of this thesis, it can be seen that both polypharmacy and copharmacy are a commonplace practice for clients in residential settings. One can again account for the discrepancy between prescriber's theoretical perspectives and what happens in clinical practice, by examining the model of prescribing in conjunction with the critical incidents of prescribing gathered. From the case histories outlined by prescribers throughout the interview material, they tended to add-on medication in an ad-hoc manner, without any scientific evidence regarding the rationale for it. Prescribers rationalized this by means of a drug being relatively ineffective for the person and so an add-on medication was required. This type of prescribing practice tended to be more for complex conditions where the existing medication was deemed ineffective and where the prescriber found it difficult to formulate an accurate diagnosis. Any subsequent diagnosis may be made in terms of the atypical presentations of many conditions seen in learning disability. Much of the present research in psychopharmacology is concentrating on atypical presentations of many conditions not readily identifiable by means of the DSM and ICD classification systems (Verhoven & Tuinier, 1997, 1998).

Finally, on answering the question of whether qualitative techniques account for the findings of the first phase of this study, one must examine the type of material gathered when undertaking qualitative research. Unlike part one of this thesis, which was quantitative in nature, very different information was gathered in part two of this thesis. From analysing the interview material and generating a model of prescribing by means of the grounded theory approach, it enabled the author to gain an understanding of the complexities involved in prescribing, while also outlining the factors influencing decision making amongst prescribers. If one takes this information and applies it to the quantitative data gathered it does offer the author an explanation as to why psychotropic and psychoactive medications were prescribed to such a high frequency. In addition it also sheds some light on the rationale of why these medications were prescribed, both in terms of mental illness but also and perhaps more importantly, in terms of the presence of challenging behaviour. In such instances prescribers felt a sense of responsibility, and the "need to be seen to be doing something", regardless of whether the prescribing was rational or otherwise. The implications of such prescribing behaviours will be discussed later in this chapter. Prior to this discussion however, the author feels it necessary to discuss issues regarding methodology, and ethical considerations in carrying out research of a similar nature to the present project.

13.4 Methodological considerations

The methodology utilized in part two of this thesis is a somewhat unique methodology in the study of prescribing for persons with learning disability. As mentioned earlier in this chapter research to date on pharmacotherapy in this population has traditionally been of a quantitative nature. However in order to gain a more meaningful insight and understanding of this most complex area, the author felt the need to explore avenues which to date have not been explored. In addition the use of qualitative techniques in

addition to the quantitative techniques used in part one provide a more global perspective on prescribing in the field of learning disability.

Within the field of healthcare research generally, the vale of qualitative techniques is being increasingly recognized by both researchers and clinicians in turn. Qualitative techniques prove most useful where the subject under study is complex and not readily studied by means of more traditional quantitative or experimental methods (Green & Britten, 1998). In terms of the advantages of qualitative research methods in terms of their usefulness in clinical practice, Green and Britten (1998) outline four points regarding the usefulness of such techniques in evidence based medicine, by stating:

1. qualitative methods can help bridge the gap between scientific evidence and clinical practice.

2. qualitative research findings provide rigorous accounts of treatment regimens in everyday contexts.

3. this can help us understand the barriers to using evidence based medicine and its limitations in informing decisions about treatment.

4. recognizing the limits of evidence-based medicine does not imply a rejection of research evidence but awareness that different research questions require different kinds of research.

The above points are useful to our understanding of the present thesis. By applying traditional experimental techniques to the study of pharmacotherapy in learning disability, it enabled the author to compare prevalence figures from an Irish context to similar study conducted elsewhere. However, by then incorporating a qualitative element to the

study, it has added considerably to the literature on this topic by means of the type of information presented in part two of this thesis, while also presenting a conceptual model of prescribing for this population. Despite this model being a tentative conceptual model, it is the first of its kind developed within the field of pharmacotherapy and learning disability.

Perhaps one of the principle strengths of this thesis from a methodological perspective is the fact that by incorporating both a quantitative and qualitative technique, it enabled the author to research an area from a psychological perspective, which traditionally has been notoriously difficult to study – difficult from the methodological point of view, but also from the point of view of a discipline other than psychiatry researching this area. This has also lead to some difficulties with the study and these issues will be discussed in the next section entitled ethical considerations.

Another strength of the study lies in the diversity of areas discussed by prescribers in part two. Whereas qualitative studies in general practice have tended to concentrate solely on one area such as uncomfortable prescribing decisions (Bradley, 1992c) or changes in clinical practice (Allery et al., 1997), part two of this thesis had several foci of attention. This was an important aspect in generating a global impression of prescribing practice for persons with learning disability. By means of gathering critical incidents of prescribing (in the real world setting) this enabled the author not only to gather important information regarding factors affecting and impinging upon prescribing as outlined in the prescribing checklists, it also enabled the author to discuss these issues more thoroughly throughout the interview process. Hence in this respect prescribers discussed issues regarding assessment and diagnosis of mental health problems, the issues they themselves as prescribers felt were important in prescribing, how prescribing relates to challenging behaviour and instances where they may have felt uncomfortable around prescribing decision made. By discussing

such broad issues within the confines of the study, it thus enabled the author to generate the current model of prescribing put forward in chapter eleven of this thesis. This model of prescribing clearly goes some way towards our understanding of prescribing and does account in part for why psychotropic and psychoactive medications are prescribed to the frequency with which they are in many services throughout Ireland.

Despite the advantages of qualitative techniques within part two of this thesis, there were also disadvantages with this technique. The first of these relates to the technique of interviewing and the type of material generated throughout. Prior to commencing study two, the author had to give assurances to all prescribers involved in the study that the interview material generated would remain anonymous. The fact that all interviews were recorded (and consent was agreed upon prior to interviews) did generate some dissatisfaction amongst a small number of participants, particularly once the study was completed. Prescribers were informed beforehand that the methodology was qualitative in nature and that extracts from interviews would be used but despite this there was some concern once the study was completed. This concern was voiced by a number of prescribers who wrote and telephoned the author in order to "see what was being done with the data". Although not easily explained, this concern seemed to grow out of the "apprehension" of those prescribers *not* involved in the study. These issues will be discussed in the next section but such concerns due warrant discussion within the context of methodologies for future research.

The present author believes that it was not the research techniques used or the recording of the interview which was the root of the problem but how this material was going to be used. Essentially those prescribers who were not involved, did not participate due to a discipline other "than their own" researching an area with many complexities. From discussing the study with a number of prescribers prior to commencing the research, their

apprehensions lay within the realm of the discipline of psychology researching this area. Some prescribers felt that the discipline of psychiatry should be involved in implementing a suitable methodology, while others felt the discipline of psychiatry should be implementing an independent audit of prescribing behaviours. It should be noted that while these are valid criticisms of the present study and despite the author welcoming any suggestions from the discipline of psychiatry regarding implementation of the study, all prescribers at the time were not interested in actively partaking in an inter-disciplinary approach to any such study.

13.5 Ethical considerations

As discussed above there was some discontent amongst the discipline of psychiatry within the Republic of Ireland regarding implementation of the second study of this thesis. Interestingly there was little, if any comments regarding the discipline of psychology undertaking a drug prevalence study, a research process traditionally undertaken by psychiatry. The fact that an independent review of all psychotropic and psychoactive medications was welcomed by the authors employing organization (and ethically approved) may have been highly advantageous to the author. Within the era of audit, litigation and legislation surrounding medication administration for persons with learning disability in many countries, the implications and applications of the first study should not go unrecognised and the fact that a drug database now exists for all service users within the region is highly advantageous for future research and audit efforts.

The fact that the second study grew beyond the confines of the author's organization and incorporated a cross section of the discipline of psychiatry within learning disability in Ireland, was perhaps the greatest source of concern for some prescribers. By incorporating consultant psychiatrists from a number of different service providers for persons with learning

disability, the profile of the study was raised considerably in addition to the possible recommendations from conducting such research. The fact that the author was not known by many prescribers also generated some level of discomfort regarding inclusion in the study. Hence this may in part account for a 40% final inclusion rate for the study.

A discussion of the ethical considerations within the confines of the present study is not only important in taking the findings of the study into account, but it is also important in terms of future research in this area. As mentioned earlier above, the main sources of concern for prescribers grew from the views of prescribers not involved in the present piece of research. Hence from "colleague communication", prescribers discussed among themselves the nature of the research, the discipline undertaking such research and the possible implications of same. The fact that the study was a novel means of studying prescribing behaviour within the context of learning disability may have also added to their concerns, despite the methodology being employed previously within general practice.

In addition to the above point on "colleague communication", an interesting point regarding the study emerged upon completion of all interviews. Those that participated in the second study of this thesis did so willingly and were interested in receiving feedback on the findings from the study. Those that were not involved in the study essentially comprised of two distinct groups – those that were uncomfortable with a discipline other than psychiatry studying the process of prescribing and those that wished to consult with their colleagues at the learning disability section meeting (a meeting which takes place approximately once every six months attended by members of the Royal College of Psychiatry – learning disability section). The first group refused to participate in the study due to "ethical problems" – this was conveyed to the author via telephone conversation. At no time were any of the concerns of prescribers forwarded to the author by means of writing and

hence the notion of "ethical problems" was not explained to the author at any time. Those comprising of the second group were not willing to partake in the study on the basis of "not having enough information about the study" and "wishing to consult with colleagues regarding participation in the research". Quite clearly both groups were very uncomfortable with the discipline of psychology studying prescribing, but members of the second group essentially wished to place a veto on the study, so that the learning disability section (as a group) would have to form an opinion of whether all members would be involved or none. In this respect it was an "all or nothing situation" regarding participation in the study.

Not only was this a worrying aspect for the author and researcher of the study at the time, but also the issue of "vetoing" research goes beyond this single isolated study and has implications more broadly for research of this kind. As the author was expecting some level of discomfort from prescribers regarding the study, those that were willing to complete prescribing checklists and be interviewed were asked to partake in the study immediately. Hence prior to any learning disability section meeting taking place, the author had completed a total of nine interviews with consultant psychiatrists. Data was also collected for the consultants who completed prescribing checklists at this point. On the basis of this learning disability section meeting taking place and the authors research project being on the agenda and actively discussed at this meeting, one prescriber corresponded with the author and asked that all information be withdrawn from the study. The reason given for withdrawal of this prescriber's information was due to ethical problems regarding involvement in the study. On the basis of this prescribers wish to be withdrawn from the study the analysis conducted and reported here has been based on the responses and data gathered for a total of eight prescribers.

The issue of attempting to place a veto on research conducted by different members of the multi-disciplinary team is a worrying sign in terms of the health care profession. Granted the present thesis was conducted on a very sensitive and complex topic, but at all times confidentiality and ethical considerations were of paramount importance. What has been presented in this section is a cautionary tale for future researchers attempting to research a sensitive area such as prescribing. It is disappointing however that members of different professions do not realize the value of other disciplines in studying areas of relevance and significance to themselves. The issue of "professional rivalry" is still unfortunately very much in existence, not only in terms of clinical practice but also in terms of research. How this will be overcome has yet to be given some thought but for the purposes of the present thesis, perhaps by implementing a more inter-disciplinary approach to the framework by which the study was developed may have helped to overcome levels of discomfort while also increasing participant numbers.

13.6 Theoretical & practical implications of research to date.

Research undertaken to date in the area of medical decision making and general practice have offered much to the present thesis. Not only has such research given the author a number of theoretical frameworks by which to study the area of prescribing, such studies have also served to address a number of questions with regard to the practical applications of undertaking such research. Regardless of what professional background one has trained in, there is the need to further understand the processes by which prescribers made decisions. While a substantive volume of literature exists in the area of shared decision making within general practice, considerably less is known about this in the area of learning disability. Even in terms of shared decision making in general practice, little is known about why patients may be reluctant to share their preferences (about medication) with their doctor. Granted there are those who will share their preferences

openly with their practitioner, but there is also a considerable number of patients who do not wish to engage in this process.

On the other hand, much of the research, such as the studies of Bradley (1992, a,b,c) have focussed on the complexities around prescribing. From a theoretical perspective, perhaps this is the most significant contribution that these studies have brought to the present thesis. The decisions around whether to prescribe or not are both complex and multi-faceted. If one examine the literature in detail, both from a general practice perspective and also from a learning disability perspective, on the basis of Parish's and Barber's definitions of rational prescribing, there is no doubt much prescribing is irrational. However one must also take into consideration the dilemmas which practitioners face when contemplating whether to prescribe or not. What is particularly problematic is the issue of prolonged drug treatment, without appropriate review. In dealing with such issues of irrational prescribing, recent professional efforts have been directed at reducing such irrational prescribing by means of educating prescribers. This is an important theoretic and practical implication of the research from general practice. It is also an issue which not only faces general practitioners but all practitioners prescribing medications including psychiatrists. Education around when not to prescribe a medication is equally as important as education around when to prescribe appropriately. The issue of cognitive dissonance is of relevance here in attempting to formulate an educational programme for prescribers in all discipline of medicine. On this issue Allery et al. (1997) note the importance of researching the beliefs of clinicians in an attempt to gain a deeper understanding of the strategies involved in changing doctors prescribing patterns. These authors note that "education providers should develop more multifaceted strategies, integrating their activities with the broad range of other factors which affect changes in clinical practice" (p.873).

In terms of the practical implications of the research from general practice, and indeed the pharmacological research from the area of learning disability, firstly, it was possible to develop a protocol regarding the issues to be studied, but perhaps more importantly, these studies provided the author with the means of how to go about such research. While quantitative techniques have proven useful in a wide variety of areas, the value of qualitative techniques cannot be over-emphasised in researching how clinicians make, and rationalise decisions around their prescribing. Much of the work from general practice has utilised qualitative techniques in order to get a snapshot view of how clinicians make decisions, or indeed how and why they change their prescribing behaviour.

The author will now review some of the implications of the present study, with regard to issues in learning disability, mental health services, and more specifically, implications for our understanding of psychotropic and psychoactive prescribing for this population.

13.7 Implications of the present study in understanding learning disability

Throughout the twentieth century there have been significant advances made regarding the way persons with learning disability have been supported and treated (MH-SIRG, 2000). Methods of treatment have changed considerably over this time to the advantage of those with learning disability. As new research emerges, different approaches are utilized in the treatment of this population. The issue of treatment in terms of psychoactive and psychotropic medications however still remains controversial due to the efficacy of using such medications for challenging behaviour in the absence of any underlying psychopathology. As stated by Santosh and Baird (1999) "there is no consensus about the use of these drugs for the control of aggressive and disturbed behaviour, hyperactivity, and stereotypical behaviour, in the absence of mental illness" (p.234). Even when a diagnosis

of mental illness has been made, the area of assessment and classification systems utilized are fraught with difficulty (Moss, 1999).

The present thesis examined issues relating to drug prevalence and decision making factors regarding the prescribing of such drugs for persons with learning disability. Implications of these studies are wide-ranging and go beyond the realm of research within this field. They have implications for mental health services for persons with learning disability, not only in terms of service provision but also in terms of clinical practice in the treatment of this population.

13.7.1 Implications for mental health services for persons with learning disability

Although the principle focus of attention of the present thesis was concentrated on prescribing, issues pertaining to mental health services for persons with learning disability are of paramount importance to our understanding of the process of prescribing. Chapters six and seven of this thesis have been devoted to a discussion of mental health issues in this population. Elsewhere the present author has critically analysed the use of models such as ICD and DSM in diagnosing mental health problems in the learning disabled population (Coughlan, 2000b) and the problems associated with such models developed for the general population.

Throughout the second phase of the study, many prescribers made reference to the inherent difficulties associated with making a diagnosis within this population. The most common cause of concern for prescribers was the client's lack of ability to verbalise what they were feeling. Rather than utilizing the existing psychometric tools, prescribers tended to make their diagnoses based on third party reports. Although there are many problems associated with these existing psychometric tools, they do prove

useful in gathering information regarding the client in question. However at no point did any prescriber within the study make reference to utilizing such tools. Rather they made their decisions regarding the client's diagnosis on the basis of third party reports, which many prescribers reported to be inaccurate and speculative.

Quite clearly there is a dilemma faced here, the implications of which are of a very serious nature. Diagnoses are being made by prescribers on seemingly dubious grounds and such diagnoses are commonly being treated by means of psychotropic medications. The evidence of this statement has been presented in chapter eleven and is clearly grounded within this interview material as discussed earlier. The fact that prescribers have suggested that the third party information, which they rely upon, is "speculative" and inaccurate raises a number of considerations. As discussed in earlier chapters the pathway to mental health services is a difficult process but once a client reaches this service, one would hope for an effective model of service delivery based on scientific merit and not merely on clinical speculation on the part of the professional. Evidence presented throughout this thesis suggests that this is not the case in many services throughout Ireland, based on the responses of prescribers in this study.

Hence not only is there problems in the detection of mental health problems in the learning disabled population but there are also problems in terms of its assessment and more importantly treatment. It was interesting to note that a number of prescribers felt that "education" plays a vital role here. In particular education of direct-care staff who are the one's responsible for the clients needs on a daily basis. In the opinion of the author, this is merely a starting point and the role of education goes beyond the direct-care worker and involves all members of the multi-disciplinary staff working with this population. Thus the implication here is that the process of assessment,

diagnosis and treatment of mental health problems should be a multi-disciplinary process and be subject to critical evaluation at all times. As stated by a recent report compiled by the Special Interest Research Group on Mental Health (September, 2000) "the complexity of the potential problems that arise invariably requires a multi- or inter-disciplinary approach. Different disciplines apply their theoretical perspectives in attempting to arrive at a comprehensive understanding ... in many instances, comprehensive assessment will indicate the need for interventions characterized by a combination of several of these strategies" (p.18).

13.7.2 Implications in understanding psychotropic and psychoactive prescribing in learning disability

On reviewing the current status of literature at the end of the 1980's, Aman and Singh (1991) made the following statement: "we have now witnessed 35 years of drug research in this field, and it is disappointing that more cannot be gleaned with some degree of confidence from the existing literature" (p.364). On reading this statement one could adopt quite a pessimistic view of the research undertaken, up until this point. However the present author feels that a far different picture exists at the end of the 1990's, the period during which the present thesis was conducted. The author will now examine the current status of research and clinical practice in this field and outline some of the implications of the present piece of research.

In terms of prevalence studies, the most positive development to date has been the change in the impetus of these types of studies. Recent efforts have been based more towards effectiveness of prescribing rather than prevalence per se. In addition from recent drug prevalence studies published the rates of prescribing are decreasing (Kiernan et al., 1995, Aman et al., 1995), while many papers tend to examine the effectiveness of multi-disciplinary teams in reducing such medication (James, 1983, Jauernig

and Hudson, 1995, Jordan, 1994, Findholt and Emmett, 1990 and Lepler et al., 1993). Such research efforts have changed considerably the perspective from which psychopharmacological research in the present era is conducted, while also proving beneficial in terms of clinical practice in many services worldwide.

Although part one of this thesis reports the findings solely in terms of prevalence of prescribing, it was a useful undertaking in our understanding of prescribing. As mentioned earlier no published studies undertaken in an Irish context are available at the time of writing. Hence this study was of particular usefulness in comparing Irish patterns of prescribing to studies of a similar nature conducted in the UK, the USA and elsewhere. Part two of this thesis has afforded the author the opportunity to research a particularly sensitive and complex area of prescribing – factors affecting prescribing and how decisions are made by prescribers themselves. Although prescribing of medication must be seen within its "medical" context, there are also a host of social variables which impact upon prescribing, and there is no doubt but this area is poorly researched within the field of learning disability, in addition to other areas such as paediatric pharmacotherapy (Werry, 1999). The aim of the present thesis was to gain a deeper understanding of the many variables at work when prescribing for persons with learning disability.

Perhaps one of the most significant implications of the present thesis is the fact that the author has undertaken research and produced findings, which from a psychological perspective have implications for prescribing practice in addition to mental health services for the learning disabled population. One of the main values of this thesis lies in the presentation of the many complexities prescribers face when prescribing for this population. Unlike general practice (where a significant volume of research on prescribing exists), many clients with learning disability do not have the capacity to understand their condition, nor do they have the capability to subjectively

report how they are feeling. Hence the prescriber is faced with the dilemma of attempting to extrapolate information from carers or family members. As discussed earlier, there are many problems with this approach, not only in terms of diagnosis but also in terms of treatment.

Due to the global nature of the topics covered throughout this thesis, it affords the author the unique ability to understand the complexity of conditions presented prior to prescribing, the types of dilemmas faced by prescribers and the decision making processes employed by the present sample of Irish prescribers. To date no such similar efforts have been undertaken from either a quantitative or a qualitative perspective.

Similar to the studies of Bradley (1992b) and Howie (1976), decisions made by prescribers seem to be based on an interplay of social and clinical factors. However in terms of the social factors involved, prescribers in the present study were not faced with the dilemma of damage to the doctor-patient relationship if they did not choose to prescribe. Rather they were faced with the dilemma of further pressure from families or staff to prescribe a "magic bullet" in order to treat the condition. In other instances in the present study, where prescribers were involved in crisis intervention, they felt under pressure to prescribe, due not only to staff or family pressure, but also due to prescribers themselves having a sense of responsibility to "do something". This interplay of factors seems as pertinent to consultant psychiatrists in learning disability as it does to general practitioners, and as supported in the general practice literature to date (Kuipers, 1988).

On the basis of all data collected within this thesis, the following main points of interest emerge, which may be considered the principle findings of the study:

1. *Psychotropic and psychoactive medications are widely prescribed to service users within the Brothers of Charity Services, Mid-West region. Residential figures are significantly higher than those obtained for community facilities.*

2. *The rationale for such prescribing is poorly understood in terms of psychiatric diagnoses or specific target behaviours. Prescribing within this study seems to be based on clinical impressions rather than on scientific evidence.*

3. *Selection of target behaviours for the purposes of treatment by medication were not apparent at any stage of the study. Nor were they reported.*

4. *Polypharmacy and copharmacy were widely used, especially in residential service users. The rationale for multiple drug usage was not reported.*

5. *Long-term prescribing of medication for many clients was in existence with older drugs such as Phenobarbitone and Primidone being prescribed to a small number of service users in the community (five in total).*

On a more global scale and in line with part two of this thesis, the principle findings are outlined as follows:

6. *All prescribers noted the many complexities involved in making a diagnosis in the learning disabled population. This stems from poor verbal abilities and the atypical presentation of many conditions.*

7. *Prescribers tended to strive for a diagnosis and once they formed a diagnosis, this rationalized their later prescribing. Very often diagnoses were based on third party reports, which many prescribers felt were inaccurate and speculative.*

8. *The decision of whether to prescribe or not lays solely with the prescriber and decision-making tends not to be multi-disciplinary. The role of the multi-disciplinary team tends to be seen by prescribers as a more global role. Hence the author uses the term "clinical information gatherers".*

9. *The factors influencing the complexity of prescribing included drug profile and side effects, having to rule out underlying physical causes and pressure from others to prescribe.*

10. *Prescribers did not feel comfortable prescribing solely for challenging behaviour yet in practice this is a common occurrence.*

11. *Prescribers felt particularly uncomfortable when they are called for crisis intervention and feel prescribing is the last option left.*

12. *Although prescribers felt uncomfortable with prescribing two or more medications (polypharmacy or copharmacy), in clinical practice this is a routine practice.*

13. *Despite litigation and legislation around the issue of informed consent, one prescriber felt this to be a source of discomfort.*

14. *No prescribers in the study made reference to guidelines regarding appropriate prescribing. In terms of an educational model of mental health & psychopharmacology, prescribers felt this necessary for front-line staff and not members of the multi-disciplinary team.*

From the above synopsis of findings of this thesis, an overall underlying theme emerges, and this relates to the application of guidelines regarding appropriate prescribing for the learning disabled population. To date in many organizations there are no guidelines in place which regulate the prescribing of such medications. This is an area which requires urgent attention on the part of service providers in Ireland as in many countries such as the UK and USA such guidelines are implemented and enforced (Kalachnik et al., 1998).

Elsewhere the author has reviewed the implementation of such guidelines and the importance of a multi-disciplinary approach in prescribing. To conclude this section, the author will present a synopsis of *the fourteen guidelines of appropriate prescribing* as developed and discussed by Kalachnik and colleagues (1998). The importance of further developing these guidelines for

Irish learning disability services will be discussed in the final section of the current chapter.

Table 13.1: A table outlining a synopsis of Kalachnik et al.'s (1998) Psychotropic Medication Guidelines. Taken from Coughlan (2000c)

Synopsis of Kalachnik et al. (1998) Psychotropic Medication Guidelines.	Key Elements.
1. Know the purpose of the drug being prescribed	Psychotropic versus psychoactive medication – refer to Aman & Singh's (1991) definitions.
2. Any medication prescribed should not be used in excess, or in place of any other form of treatment for purposes of convenience.	Medication as a means of chemical restraint – utilise other treatment methods if appropriate & applicable
3. Medication should be prescribed as part of a multi-disciplinary team approach.	The multi-disciplinary team of professionals should decide the best possible treatment plan for each individual.
4. Any prescription should arise from a thorough functional analysis and psychiatric assessment.	Hypotheses should be generated as to the individual's condition and underlying causes.
5. Written informed consent must be obtained.	Informed consent of the individual or his/her guardian must be obtained prior to the use of any agent.
6. Importance of Index behaviours & Quality of Life measures	Index or target behaviours need to be specified and measured throughout treatment.
7. Side effects need close monitoring	Importance of the use of a standardised rating tool to monitor any possible side effects of medication.
8. Monitoring of Tardive Dyskinesia	Tardive Dyskinesia may develop in some individuals treated with certain psychotropic medications (Dopamine blocking agents). This needs careful monitoring.
9. Systematic & regular review of psychotropic prescribing should take place.	Regular reviews are essential is order to determine if medication is having its desired effect.
10. Minimal Effective Dosage should always be used.	The minimum effective dosage of any drug should be used in the treatment process. Avoid excessive dosages.
11. Avoid frequent changes in medication	Frequent changes of medication should be avoided at all costs due to processes of pharmacokinetics and pharmacodynamics.
12. Avoid Polypharmacy	Polypharmacy (use of two or more

	medications) should be avoided if possible. Where an "add-on" drug is needed, a tapering off process (for the initial drug) is needed.
13. Aim for a "best-practice" model of drug treatment.	Avoid older medications where newer "atypical" medications may be more effective, avoid excessive dosage, avoid long-term use of PRN, avoid use of drugs where negative side effects are known.
14. External or peer review should take place – clinical audit.	All prescribing should be subject to peer or external review so as to maximise effectiveness and avoid excessive prescribing

13.8 Chapter conclusions: The need for confirmatory follow-up research and the implementation of prescribing guidelines

The present thesis, comprising of two studies addressed the issue of prescribing for persons with learning disability from both a quantitative and qualitative perspective. Hence a global picture of prescribing within Irish services was ascertained by means of conducting this piece of research. Not only does this thesis provide a unique understanding of prescribing for the learning disabled population, it also highlights the issues within this field which need to be addressed not only from the clinical practice perspective but also from the perspective of future research endeavours. The purpose of the final section of this thesis is to highlight the need for follow-up confirmatory research within this area in addition to the development and implementation of prescribing guidelines within Irish services for persons with learning disability.

On the issue of follow-up research of this nature, there is now the need to undertake confirmatory-type research in order to further validate and develop many of the ideas expressed within this thesis. Although part one of this thesis is based on traditional quantitative research techniques and is strongly supported by previous studies of this kind, part two of this thesis must be viewed within its current limitations. Although qualitative research

techniques are not new to healthcare research, no similar studies of this kind exist within the field of learning disability at the time of writing. As a result comparison of studies is difficult, and the author discusses the findings within the context of similar research from general practice and how the findings of such studies have implications for prescribing in learning disability. Not having an extensive literature on this area in which to compare and contrast findings could be said to be the most significant limitation of this study. However this is true of all novel or unique studies and it is the role of future research to further elaborate on the ideas and theories expressed in the writings of this thesis.

Regarding the development and implementation of prescribing guidelines in Irish services, most services fall somewhat short in this area. This is not to say that services are not actively seeking the implementation of such guidelines, but they are certainly in their infancy in the vast majority of services. Guidelines for the use of psychotropic medications put forward by Kalachnik et al. (1998) offer a useful starting point in developing appropriate and useful guidelines for Irish services. Rather than such guidelines developing from legislation and litigation as in the USA, a more appropriate framework would be for each service to independently review such guidelines and apply those of most relevance, prior to any such litigation. However, whether this will happen in practice remains to be seen. As a starting point research of a similar nature to the present thesis is required in order for service providers to be aware of the frequency of prescribing for clients in their care and the factors, which impinge upon prescribing. In this respect the development and implementation of guidelines should be "rational (controlling principles and underlying reason) and empirical (capable of being verified or disproved by observation)" (Kalachnik et al., 1998, p.68).

13.9 Final Comments

To conclude, many exciting developments are continuing to emerge within the field of learning disability in recent years. Perhaps the one area where this is particularly evident is in the provision of mental health services to persons with learning disability (Moss, Bouras and Holt, 2000) and how services respond to the needs of such individuals (Day, 1994, Bouras, 1999 and Jacobson, 1999). Recent publications suggest further development of existing models of service provision so as to accommodate the complex needs of those with dual diagnosis (Moss et al., 2000) and the development of specific guidelines for assessing and diagnosing mental health problems in this population (Einfeld and Tonge, 1999, Clarke and Gomez, 1999). A typical example of such an approach is the development of the "matrix model" of mental health services as developed by Thornicroft and Tansella (1999) for the general population, and further elaborated on, and developed by Moss et al. (2000) for the learning disabled population.

The implication of such developments for the present thesis lies in the usefulness of adapting models and theories from the general population and examining their usefulness for the purposes of the learning disabled population. Although perhaps as yet in their conceptual stages, they do represent a challenge for the future, not only in terms of the mental health needs of this population but in terms of the interventions used to treat conditions. After all it is the process of assessment, diagnosis and formulation that guides the treatment regimens used (MH-SIRG, 2000).

In conclusion the present thesis outlines the usefulness of both quantitative and qualitative perspectives in understanding the process of prescribing for persons with learning disability. Quality evidence-based research is continually required in order to make progress in this area, which will in turn have implications for clinical practice. It is hoped that by addressing these

issues the present thesis will stimulate interest among professionals of all disciplines working with the learning disabled population.

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APPENDIX A

DRUG SURVEY FORM

DRUG SURVEY FORM

Client Name: _____

Client ID: _____

Gender: _____

Date of Birth: _____ **Age:** _____

Level of Learning Disability: _____

Residential/Community House: _____

Address: _____

Workshop facility: _____

Psychotropic Medication currently prescribed:

1. _____ **Dosage:** actual/PRN
2. _____ **Dosage:** actual/PRN
3. _____ **Dosage:** actual/PRN
4. _____ **Dosage:** actual/PRN
5. _____ **Dosage:** actual/PRN
6. _____ **Dosage:** actual/PRN
7. _____ **Dosage:** actual/PRN
8. _____ **Dosage** actual/PRN

Other information of interest:

_____

_____

_____

APPENDIX B

PRESCRIBING CHECKLIST

Medication Prescribing Checklist.

Over a time period of five days, please fill out all relevant details below for ***every third*** *service user for which* ***any form of medication*** *is prescribed.*

Demographic/Service User Information

Gender: *Male* – *Female* –

Age:

Under 18 yrs.	*18-30*	*31-40*	*41-50*	*51-60*	*60+*
–	–	–	–	–	–

Level of Learning Disability:

Mild	*Moderate*	*Severe*	*Profound*
–	–	–	–

Living Environment:

Home	*Community*	*Residential/Institution*
–	–	–

Information about Service Users Presenting Behaviour(s)/Symptoms.

Medical/Physical:

Viral Infection	–	*Neurological Disorders*	–
Respiratory Disorders	–	*Skin Disorders*	–
Sexual Disorders	–	*Allergic Disorders*	–
Pain Disorders	–	*Gastrointestinal Disorders*	–
Cardiovascular Disorders	–	*Nutritional Disorders*	–

Other (please specify) _____

Behavioural:

Hitting/kicking staff or peers	–	*Anxiety*	–
Damage to property	–	*Withdrawn*	–
Screaming & Shouting	–	*Hysterical/Hyperactive*	–
Self-injurious behaviour	–	*Sleep problems*	–
Depression	–		

Other (please specify) _____

Situational/Other Factors:

Recent change of environment (institution/community move) –

Shortage/change of staff –

Medication specifically requested by staff member(s) –

Expectation of client themselves –

Other (please specify) _____

Resulting Medication(s) Prescribed:

Please tick/outline medication(s) prescribed:

Hypnotic	–	*Anti-emetic*	–
Anxiolytic	–	*Anticonvulsant*	–
Antipsychotic	–	*Movement Disorder*	–
Antidepressant	–	*CNS Stimulant*	–

Other (please specify) _____

Dosage: Actual – PRN –

Information about Prescriber:

Gender: Male – Female –

Length of time prescribing:	0-5 yrs.	6-10yrs.	11-15yrs.	16-20yrs	>20yrs
	–	–	–	–	–

Do you prescribe mainly for:

Adults with Learning Disability	*Children with Learning Disability*	*Both Children & Adults with Learning Disability*
–	–	–

Any Comments/views:

_____

_____

_____

APPENDIX C

SEMI-STRUCTURED INTERVIEW SCHEDULE

Dr. XXX,
Consultant Psychiatrist,
Address XXX,
Address XXX,
City XXX.

Date XXX.

Dear Dr. XXX,

Presently I am undertaking my Ph.D. (UCC), while working as Psychology Assistant with the Brothers of Charity Services, Bawnmore, Limerick. My Ph.D. to date has examined patterns of prescribing for persons with learning disability in both residential and community facilities throughout the Mid-West Region. For the final stage of my study I am hoping to expand upon, and further research some of the issues raised in relation to prescribing for people with learning disability.

For the next phase of my research I am hoping to interview Consultant Psychiatrists working in Learning Disability Services throughout the Republic of Ireland.

I write this letter in the hope that you would be interested in participating in the study. To participate in the study, the following two phases would be involved:

Phase 1:

A brief *Prescribing Checklist* will be forwarded to all Consultant Psychiatrists interested in participating in the study. This Checklist is brief (1 page approx.) and will involve recording details about service users for whom they prescribe any form of medication over a one week period.

Phase 2:

The second phase of the study will involve a short semi-structured interview with Consultant Psychiatrists. This recorded interview will be approximately twenty minutes in duration and

will examine some general issues in relation to prescribing for the learning disabled population.

Note on Confidentiality:

As with any type of research, confidentiality is of the utmost importance. The present study will involve completion of Prescribing Checklists by Consultants. It will also involve recording information by means of an interview.

Once each phase of the study has been completed, all data will be transferred and original manuscripts will be destroyed immediately. In relation to data gathered from interviews, such data will be transcribed by the author and any recording devices such as tapes or discs holding this information will be subsequently destroyed.

Finally, by participating in this study, it is envisaged that it will have a significant impact on both current academic knowledge and clinical practice.

I thank you for taking the time to read this letter and I will be following this letter up by means of a phonecall within the next ten days.

Best Regards,

Barry J. Coughlan

APPENDIX D

COPY OF LETTER SENT TO CONSULTANTS

Prescribing Interview Schedule – Revised 2.

List of questions to be asked throughout interview.

1. **Can you describe a recent case in which you prescribed medication?**
   - *can you tell me something about the background to the case?*
   - *What were the presenting behaviours?*
   - *What kind of medication did you prescribe for this person?*
   - *How did you feel about prescribing for this person?*

2. **From your experience in the field of learning disability, what are the common presentations which give rise to prescribing?**
   - *could you give me some relevant examples?*

3. **What factors do you feel influence the complexity of prescribing?**
   - *what would you do in the case of a client who is non-verbal who cannot describe how they are feeling?*
   - *in what instances would you rely on third-party information?*
   - *how would you describe the kinds of records kept that you would have access to prior to prescribing?*
   - *in general, how do you feel about this sort of information?*
   - *how much do you think other peoples expectations may influence prescribing?*

4. **What issues do you feel are important in relation to prescribing and challenging behaviour?**
   - *could you describe some of these issues?*
   - *how do you feel they relate to prescribing?*
   - *what do you feel is the role of medication in relation to behavioural difficulties?*

5. **Can you describe a case in which you felt "uncomfortable" about prescribing?**
   - can you tell me about the case?
   - presentation of the problem?

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