FAMILY CONTACTS OF PEOPLE WITH LEARNING DISABILITY WHO ARE IN RESIDENTIAL CARE.

Stephen Ronald Clarke.
B. Sc. (Hons.), M. Psych. Science (Clinical).

A portfolio of study, clinical practice and research submitted for the degree of Doctor of Psychology (Psych D) in Clinical Psychology.

Conversion Programme.

Department of Psychology.
University of Surrey.
Guildford.

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STUDY PLAN AND OVERALL AIMS.

Stephen Ronald Clarke.

Date of Registration:- 1st April 1996.
Registration Number:- 3518876.
Date of Study Plan:- 1st August 1996.

The main aim was to fulfil the requirements for the Surrey Psychology Doctorate Conversion Course by completing the assignments of literature reviews, clinical dossier and research study. Since I had been working for nine years since obtaining my M. Psych. Science (Clinical), a subsidiary aim was to provide an account of much of the work, projects and organisational achievements which had been completed during that period, and this is documented in the Clinical Dossier Section of this portfolio.

ACADEMIC SECTION.

Two critical reviews were chosen on the basis of their interest and relevance with regard to my current work as a clinical psychologist.

Critical Review One.
Depression and Severe Learning Disability.

This review related to my clinical specialisation within learning disability and represented a focus on clinical and treatment issues for people showing potential symptoms of depression, which can be difficult to diagnose in people with severe learning disability.

At issue was whether people with severe learning disability have sufficiently complex
mental processes for the development of depression:- if they present with a different central cluster of symptoms for depression, this can lead to a controversial conclusion that people with severe learning disability evidence a different sort of depression from able people, and might require a different treatment approach. But if precisely the same cluster of symptoms as for able people is used for distinguishing depression in people with severe learning disability, this can lead to under-recognition of the condition and failure to deliver treatment.

A literature review was undertaken to examine the theory and evidence for depression in people with severe learning disability with these issues in mind.

Critical Review Two.

Eating Disorders in Adults with Severe Learning Disability: Problems of Diagnostic Classification.

A comparable approach was followed in the second review in which the diagnostic adequacy of the DSM-IV classification system was considered in a review of the literature on eating disorders in people with learning disability.

Problems of disordered eating are relatively common among people with severe learning disability, yet this area would seem to receive inadequate coverage in DSM-IV which reserves some diagnoses for children only, and places restrictive conditions on other diagnoses which cannot be fulfilled by people with severe learning disability. It is important that problems of disordered eating in people with severe learning disability are adequately accounted for within the international systems of DSM-IV and ICD-10 because the administration of funding, services and research is increasingly determined by needs which are stated within this framework.

The personal interest in this area stemmed from my clinical involvement with people with severe learning disabilities within the residential service of the area health authority, because a significant proportion present with disorders of eating which infringe severely
on their health and independence.

SECTION TWO. Clinical Dossier Section.

The main aim of the Clinical Dossier was to provide a coherent account of my work, research projects, development of databases and clinical practice during the nine year period from completion of my M. Psych. Science (Clinical) course up until completion of the Surrey Psych. D. Conversion Course. Three subsidiary aims were:

1) to provide a factual account of work, courses and training undertaken during that period,
2) to provide a thematic account of the lines of psychology department development, personal development and development of lines of research studies undertaken during this period. These themes or lines of enquiry included a) the usage and influence of information technology within a psychology department b) the effects of implementation of community care policies for people with learning disability, and c) changing attitudes and practices among psychologists working within the specialisation of learning disability.
3) to provide some critical reflection on the interaction of research and theory with psychologists' clinical practice. One representative piece of the writer's research projects was chosen to illustrate this.

Research Study.

Family Contacts of People with Learning Disability who are in Residential Care.

Surrey Research Supervisor: - Dr. Clare Twigger-Ross.
Local Supervisor: - Dr. Sean Denyer.

Mission statements and policies for the care of people with learning disability within residential units emphasise the importance of family involvement in the care process. There is an assumption that families will continue to have regular contact with the client in residential care during holidays, weekends and visits. Care staff might point out that
some clients are never visited and never go home, but there is very little objective information on the overall pattern of family visitation for people in residential care, and the factors which promote or restrict family contacts.

The present study on family contacts of people with learning disability who are in residential care, was carried out in pursuance of my specialisation in learning disability. It related to my masters thesis on ‘Community Contacts and Neighbours’ Experience of Group Homes for People with a Mental Handicap’, which is also included within this portfolio. Both studies reflected my abiding interest in the interaction of community care policies at the national level with the experience at the small group and individual level.

In both studies a general aim was to examine critically some of the questionable assumptions about community and family in so far as these assumptions have influenced policies and practices in the care of people with learning disability. More specific objectives of my doctorate study were to provide a descriptive account of the family contacts of a representative group of people in residential care, and to determine which factors were associated with higher levels of family contact.

Issues of interest included whether or not people in community group homes receive more family contacts than people in large residential units, to what extent are personal characteristics such as age, sex, degree of learning disability and level of social competence associated with family contacts, and whether special difficulties such as behaviour disturbance or an additional psychiatric disorder militate against family contacts.

Work carried out within the five year period preceding the Doctorate Conversion Course, led directly in to this research project. This included detailed assessments of all the people with learning disability who were in the residential care of my employing Health Board, the development of a learning disability database, and the projects which were carried out monitoring the transfer of clients from institutional to community residential units. This work is documented in some detail in the Clinical Dossier section.
SECTION ONE.

ACADEMIC REVIEW SECTION.

Critical Review One.

DEPRESSION AND SEVERE LEARNING DISABILITY.
DEPRESSION AND SEVERE LEARNING DISABILITY

Introduction.

A seminal paper by Sovner and Hurley (1983) highlighted that the psychiatric community had devoted very little attention to affective disorders among people with learning disability. Until fairly recently there was an assumption that learning disabled people did not have sufficiently complex mental processes for the development of an affective disorder (Szymanski, 1994). Within the last two decades evidence has been adduced that people with learning disability do indeed suffer from a range of mental illnesses, including depression (Wright, 1982; Reiss, 1990).

There remains at issue the question of whether it is the same kind of depression as for non-disabled people in terms of symptoms, aetiology, course of illness, treatments and outcomes. Analogous issues have been considered by researchers studying childhood depression (Kovacs, 1997; Birmaher, Ryan, Williamson, Brent, Kaufman, Dahl, Perel and Nelson, 1996), yet curiously there has not been any comparison of depression of children and depression of people with learning disability.

It will be argued below that there are contradictions within current formulations of depression in people with severe learning disability which cannot be resolved without taking into account aspects of their developmental, cognitive and affective level which arise from the severe learning disability itself. Providing a definition for depression brings to the fore contradictions and difficulties in the diagnosis of this condition for people with severe learning disability.
Definitions.

The term *depression* is used to refer to the following tabulated conditions.

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<td>296xx</td>
<td>F32x, F33x</td>
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MAJOR DEPRESSIVE DISORDER.

DYSTHYMIC DISORDER.

DEPRESSIVE DISORDER not otherwise specified.

Because of their comparative rarity, bipolar affective disorders (i.e. depression with manic or hypomanic episodes) will be considered separately.

The general reference to people with learning disability is used to describe people with a developmental disorder whose IQ is less than 70. Severe learning disability refers to that section whose IQ is between 20 and 34. Learning disability is taken as being not a specific disease, but rather a behavioural syndrome, and even the subgroup of those with severe learning disability are not a homogeneous group: a broad spectrum of disability, symptoms and behaviour can be observed in this group.

The difficulty for providing a definition of depression in people with severe learning disability lies in that the central cluster of symptoms are cognitive and affective rather than behavioural, and can be difficult to evince in people with limited cognitive abilities. People with learning disability are less likely to express some of the classic symptoms of affective disorders, such as feelings of hopelessness, suicidal ideation, and reports on mood disturbance because they do not have the required verbal and conceptual abilities with which to express their mental state.

It is assumed here that depression is a syndrome rather than an illness (Harrington, 1994)
because the illness model leads to contradictions of disparate aetiology, disparate symptoms and different types of comorbidity among different groups of sufferers. Formulating depressive disorders as syndromic can help to integrate the findings that people with learning disability may display a different clustering of symptoms from non-disabled people. Contradictions arise if the clustering of symptoms is markedly different for people with learning disability than for non-disabled people, because this can lead to a conclusion that learning disabled people have a separate type of depression which should be distinguished by different diagnostic categories. In particular, both behaviour disturbance and agitation have been mooted as symptoms for depression in people with learning disability (Meins, 1995), and some of the contradictions which can arise from this are considered below.

**Diagnosis difficulties.**

Despite the pervasive difficulty of accurately diagnosing any kind of mental health problem in people with severe learning disability, Moss, Patel, Prosser, Goldberg, Simpson, Rowe and Lucchino (1993) have been able to develop a Psychiatric Assessment Schedule for Adults with a Developmental Disability (PASS-ADD) based on both patient and informant semi-structured clinical interviews. For people with learning disability over 50 years of age their system distinguished 11.4% who were suffering from depression and anxiety (excluding cases of dementia). Significantly, 75% of these were unknown to mental health services.

Specialists in the area of diagnosis of psychiatric disorders among people with learning disability have noted the importance of using both client interview and careful history taking from a caret/informant (Sovner and Hurley, 1983; Moss, 1995) but these commentators also note that it is unlikely that this degree of diagnostic precision will be made by a non-specialist G.P. Since D.S.M. III-R the substitution of caregivers reports of depressed mood and symptoms for the patients’ own reports has been permitted. Meins (1995) made a controlled attempt to diagnose 32 people with learning disability and major depression using D.S.M. III-R criteria and found successful application for 19 out of 20
of those with mild learning disability, but among 12 with severe learning disability the
criteria of feelings of worthlessness/guilt, suicidal ideation/attempt and decreased
concentration/indecisiveness were only partially assessable. Instead, people with severe
learning disability and major depression had symptoms more often marked by
psychomotor agitation and irritable mood, and disturbed behaviour.

The carer or informant can provide important information about changes over time, subtle
alterations of routines and behaviour and details about sleeping, eating and activity
patterns.

**Under-recognition and Prevalence.**

The term diagnostic over-shadowing refers to the tendency for mental illnesses to be
under-recognised by diagnosticians dealing with the learning disabled population, and to
inappropriately attribute symptoms of emotional disorder to the person’s learning
disability (Holt, Kon and Bouras, 1995). The tendency for mental illnesses to go under­
recognised in the learning disabled population has been commented on by nearly all
practitioners in this field, and has led to the development of diagnostic schedules designed
to overcome this problem (Moss *et al.*, 1993; Matson, Gardner, Coe and Sovner, 1991).

**Prevalence rates for psychiatric disorders.**

Campbell and Malone (1991) reviewed literature investigating rates for psychiatric
disorders in adults with learning disability, and found point prevalence rates of between
14.3% and 67.3%, but studies quoting the higher rates are based on populations within
residential care. The sheer range of different prevalence rates is indicative of the confusion
about diagnosis of psychiatric disorder in general among people with learning disability,
as well as reflecting different methodologies in studies and different definitions. Studies
based on large population surveys have produced rates as low as 10.2% for children
(Reiss, 1985), and 39% for adults (Reiss, 1990), where behavioural disorders were
included among psychiatric disorders. Other studies which have produced prevalence rates of 35% to 45% also included behavioural and personality disorders.

Part of the variability of prevalence rates can be accounted for by the inclusivity of the diagnoses. If behavioural changes and disturbance are included within the definition of psychiatric disorder, higher prevalence rates are found. If definitions of psychiatric disorder are restricted to cognitive and affective symptoms, then lower prevalence rates are found. Since having disturbed behaviour is a major factor precipitating a person with learning disability towards residential care (Bouras, 1994), the higher rates of psychiatric disorder found among residential populations may contain several confounded variables. One of the best prevalence studies was carried out in Denmark by Lund (1985) who sampled by strict epidemiological criteria and found a rate of 27% for psychiatric disorder. For neurotic and affective disorders Lund (1985) found a rate of 3.7% within the general population of adults with learning disability.

In the context of generally ageing populations in western countries, a number of studies have focused on the older people with learning disability who have psychiatric disorder (Day, 1985; Patel, Goldberg, and Moss, 1993; Das and Mishra, 1995), where symptoms of cognitive decline contribute to increased rates of psychiatric disorder. Patel, Goldberg and Moss (1993) found that a prevalence rate of 11.4% for psychiatric disorder was nearly doubled to 21% if dementia was included. The findings of Day (1985) indicated a prevalence rate of 30% for psychiatric disorder among long-stay residents, but the data did not lend itself to an analysis of rates for affective disorder because of use of the terms “neuroses” and “affective psychoses”.

**Prevalence rates for depression.**

Wright (1982), in a survey of 1,507 residents, most of whom had severe learning disability, found a rate of 6% for mood disorders. This accords with other large sample studies which have found point prevalence rates of between 2% and 6% for affective disorders (Corbett, 1979; Ballinger and Reid, 1977), where the higher figures are for
residential populations and the lower figures are for people living in the community.

Reiss (1990) concluded that the point prevalence rate for depression among people with learning disability was between 3 and 6%. Even taking the lower estimate of 3%, this is still considerably higher than the prevalence rate for non-disabled people- 0.36 to 0.90% (Rutter, Taylor and Hersov, 1994).

For people with Down's syndrome in particular, Collacott, Cooper, and McGrother (1992) have found the rate for depression to be three times higher than the for people with less specific learning disability or other aetiologies.

Because of evidence of diagnostic over-shadowing and difficulties in diagnosis (Moss et al., 1993; Reiss et al., 1982), it is suspected that the real prevalence rate for depressive disorders may be higher than those found in most studies. There is a general problem of comparing different prevalence rates because different populations have been sampled, levels of learning disability have varied widely, different measures for depression have been used, and the basic concept of depression in people with learning disability is still being developed.

**Behaviour disturbance and depression.**

The findings of Meins (1985) were representative of a number of other studies which have found that people with severe learning disability and depression are more likely to show regressed or disturbed behaviour, deterioration in body functions and a reduced level of adaptive functioning as symptoms of depression (Fraser and Nolan, 1994; Cooper and Collacott, 1993; Charlot, Doucette and Mezzacappa, 1993). In particular, the finding of the emergence of behaviour problems or an increase in pre-existing behaviour disturbance as a major symptom of depression among people with learning disability has been well identified and replicated (Moss et al., 1993).

Meins (1995) recognised there would be a contradiction if behaviour disturbance was
used both in the diagnosis of depression, and then as an associated or emergent symptom. He focused first on symptoms that were clearly part of the DSM III-R spectrum of depressive symptomatology, and then assessed the association of depression with behaviour disturbance and other phenomena. But there is still a problem that behaviour disturbance is linked to a number of other disorders, including schizophrenia and physical illness, as well as being a diagnostic category in its own right.

Behaviour problems have been identified as a comorbid condition among children with depression (Kovacs, 1997; Birmaher et al., 1996). There is a potential contradiction if behaviour disorders are considered as a separate comorbid diagnosis for children with depression, but may be considered as a symptom of depression in people with learning disability. Harrington (1994) argued for a distinct subcategory of depressive conduct disorder for children, and ICD-10 allows for the concept of such mixed disorders, whereas DSM-IV treats them as separate comorbid conditions. Treating behaviour disturbance as a primary symptom of depression in people with learning disability leads to a conclusion that depression must be qualitatively different for people with learning disability. Day (1985) noted that behaviour problems among people with learning disability did not show the expected amelioration with remission of depression and with ageing, as reported in non-handicapped people.

Sovner and Hurley (1983) considered depression to be essentially the same for people with or without learning disability. In summarizing the clinical literature they concluded that the impaired intellectual and social functioning of people with learning disability did not preclude the development of affective disorders, though the symptom range was narrower, and more weight had to be given to levels of motor activity, sleeping and eating patterns and careful history taking from informants in the diagnosis of depression.

Contradictions.

The issue is not as simple as this. Eaton and Menolascino (1982) pointed out the comparative rarity of exogenous factors leading to depression in people with severe
learning disability. Cooper and Collacott (1995) were tempted into suggesting substitution of different symptoms such as tearfulness and hypochondriasis to replace the lack of depressive cognitions among people with Down’s Syndrome. Moss et al. (1993) were well aware that the more they modified their PASS-ADD diagnostic system to suit people with severe learning disability, the more they would be drawn into a “different sort of depression” conclusion, and so they resisted modifications to item organisation and wording.

The well established and strong association of behaviour disturbance with depression in people with learning disability has led a number of commentators to recommend that it be included as a symptom of depression (Meins, 1995; Cooper and Collacott, 1995). There is pressure to do this because of the frequent dearth of any cognitive and affective symptoms in people with severe learning disability, and in cases where clinicians might have good reason to suspect the presence of depression, such as bereavement. Meins (1995) and Matson, Gardner, Coe and Soyner (1991) recommended a number of adaptations to existing DSM-III criteria, in order to diagnose depression in people with severe learning disability, including using irritability of mood (otherwise restricted to children under DSM-III), aggressive and self-injurious behaviour, stereotype behaviour and tearfulness. One danger of this is that symptoms such as stereotyped and self-injurious behaviour can be relatively common in people with severe and profound disability.

There is an analogy here with the erstwhile concept of masked depression in children, which has been abandoned. In the absence of other supportive evidence it is not reasonable to assume that depression must be present, but in masked form, when the only evidence for its existence is problem behaviour. Without other strong indications of depression, over-inclusivity of behavioural symptoms could lead to over-diagnosis as well as confusion on the nature of depression among people with severe learning disability. Meins (1995) suggested an important restriction should be made in allowing behaviour disturbance to be considered as a symptom of depression- it should only be included if there are at least two clear symptoms of depression, including loss of interest or mood disturbance, already present.
Comparison with children.

Comparison of depression among children and depression among people with severe learning disability reveals interesting similarities and differences. For both groups there is an association with behaviour problems as noted above. Suicide attempts are extremely rare among people with severe learning disability but as many as 25% to 34% of depressed children and adolescents had attempted suicide (Ryan, Puig-Antich, Ambrosini, Rabinovich, Robinson, Nelson, Iyengar and Twomey, 1987). For children there is a great deal of evidence that their depression is a familial disorder, whatever the transmission mechanism (Rutter et al., 1994), whereas no such evidence has been adduced for depression in people with learning disability.

For both children and people with severe learning disability there has been debate about whether the two groups have sufficiently developed intellectual capacity for the full symptom range of depression to be present to warrant a diagnosis of depression as such (Kovacs, 1997; Eaton and Menolascino, 1982). In both groups the evidence for exogenous factors leading to depression is poor (Birmaher et al., 1996; Moss, 1995).

In both non-handicapped children and people with learning disability the rates for males and females are the same (Matson et al., 1991; Birmaher et al., 1996), whereas for non-handicapped adolescents and adults the ratio is 2:1 female: male. For both groups several genetic, familial and biological correlates have been identified (Birmaher et al., 1996) and these are reviewed below for people with learning disability.

In the case of children, Harrington (1994) has argued that age-appropriate symptoms such as school refusal and behaviour problems need to be included in the diagnosis of depression. But an important caveat is that it would be dangerous to count behaviour disturbance as the main or only symptom of depression. Careful case history over an extended period of time needs to be carried out, taking account of changes in motor activity, eating and sleeping habits, social behaviour and patterns of behaviour (Moss et
As is the case for children, symptoms which demand a high level of cognitive functioning, such as guilt feelings, suicidal ideation and patterns of negative thinking cannot be expected from people with learning disability. But changes in behaviour patterns, vegetative functioning and motor activity are within the scope of the behavioural repertoire of people with severe learning disability, and can reasonably be included as symptoms of depression. To exclude them could lead to the earlier position that people with severe and profound learning disability cannot suffer from depression.

**Genetic and physiological factors.**

Learning disability is not a homogeneous disorder but a number of specific genetic and neurological conditions have been found to be associated with depression. In particular, the cognitive decline which is a typical feature of older people with Down’s Syndrome has also been reliably shown to predispose towards depression (Cooper and Collacott, 1993). People with Down’s Syndrome have three times the rate for depression than people with other learning disability aetiology (Collacott *et al.,* 1992). Depression in this group can frequently be misdiagnosed as dementia, and a loss of adaptive functioning together with physiological symptoms of cognitive decline can also tend to mask otherwise obvious symptoms of depression (Das and Mishra, 1995).

Wing (1976) pointed out that states of severe depression can be found in childhood autism. Singh and Rajkowa (1986) noted an association of Klinefelter’s Syndrome with episodic depression, and Bryan and Herjanic (1980) found depression to be associated with a variety of other disabling conditions in a review of literature.

The search for underlying metabolic and neurotransmitter dysfunction which might be common to both depression and particular genetic disorders has been disappointing—no clear associations have been found (Kendall and Zeally, 1993). A parallel approach has been to examine the way that antidepressant drugs influence depressive symptoms and
underlying neurotransmission processes, which is dealt with in the treatment section below. The monoamine deficiency theory and theorised neuroendocrine function deficiency have given rise to numerous studies revealing some degree of association, but no clear biological pathways leading to depression (Kolb and Wishaw, 1990).

One development from neurotransmitter studies has been the dexamethasone-suppression test (Mattes and Amsell, 1993) as a diagnostic tool in the detection of depression in people with learning disability, particularly for people with no speech where language based diagnostic schedules cannot be used. The limitations in accuracy of this test have led to a recommendation for abandonment of its use (Mudford, Barrera, Murray and Boundy, 1995). Interestingly, in both the proposal and the abandonment studies for this test, behaviour disturbance was used as an unquestioned symptom and validation measure for depression in people with severe and profound learning disability.

**Specific cortical dysfunction and depression.**

Most definitions of learning disability including ICD-10 and DSM-IV place emphasis on the functioning of the individual, leaving open the question of aetiology, although the W.H.O. model of handicap does include the concept of impairment not only of function but also of anatomical structure (Holt et al., 1995). Brain dysfunction, whether genetic, biological, structural or unspecified, is usually presumed rather than proven in people with learning disability. There is overwhelming evidence that cortical dysfunction in general, whether in development leading to learning disability, or as an event in adulthood, does predispose towards mental illness including depression (Lezac, 1983; Moss, 1995). But surprisingly little is known about the mechanisms by which cortical dysfunction can lead to a mental illness, even for schizophrenia, and gross correlations can be quite weak. Many of the abnormalities initially presumed to be specific to schizophrenia such as enlargement of the lateral ventricles and “hypofrontality” have also been reported in people with unipolar and bipolar depression (Dolan, Calloway, and Mann, 1985).
Nonverbal learning deficits.

If depression was a highly probable sequela of cortical dysfunction the rates for depression among the learning disabled population might be expected to be much higher than is observed. One group which has been identified as having an increased risk for depression has been people with nonverbal learning disability. Rourke, Young and Leenaars (1989) suggested that people who as children showed the specific learning disorder associated with low nonverbal intellectual functioning were at particular risk for depression and suicide in adolescence and adulthood. The evidence is still equivocal and further replications would be needed before any reliable conclusions could be made about an association of depression with right-sided cerebral dysfunction. Right hemisphere cerebral dysfunction can also be associated with behavioural disorder, attentional deficit and hyperactivity disorder (ADHD), and can possibly be a risk factor for schizophrenia and bipolar affective disorder (Lezak, 1983; Kolb and Wishaw, 1990; Rutter et al., 1994).

Bipolar affective disorder.

The prevalence rates for bipolar depression among people with severe learning disability are extremely low and accuracy of diagnosis is difficult to achieve because mania in this group is rarely euphoric, active or cheerful. Instead a person with severe learning disability and mania is more likely to show symptoms of irritability, aggression, noisiness and wandering (Lund, 1985), and these are also symptoms of increased behaviour disturbance. Differential diagnosis needs to be made on the basis of careful history-taking and observation of behaviour and vegetative functions (Reid, 1982).

Because of the rarity of bipolar disorder, even prevalence studies end up as single case studies in consideration of persons with both learning disability and bipolar depression, and no firm associations have been identified (Sovner and Hurley, 1983)
Precipitating factors.

For children, Kovacs has reviewed research on "depressogenic factors" in children and adolescents, which can include the death of a loved one, abandonment, rejection and life events, and she concluded that there was only a modest association between triggering agents and the onset of depression. For people with learning disability there is some impressionistic literature, prescriptive for the most part, on the importance of recognising bereavement and depression (Kennedy, 1989; James, 1995). But there are no reliable findings on which stressful events may trigger depression, and more importantly, stressful events which fail to trigger depression in people with learning disability.

The dearth of evidence may be significant itself. Because of the extended parental care period required for people with learning disability, a majority experience parental loss or abandonment before achieving any emotional independence, yet there is no research showing any reliable association of depression with entry into residential care (for example, Sherman, 1988; Baker and Blacher, 1996).

Other reasons why a high prevalence for depression among people with learning disability might be expected could include poor social competence, low self-esteem because of coping difficulties and repeated failures, and social isolation because of language deficits (Fraser and Nolan, 1994).

Kendall and Zeally (1993) concluded for non-handicapped people that the literature on the relationship between depression and separation/loss is conflictual and inconclusive. A study by Bryan and Herjanic (1980) suggested that people with milder disability were more prone to depression because they were able to realise their own limitations, whereas those with more severe disability could not. But no such protection factor is indicated by prevalence rates over the different levels of disability (Wright, 1982; Lund, 1985; Reiss, 1990).
The evidence for depression following the death of a carer, friend or pet, or a change of living circumstances is anecdotal or based on single case examples (James, 1995; Kennedy, 1989). Studies on the management of bereavement in people with learning disability invite a conclusion that bereavement leads to grief and to depression, which may manifest itself in disturbed behaviour. This is still speculative because the examples of depression following bereavement are not matched by any studies of the people with severe learning disability who have failed to react to bereavement. Also, if behaviour disturbance follows a bereavement, this may be a reaction to changed circumstances rather than depression as such.

Placement changes which involve loss of carers, major upheaval and change of lifestyle might be expected to provoke depressive reactions among people with learning disability, yet no such evidence has been adduced despite the very large literature on effects of placement changes (for example, Emerson and Hatton, 1994). Placement changes are known to affect levels of challenging behaviour among people with learning disability (Walker, Ryan and Walker, 1993) but not in any consistent direction- it probably depends on what setting a person is coming from, and where they are going to.

**The course of depression.**

There is surprisingly little literature on the onset and course of depression in people with severe learning disability, and most evidence that there is, is based on single case studies. There is suggestive evidence that depression in people with learning disability lasts longer and that relapse rates are higher, but no conclusive evidence to affirm this (Yapa and Roy, 1990), and findings are marred by the influences of diagnostic over-shadowing and under-reaction of professionals and the services in the treatment of depression.

**Treatment.**

Reiss et al., (1982) among many others have noted that emotionally disturbed people with learning disability fall through a gap between mental health services and the learning
disability services. Ever since the rise of psychoanalysis, the area of learning disability has been an unpopular area for psychiatrists to work in (Szymanski, 1994) and many positions remain unfilled.

The move of people with learning disability from larger residential units into group homes in the community has not been an unmitigated success from the point of view of the mental health needs of people with learning disability, because many services have interpreted normalisation principles to mean that people with learning disability should rely on the same G.P. and generic mental health services as anyone else (Szymanski, 1994). This can lead to under-recognition and under-treatment of depression in people with learning disability because generic professionals may have little experience or training for working with people with learning disability. For these reasons, Day (1994) recommended the continuance of specialised psychiatric and psychological services for people with learning disability.

The two most common treatment responses for people with depression and severe learning disability are residential treatment (or change of this), and medication. Residential treatment can very often be a response to families' difficulties in continuing to care for the person with learning disability, particularly if severity of handicaps and behaviour disturbance are prominent features (Sherman, 1988; Tausig, 1985). Residential treatment would rarely be a response to depression *per se*, but if someone with learning disability living in the community suffers depression to an extent that makes adaptation to community life impossible, then transfer to a hospital-like residential setting is a common treatment option (Baker, Blacher and Pfeiffer, 1993).

**Pharmacotherapy.**

Medication with anti-depressants is by far the most frequent treatment option for depression even though its effectiveness has not been adequately established yet (Crabbe, 1994). It is clear that anti-depressant treatment can significantly reduce the levels of behaviour disturbance and psychomotor agitation, but it cannot be concluded from this
that depression itself has been successfully treated - the same drugs which are widely used for treatment of depression also have a known efficacy in the treatment of behaviour disturbance. Research findings on this are remarkably similar to those for drug treatments for children and adolescents with depression: widespread drug treatment but very little evidence for efficacy compared with controls or placebo controls (Crabbe, 1994).

It would be unwise to conclude that medication is ineffective, even if it remains more of an art than a science. Aggressive treatment with anti-depressants is sometimes very necessary to prevent a short-term episode from becoming a long-term condition. A further complication for people with learning disability is that once a medication course has been started, there is a tendency for it to continue unless rigorous review procedures are put in place (Day, 1985).

**Psychotherapy.**

Formal psychotherapy treatment for people with severe learning disability would seem to be relatively rare, judging by the dearth of published studies. Yapa and Roy (1990) provided two case studies of the monitoring and treatment of depression. James (1995) and Oswin (1996) have provided good practical advice on helping people with learning disability to cope with bereavement.

Input by clinical psychologists is usually made through multi-disciplinary teams within learning disability services. It is possible that behavioural strategies such as functional analysis which are designed to address challenging behaviour, and that individual programme planning have sometimes resulted in the relief of causes of depression, but there is no published direct evidence on this.

It was not possible to find any evidence of cognitive behavioural methods being used with people with depression and severe learning disability. The parallel with children is interesting. The theorists of cognitive therapies are circumspect about stating whether or not there is any lower age limit on a person's age or mental age which would counter-
indicate use of such therapy.

Dujovne, Barnard and Rapoff (1995) found no studies specifically employing Beck’s approach for the treatment of children, and noted that some have argued that the concept of logical errors would require an ability level beyond that of most children.

In a meta-analytic review, Joiner and Wagner (1995) concluded that attributional style (Seligman, 1975) was cross-sectionally associated with clinical depression among children across a broad age range (7-18 years). No such finding has been reported for people with more severe learning disability, tempting the speculation that a mental age higher than 6 years would be necessary in order to relate attributional style to depression. If cognitive therapies presuppose an ability level higher than that shown in young children and people with moderate and severe learning disability, then this would make such therapies irrelevant for these groups. But this can lead to the argument that depression in children and people with more severe learning disability is a different kind of condition from the adult variety. Theorists have resisted this argument for children, not least because there is a strong correlation between childhood and adult depression, even though the symptoms may be different at different age stages (Harrington, 1994).

Conclusions.

In the same way that symptoms of depression can show great variability among non-disabled people, those with learning disability can also display a wide variability in the type and intensity of their symptoms. It is useful to formulate depression as a syndrome cluster rather than an illness in accounting for the evidence from people with depression and learning disability.

As for children, symptoms which assume a high level of intellectual functioning, such as feelings of guilt and worthlessness, cannot be expected within a severely learning disabled population. In contrast, age-appropriate symptoms such as behaviour disturbance and irritability can be expected to appear as expressions of depression among people with
severe disability. But an important caveat is that behaviour disturbance should never be the main or only symptom used to diagnose depression within this group- to do so would lead to irreconcilable contradictions and to a position of learning disabled people having a different type of depression from others. An accurate diagnosis of depression needs to include at least two central symptoms of depression, such as mood disturbance or loss of interest, before behaviour disturbance should be included as an additional symptom (Meins, 1995).

Sovner and Hurley (1983) concluded that people with learning disability suffer from the full range of affective disorders and should be considered for the full range of treatments including psychotherapy. Psychotherapeutic approaches which assume a mental age of at least 7 years are probably inappropriate for people with severe learning disability, whereas an approach based on parenting and attachment theory (Bowlby, 1980) is likely to be highly appropriate for this group.

Moss et al., (1993) considered that it remained uncertain whether the general psychiatric assessment principles were applicable for people with learning disability, and argued for fundamental research into the appropriateness of DSM-IV and ICD-10 algorithms for this group. Rather than assuming symptoms to be essentially the same as for non-handicapped people, it might be better to start “from the bottom up” examining the features and variability of symptoms within the learning disabled population and only then proceed to compare and contrast with non-handicapped symptomatology.

REFERENCES.


SECTION ONE.

ACADEMIC REVIEW SECTION.

Critical Review Two.

EATING DISORDERS IN ADULTS WITH SEVERE LEARNING DISABILITY: PROBLEMS OF DIAGNOSTIC CLASSIFICATION.
EATING DISORDERS IN ADULTS WITH SEVERE LEARNING DISABILITY: PROBLEMS OF DIAGNOSTIC CLASSIFICATION.

INTRODUCTION.

The aim of this paper is to review the literature on eating disorders in adults with severe and profound learning disabilities with particular respect to examining the adequacy of the DSM-IV nosological system for these disorders (American Psychiatric Association, 1994). In this review it will be argued that the standard psychiatric DSM-IV categorisation has great limitations for use with people who have severe learning disabilities whereas the psychological approaches such as functional behaviour analysis or factor analytic systems have an advantage in that doubtful assumptions about the presence of a mental disorder can be avoided.

It is argued below that the limitations of DSM-IV apply specifically for eating disorders as separate diagnoses for people with severe learning disability. There are no problems with weight loss, anorectic reactions or food refusal being formulated as symptoms or reactions to other well established DSM-IV disorders such as schizophrenia or depression in people with severe learning disability.

An examination of the literature on pica and rumination considers the question of whether diagnostic concepts based on mental disorders of non-disabled people take enough account of the physiological considerations and behavioural factors associated with learning disability. At issue is whether the disorders of eating represent mental disorders in their own right, or whether they would be better construed as behaviours subsumed under other category headings such as stereotypic behaviour or self-injurious behaviour.

The ICD-10 system is almost identical to the DSM-IV system in its formulation of eating disorders, so that all arguments in this paper which apply to DSM-IV can also be taken
to apply to ICD-10, except where a difference is specifically stated. It is important that
problems of disordered eating in people with severe learning disability are adequately
accounted for within the international systems of DSM-IV and ICD-10 because the
administration of funding, services and research is increasingly determined by needs which
are stated within this framework.

The eating disorders recognised by DSM-IV (the Diagnostic and Statistical Manual of
Mental Disorders, American Psychiatric Association, 1994) are the following:-

1) Anorexia nervosa.
2) Bulimia nervosa
3) Eating disorder not otherwise specified- where most but not all the criteria of
anorexia or bulimia are fulfilled.
4) Feeding disorder of infancy or early childhood.
5) Pica- the eating of non-nutritive substances.
6) Rumination disorder.

Obesity is not included within DSM-IV "...because it has not been established that it is
consistently associated with a psychological or behavioral syndrome." (American
Psychiatric Association, 1994, p. 539). But DSM-IV does allow for obesity and
underweight to be indicated under "Psychological Factors Affecting Medical Condition"
(American Psychiatric Association, 1994, p. 675). Since obesity and underweight are so
frequently linked with severe learning disability conditions themselves, these conditions
are included in this review.

The main areas covered in this paper are feeding disorder of infancy or early childhood,
anorexia nervosa, obesity and underweight, pica and rumination. The disorders of bulimia
nervosa and "eating disorder not otherwise specified" are given hardly any coverage
because of the very limited relevance of these diagnostic concepts for people with severe
learning disability, reflected in the lack of published papers.

For each area of disordered eating, this review attempts to cover the diagnostic definition,
the prevalence rate, the core research findings on the condition and its management, followed by a discussion of the problems of diagnostic classification associated with the disorder. The focus will be on adults with severe learning disability, not least because this group has characteristics which challenge most critically the assumptions about mental disorders which are based on a non-disabled population.

**FEEDING DISORDER OF INFANCY OR EARLY CHILDHOOD.**

The DSM-IV category of “feeding disorder of infancy and childhood” is defined as (..the persistent failure to eat adequately, as reflected in significant failure to gain weight or significant weight loss over at least one month.” (American Psychiatric Association, 1994, p. 98). It is given only cursory coverage here because this diagnosis is mainly reserved for very young children. A restricting criterion is that the disturbance would not be better accounted for by another disorder such as learning disability. Individuals with neurological disorders are also excluded by the DSM-IV definition of feeding disorder. This is in itself a disadvantage of the DSM-IV classification system because problems of eating constitute a significant area of difficulties for people with severe learning disability.

Good accounts of the *training* of eating skills in people with severe or profound disabilities can be found in a number of manual texts (Carr, 1980; Hogg and Sebba, 1986). It is also clear that people with severe learning disability do indeed have feeding difficulties such as food- and drink-refusal problems, slow eating or eating too fast (Jones, 1982; Carr, 1980; Coe, Babbitt, Williams, Hajimihalis, Snyder, Ballard, and Efron, 1997). There do not seem to be any general prevalence studies of feeding difficulties as distinct from other eating disorders such as pica and rumination among the learning disabled population, but many practitioners refer to feeding difficulties being relatively common among people with severe disabilities or sub-groups such as children with Down syndrome (e.g. Spender, Stein, Reilly, Percy and Cave, 1996).

Most descriptions of treatments of feeding difficulties come from the behavioural literature where feeding difficulties in people with severe disabilities are most frequently described
within the context of self-injurious or otherwise challenging behaviour rather than within the context of an eating disorder as such (Carson and Morgan, 1974; Hagopian, Farrell and Amari, 1996; Johnson and Babbitt, 1993; Grossett and Williams, 1995). Many sorts of behaviour can occur in association with feeding: challenging behaviour, non-compliance, stereotyped behaviour and self-injurious behaviour (Presland, 1989). The preferred psychological treatment in the great majority of published papers in the area of feeding difficulties of people with severe learning difficulties was some form of behaviour modification and functional behaviour analysis.

It is not easy to understand why DSM-IV excluded adults with feeding difficulties from having a feeding disorder diagnosis (307.59, American Psychiatric Association, 1994), although it possibly reflected a desire to avoid comparisons of children with learning disabled people. If this was the case, an immediate contradiction is evident in that for pica and rumination there are no such exclusions on the basis of age or degree of learning disability. An unfortunate effect of the exclusion from DSM-IV of an adequate category of feeding disorder for people with severe learning disability is that surveys and prevalence studies, especially those under medical direction, are likely to exclude this important problem area from proper consideration.

ANOREXIA NERVOSA AND BULIMIA NERVOSA IN PEOPLE WITH LEARNING DISABILITY.

In the research literature no cases of bulimia nervosa in learning disability were found which could be diagnosed differentially from anorexia nervosa. Prevalence studies would seem to indicate that anorexia in people with learning disability is extremely rare (O’Brien and Whitehouse, 1990; Meins, 1995; Matson, Coe, Gardner and Sovner, 1991). Only seven case study reports of probable anorexia nervosa were found in a search of publications written in the English language (Hurley and Sovner, 1979; Fox, Karan and Rotatori, 1981; Cottrell and Crisp, 1984; Mohl and McMahon, 1980; Holt Bouns and Watson, 1988; Clarke and Yapa, 1991; Thomas, 1994). In none of these cases did the
subject have a severe or profound learning disability; the level of learning disability was within the borderline or mild range in four cases, and in the moderate range in three cases. Only brief coverage is provided here because this paper focuses mainly on people with severe or profound disabilities.

Definition.
The eating disorder of anorexia nervosa consists of an intense fear of weight gain or food intake, a significant disturbance in the perception of the shape or size of the body, a weight which is 85% or less than expected, amenorrhea and other physiological sequelae of weight loss, and often the presence of vomiting, over-exercise and loss of sexual interest (American Psychiatric Association, 1994; Margo, 1987).

These seven case studies show up the limitations of a DSM-IV system based on the non-disabled population, even for people with mild and moderate disabilities, and even more for people with severe and profound disabilities. The controversial issue is that the DSM-IV criteria for anorexia includes two essential cognitive components which are very hard to substantiate for anyone with a moderate or severe learning disability: these are the intense fear of weight gain and a significant disturbance in the perception of the shape or size of the body (American Psychiatric Association, 1994; Margo, 1987).

An analysis presented in Table 1 (p. 52) indicates that a number of the criteria for anorexia were either unfulfilled or only partially fulfilled in the seven case studies which claimed a diagnosis of anorexia nervosa in people with a mild or moderate learning disability. It was not possible to ascertain accurately from the case descriptions how many showed a clear fear of gaining weight. In only three out of the seven cases (Table 1, p. 52) was there evidence of intentional, planned vomiting or use of exercise in order to lose weight and there was a lack of use of sophisticated ploys to avoid eating in all seven cases studies. In only two of the seven case studies was there clear evidence of perceptual body disturbance (Thomas, 1994; Clarke and Yapa, 1991). It is possible that limited verbal skills precluded some individuals from expressing the cognitive disturbances which DSM-IV count as
essential features for a diagnosis of anorexia, but it is dangerous to assume or impute their presence in the absence of direct evidence.

All seven cases involved a significant degree of accompanying behaviour disturbance. At least four of the seven cases (Table 1, p. 52) had developed anorexic symptoms within the context of a depressive illness of which two were thought to be related to bereavement. Two further cases showed symptoms of a schizophrenic or schizo-affective disorder, and it is possible that six of the seven cases might be better formulated as anorectic reactions to a depressive or schizophrenic disorder.

Anti-depressants were prescribed in at least five of the seven cases. Behaviour therapy was the main treatment in six out of seven cases and success was reported in five out of these six. This pattern of predominantly behavioural treatments contrasts with the favoured treatments of family therapy and individual psychotherapy for non-disabled anorexic patients (Robin, Siegel and Moye, 1995). Weight loss associated with depression is thought to be a relatively common phenomenon, although reliable prevalence rates are not available (Szymanski and Biederman, 1984; Raitasuo, Virtanen and Raitasuo, 1998).

The argument presented here is not that DSM-IV diagnoses are generally inappropriate for people with learning disability:- co-morbid diagnoses for schizophrenia, depression and challenging behaviour, for example, are well established and entirely appropriate for people with learning disability (Meins, 1995). The problems arise for the diagnoses of eating disorders because of the restrictions put on them by DSM-IV criteria.

The overall objection being raised here is that in the first two DSM-IV eating disorders under review, people with severe learning disabilities are effectively ruled out of consideration. In feeding disorder this is because the category is reserved for children, and in anorexia because the essential cognitive criteria cannot be fulfilled by persons with severe disabilities. People with learning disability can and do suffer from underweight, as well as obesity, but here again these problems and needs can be excluded from consideration within a DSM-IV framework, because obesity and underweight are
excluded from DSM-IV as they are not mental disorders.

**OBESITY AND UNDERWEIGHT.**

In this section the focus will be on problems of overweight and underweight which are more or less special to people with learning disability. Obesity was excluded from DSM-IV (American Psychiatric Association, 1994) because it had not been shown that it was consistently associated with a psychological or behavioural syndrome although it can be included as a 'Psychological Factor Affecting Medical Condition' such as diabetes. ICD-10 follows the same logic and excludes obesity, but it does have a category, F50.4, "Overeating associated with other psychological disturbances" such as bereavement, accidents and distressing life events (W.H.O., 1992).

Whilst it is reasonable for obesity and underweight to be excluded from DSM-IV as mental disorders, this can have the disadvantage of these conditions being excluded from general consideration. Reasons are adduced below for arguing that obesity and underweight represent very important conditions for consideration and for treatment among people with severe learning disability. If the system of mental disorders within a DSM-IV system is put to one side, then it becomes easier to consider obesity and underweight as factors, important in their own right, and in their interaction with other conditions such as hyperphagia and feeding difficulties.

A number of syndromes and conditions give rise to both learning disability and a tendency towards obesity, the best documented of these being Down's Syndrome (Bell and Bhate, 1992) and Prader-Willi Syndrome (Ehara, Ohno and Takeshita, 1993). The most common health problems associated with obesity include coronary heart disease, hypertension, diabetes mellitus, decreased lung function, mobility problems and osteoarthritis (Royal College of Physicians, 1983). An additional problem for people with learning disability is that obesity is likely to contribute to increased stigmatisation and non-acceptance in an already vulnerable group (Fox, Rotatori, Mauser and Switsky, 1981).
Prevalence.

Exact prevalence rates for obesity are difficult to obtain and compare because of different measurements of obesity, different populations of people with learning disability, different age groups and different cultures. In a cohort of 20-29 year olds with learning disability in Finland, Simila and Niskanen (1991) found that 30% were underweight, a majority of these being in the severe disability range, and that severe obesity was about five times more prevalent than in the general population, although mild obesity rates were the same for this relatively young age group.

In a much larger study covering a wider age range of people living in residential homes in the U.S.A., Fox and Rotatori (1982) found 25.1% of women and 15.6% of men were overweight. In a prevalence study of people with Down’s Syndrome and other learning disabilities in the U.K., Bell and Bhate (1992) found that 70.6% of males and 95.8% of females with Down’s Syndrome were overweight, and 49.3% of males and 63.0% of females with other learning disabilities were overweight. The equivalent figures for the general non-disabled population were 40% for males and 32% for females.

Disability level, overweight and underweight.

A general conclusion which may be drawn from prevalence studies is that populations of people with learning disability tend to show weight distributions which are polarised at opposite ends of the spectrum (Simila and Niskanen, 1991; Wood, 1994).

Comparisons among several studies indicate that people with severe and profound learning disabilities are more likely to suffer from underweight whereas people with moderate and mild learning difficulties are more likely to suffer from obesity (Bell and Bhate, 1992; Wood, 1994; Gouge and Ekvall, 1975; Simila and Niskanen, 1991; Prasher, 1995). Feeding difficulties, slow eating and rumination can be factors leading to underweight among people with profound learning disability (Davis and Cuvo, 1980).

Reasons put forward for a greater tendency towards obesity among some groups with learning disability include hypothalamic dysfunction (Ehara, Ohno and Takeshita, 1993),
hypothyroidism (Dinani and Carpenter, 1990), side effects of anti-depressants and anti-epileptics (Perry, 1996) and a speculated association of low activity rates (Wood, 1994).

A small body of evidence also seems to be consistent in indicating that people living at home or in community group homes may be more susceptible to developing an obesity condition, probably because these less restrictive environments present more opportunities for people to eat high calorie snack foods (Rimmer, Braddock and Fujiura, 1994; Prasher, 1995; Perry, 1996). O'Brien and Whitehouse (1990) showed that among learning disabled adults in community placements, depressed people showed an excess of food eaten and time spent searching out food.

It is easier to consider the associations of obesity with other conditions within a multivariate framework, without taking on board any assumptions of an underlying mental disorder. It is also important that obesity and underweight would not be excluded from consideration simply because they do not come within the sphere of DSM-IV mental disorders.

**Prader-Willi Syndrome and Down’s Syndrome.**

The complex mechanisms which can lead towards obesity are still largely undetermined, even for the specific and well-researched Prader-Willi Syndrome. Alteration of hypothalamic function in Prader-Willi Syndrome is presumed rather than proven (Holland, Treasure, Coskeran and Dallow, 1995) and it remains uncertain whether the over-eating characteristic of this syndrome is due to an impaired satiety response or impaired metabolic function (Dykens, Goff, Hodapp, Davis, Devanzo, Moss, Halliday, Shah, State and King, 1997), or part of a more general obsessive compulsive disorder (Dykens, Leckman and Cassidy, 1996) or abnormalities of nutrient absorption (Ehara et al., 1993) or some combination of all these factors.

Although it is not yet possible to treat the hyperphagia itself, it is possible to manage the condition by low calorie diet, behavioural management, a programme of activity and exercise and target weights. Since over-eating and obesity in Prader-Willi Syndrome leads
to such life-threatening conditions, it seems appropriate to be pro-active in diet restrictions from an early age, especially since the disorder has a physiological rather than a motivational basis (Dykens *et al.*, 1997).

For obesity in general among groups of people with learning disability, it is by no means agreed that this condition is a necessary or acceptable correlate of learning disability. For Down syndrome there is evidence that the best approach for counteracting the effects of a reduced basal metabolic rate is not by caloric restriction but by increasing energy spent in activity for children (Roizen and Schoeller, 1997). All authors are agreed that early prevention from childhood is far easier to achieve than combating long-standing obesity in adults (Prasher, 1995; Takeuchi, 1994; Fox, Rotatori, Mauser and Switsky, 1981; Perry, 1996).

**Treatment and management.**
The research findings on obesity treatment from behavioural research carried out in the 1960's and 1970's led to the conclusion that short-lived, intensive treatments will not be sufficient for maintaining long term weight loss; what is needed is long term changes in specific eating habits and a self-control component which should last long after any treatment phase (Stuart and Davis, 1972; Fox, Rotatori, Mauser and Switsky, 1981).

Arguments about violation of people’s rights by dietary restriction are countered by arguments about the rights to dietary education, health, and in extreme obesity, the right to avoid morbidity and loss of mobility (Dykens *et al.*, 1997; Perry, 1996). It may be appropriate to decide whether a person can give informed consent to treatment in cases of doubt.

The treatment of underweight in people with learning disability seems to pose fewer ethical problems, because underweight is usually a problem for people with severe and profound disabilities related to the eating and feeding disorders comprising rumination, pica and feeding difficulties, where it seems reasonable to presume that both the carers
and the people with learning disability would want a normal weight to be achieved.

**Evaluation.**
The studies covering obesity and underweight were important and of practical relevance for the population of people with learning disabilities. These studies were also free from the constraints of psychiatric diagnosis, and this meant that obesity could be taken simply as a factor or condition rather than a mental disorder.

There was a dearth of longitudinal studies in this area, making it very difficult to ascertain what would be a typical pattern of weight gain or weight loss over the lifespan in a person with severe learning disability. The research indicated a need for greater awareness among both home carers and professionals of the problems which overweight and underweight can present. Of particular concern were the findings suggesting that those living at home and within community residences might be more susceptible to problems leading to severe obesity, and more investigative research needs to be done in this area. Far more studies have been carried out on residential populations than on community populations, and this imbalance should be redressed.

**PICA.**

The eating disorder of pica is defined as the persistent eating of non-nutritive substances such as soil, plaster or cigarette ends (American Psychiatric Association, 1994) but may also include inappropriate food such as frozen or uncooked food. It is commonly observed in infants and young children but would not be counted as a disorder unless persisting beyond about 18 months of age (Baltrop, 1966).

**Prevalence.**
Pica is relatively common in people with severe and profound disabilities, although accurate prevalence rates are hard to obtain. Danford and Huber (1982) obtained an estimated prevalence rate of 25.8% among a large sample (991) of people with learning disabilities in residential care, but McAlpine and Singh (1986) found a lower prevalence
rate of 9.2% among a comparable residential population. Both studies showed that pica tends to decrease in prevalence with age and is more common among people with more severe learning disabilities (Danford and Huber, 1982; McAlpine and Singh, 1986).

DSM-IV contains the following enigmatic qualification (American Psychiatric Association, 1994, p. 95), “If the eating behaviour occurs exclusively during the course of another mental disorder (e.g. ....Mental Retardation (p.96)) a separate diagnosis of Pica should be made only if the eating behaviour is sufficiently severe to warrant independent clinical attention (Criterion D)”. This seems to represent a tacit recognition that pica can be relatively common among people with profound disabilities and might be part of more generalised developmentally delayed behaviour, including mouthing, feeding difficulties and other problematic behaviour reflecting limited discrimination abilities (Presland, 1989; McLoughlin, 1987).

**Treatment.**

An assessment or functional analysis of the behaviour would usually be a precursor of treatments, which typically involve behavioural and ward management, reducing boredom and increasing alternative appropriate activities. Behavioural strategies have included over-correction procedures, brief restraint and the differential reinforcement of incompatible behaviour (DBS) (Singh, 1981). A survey on pica within a learning disability hospital in the U.K., if representative, suggested that only about 8% of people with this problem were receiving a behavioural management programme (Tewari, Krishnan, Valsalan and Roy, 1995).

The severity of pica can depend on extraneous factors such as the availability of inedible substances in a person’s environment, sufficient mobility and dexterity to obtain access to inedible substances, the presence or absence of other behaviours which are more rewarding, and whether or not there is a tendency for the pica behaviour to be repetitive (Mace, Lalli and Lalli, 1991). One study indicated pica was more common in children with autism (Kinnell, 1985), possibly because of repetitiveness of behaviour. There is indirect evidence suggesting that pica in children with autism may translate into food-searching

Pica of cigarette ends has been treated using a functional analysis by isolating and removing the nicotine re-inforcement component (Piazza, Hanley and Fisher, 1996). In another study taking a functional analysis approach, increasing background staff-client interaction resulted in a reduction of pica behaviour (Mace and Knight, 1986). Pica behaviour can be found to vary as a function of a background depressive illness (Jawed, Krishnan, Prasher and Corbett, 1993).

These findings call into question whether it is meaningful to consider pica as a mental disorder in its own right; sometimes it may be a symptom of a depressive disorder, sometimes it may be a stereotypic behaviour associated with other behaviours such as hoarding or rumination, and sometimes it may represent a special variant of substance abuse (nicotine).

**Evaluation.**

Most studies are understandably concerned with the context and treatment of pica, and nearly all of these took a functional behaviour analysis approach. The absence of longitudinal studies on this condition makes it difficult to distinguish between pica which has developed as regressive behaviour and pica which has always been present in a person with severe learning disability. There is an absence of controlled outcome studies on treatments in this area.

**RUMINATION.**

**Definition.**

Rumination is defined as the repeated voluntary regurgitation of gastric contents, without associated nausea, disgust or gastro-intestinal disorder (American Psychiatric Association, 1994). The food is either rejected from the mouth (emesis) or, more frequently, rechewed and re-swallowed. This definition is problematic for two reasons. First, for the two groups in which rumination is most commonly found, infants and people with severe to profound
learning disabilities, it is usually not possible to determine whether or not there is associated nausea (Skuse, 1994). Nausea implies discomfort but it is possible that this experience can be rewarding to people with profound disabilities, and form part of a self-stimulation mechanism (Osborne, Peine, Darvish, Blakelock and Jenson, 1995). Second, in long-standing cases of rumination, gastro-intestinal and gastro-esophageal disorders can be present in up to 90% of cases, not least because rumination itself can give rise to these medical problems (Rogers, Stratton, Victor, Kennedy and Andres, 1992).

ICD-10 does not have a separate category for rumination disorder (W.H.O., 1992), although it allows rumination to be integrated under “feeding disorder of infancy and childhood”.

**Prevalence.**
The prevalence of rumination in people with learning disability varies between about 5% and 15% depending on whether cases with gastro-intestinal or other medical abnormalities are included or excluded, the age range which is covered and whether the prevalence study covered a residential population or a whole population (Singh, 1981; Rogers et al., 1992). A prevalence rate of 10% for people with moderate, severe or profound disabilities is probably the best estimate (Davis and Cuvo, 1980).

**Features of rumination in people with severe learning disability.**
Rumination can give rise to a range of serious health problems including gastro-intestinal disorders and damage to the teeth and gums and the chronic condition can also result in malnutrition, dehydration and lowered immunity to disease (Davis and Cuvo, 1980). The condition is potentially fatal by choking. Deliberate, non-erotic self-choking can be a complication in a minority of cases and both regurgitation and self-choking are presumed to emanate from self-stimulatory internal mechanisms- the behaviours are presumed to be self-rewarding and to block out other reinforcers (Osborne, Peine, Darvish, Blakelock and Jenson, 1995). Anecdotal evidence from solvent abusers and people with psychiatric problems might suggest that regurgitation and choking can lead to a brief “rush” or “high” which could be rewarding to a profoundly learning disabled person with a severely limited
behavioural repertoire and means for seeking out rewards (Osborne et al., 1995).

**Treatment.**

Aversive procedures have been shown to have some beneficial effects on rumination (Mestre, Resnick and Berman, 1988) but ethical and legal concerns about aversive procedures have led to other approaches being favoured. In particular, for rumination, the differential reinforcement of other behaviour (DRO) and food satiation procedures have been used with some success (Lancioni and Hoogeveen, 1990). Paced eating procedures have also proved effective in controlling postmealtime rumination (McKeegan, Estill, and Campbell, 1987; Osborne et al., 1995). Unsuccessful treatments have included increased handling and attention, dietary changes and drug therapy (Davis and Cuvo, 1980).

Because of the complex interaction of medical, dietary, nursing and behavioural factors underlying rumination among severely disabled people within residential care, there is a clear need for inter-disciplinary co-operation to treat this condition (Rogers et al., 1992). A greater awareness of these dangerous conditions could lead to more people being treated successfully and an avoidance of the factors which give rise to the conditions and the environmental factors which exacerbate them (Mace, Lalli and Lalli, 1991).

**General discussion on pica and rumination.**

Deliberate vomiting and regurgitation can occur among non-disabled people with anorexia and bulimia, but the reasons are contrastingly different. Among people with anorexia/bulimia the vomiting is planned, secretive, goal-oriented to avoid weight gain and is typically accompanied by feelings of guilt and disgust (Palmer, 1989). Among people with severe learning disability the same behaviour is a goal in itself, unplanned and subject to immediate conditions such as satiety and the availability of other reinforcers, and there is no evidence of guilt and disgust (Osborne et al., 1995, Skuse, 1994). Although the behaviour may be similar and the outcome- underweight - may be the same, the significance of the behaviour for the two groups is very different.

There is evidence suggesting that the context of rumination among children is different.
from the context of rumination in people with severe disabilities (Parry-Jones, 1994). Among infants and children rumination can signify failure to develop an interactional feeding pattern, distortions of the parent-child relationship and neglect; the treatment would usually involve parenting procedures including providing affection, attention and stimulation, and teaching an interactional feeding pattern (Mayes, Humphrey, Handford and Mitchell, 1988). For people with severe learning disabilities rumination occurs typically within an institutional setting and the behaviour may be reinforced by the re-consumption of food and by a self-stimulatory mechanism; the most favoured treatments are DRO (differential reinforcement of other behaviour), satiation procedures and paced eating (Osborne et al., 1995; Davis and Cuvo, 1980).

DSM-IV is a classification system which has developed from research within populations of predominantly non-disabled people. For eating disorders, it is uncertain whether such a system has validity for the population of people with learning disability. Rumination is treated as the same disorder for both young children and people with severe and profound disabilities, essentially because the behaviour itself seems to be the same. But if the context is different for the two groups, if the reasons underlying the behaviour are different and if the motives are different, there may be a case for rumination behaviour being classified in different ways for the two groups.

It is suggested that the DSM-IV classification system places over-reliance on definitions based on observable behaviour and does not take enough account of differences in underlying motives or reasons for that behaviour. Pica in a man with profound learning disability within a large hospital ward setting may take place because of conditions of undeveloped discriminatory senses, the presence of self-stimulatory behaviour, absence of other appropriate activities and access to inedible substances. Pica in a three year old child taken into care may take place because of a disturbed parent child relationship, as part of other regressed behaviour in a context of stress and change, and against a background of environmental deprivation (Madden, Russo and Cataldo, 1980). It may prove to be unreasonable for both conditions to be classed as the same disorder only because the behaviour looks the same.
Factor analysis and behaviours associated with disordered eating.

This argument can be approached from a different side. What if the behavioural disorders of people with learning disabilities were approached for classification without preconceptions about fitting the disorders into the categories used for the non-disabled population? Matson, Coe, Gardner, and Sovner (1991) have attempted to do this using a diagnostic instrument which they developed: the Diagnostic Assessment for the Severely Handicapped Scale (DASH), (Matson, Gardner, Coe and Sovner, 1991). Although the DASH subscales were organised along the lines of DSM III-R disorders, when their scale was used in a factor analytic study of 506 people with severe and profound learning disabilities, the analysis revealed just six orthogonal dimensions of behaviour which did not conform closely to DSM categories. These were emotional lability, antisocial behaviour, language disorder, social withdrawal/stereotypy, eating disorder, and sleep disorder. Level of learning disability and ambulatory status proved to be significant determinants of factor ratings whereas sex was not related.

Although the Matson, Coe, Gardner, and Sovner (1991) study represents an initial attempt in this direction, and although they started out initially with DSM categories, their results suggest that a very different nosological system could be developed for disordered eating behaviour within this group. Rumination might be considered more reasonably as a special variant of self-stimulatory and/or self-injurious behaviour. Pica might be better classified as a particular variant of delayed early development, or a variant of other associated stereotypic behaviours, in line with the view of Presland (1989) that eating difficulties can co-occur with a range of other problem behaviours.

Another isolated study (Jones, 1982) also indicated that a taxonomy of eating problems based on behavioural causes and problem-eating area could account for the research studies better than a taxonomy based on psychiatric disorders. Jones (1982) distinguished between behaviour-related causes, neuromotor-related causes and physical-related causes as one taxonomic dimension, and then went on to distinguish between different problem areas (drinking, eating, self-feeding, social and self-injurious). Although some objections could be made to this system—is self-injury a behavioural ‘cause’ or an area of behaviour?
it is an example of an attempt to develop a more logical system outside of the constraints of a taxonomy of mental disorders. The fact that problematic behaviour occurs within the area of feeding and eating may not be sufficient to justify a diagnosis of an eating disorder.

Until factor analytic studies are carried out which exclude the preconceptions of diagnostic categories based on non-disabled child populations and non-disabled adult populations with mental health problems, it will remain uncertain whether the present DSM-IV categories of eating disorders are appropriate for use with the populations of people with severe and profound disabilities. It may transpire that the best nosological system would be obtained from a combination of clinical approaches and factor analytic techniques (Matson, Coe, Gardner, and Sovner, 1991), or an integration of causes of behaviour with areas of problematic behaviour (Jones, 1982).

It is difficult to resolve the dilemma presented by the limitations of DSM-IV for eating disorders in people with severe learning disability. ICD-10 recognised its limitations for learning disability taxonomies, “...acknowledging that justice can only be done to this topic by means of a comprehensive, possibly multiaxial, system. Such a system needs to be developed separately.” (p. 18, W.H.O., 1992). But the development of a separate system goes against normalisation principles by leading towards this group being given separate consideration from non-disabled people.

It might be possible to resolve some of the contradictions if such a system incorporated the same essential features of the mental disorders of non-disabled persons, but relaxed and adapted many of the restricting criteria in order to take account of the special physiological and behavioural factors associated with learning disability. For example, a relaxation of the age restrictions of DSM-IV for feeding disorders “of infancy and childhood” would be appropriate in allowing people with severe learning disability to be included for consideration within this area of disordered eating.

An adapted approach might make it easier to incorporate pica and rumination into eating disorders, challenging behaviour and severe disability itself, whereas the present DSM-IV
system strongly discourages such over-inclusivity.

SUMMARY AND CONCLUSIONS.

For anorexia nervosa and feeding disorder the DSM-IV classification system is less than adequate for adults with severe learning disability, because the defining criteria effectively rule out of consideration this group. For anorexia this is because the essential cognitive cannot be fulfilled by people with severe learning disabilities; for feeding disorder this is because the condition is reserved for very young children.

Problems of obesity and underweight can be widely prevalent within some groupings of people with learning disability. DSM-IV does not class these conditions as mental disorders, and this is quite correct, but a system which could deal with conditions and factors such as obesity would be more useful for people with learning disability, without the problematic function of defining these as mental disorders or not. Greater awareness, prevention and treatment can be highly beneficial in avoiding the stigmatisation, medical and mobility problems which can otherwise accompany obesity and underweight.

The behavioural disorders comprising pica, rumination and feeding difficulties are better accounted for without the constraints of DSM-IV which treats these behaviours as mental disorders based on a non-disabled population. Both DSM-IV and ICD-10 place great emphasis on individual psychopathology which is unfair towards people with severe learning disabilities in the light of a great deal of evidence indicating the influences of environmental conditions on pica and rumination behaviour (Mace, Lalli and Lalli, 1991; Osborne et al., 1995; Rogers et al., 1992).

A more coherent, consistent account could be provided by a combination of clinical concepts with a behavioural and factor analytic approach. This might lead to much pica- and rumination-behaviour being seen within the context of other stereotypic, self-stimulatory or self-injurious behaviour in people with severe learning disability, rather than
pica and rumination being classed as isolated mental disorders in their own right.
Table 1. Characteristics of the seven individuals in seven cases studies of people with learning disability and “anorexia nervosa”.

<table>
<thead>
<tr>
<th>Sex of the person.</th>
<th>F</th>
<th>F</th>
<th>M</th>
<th>F</th>
<th>F</th>
<th>F</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of the person.</td>
<td>35</td>
<td>16</td>
<td>33</td>
<td>35</td>
<td>33</td>
<td>20</td>
<td>15</td>
</tr>
<tr>
<td>Disability level.</td>
<td>Moderate</td>
<td>Mild</td>
<td>Moderate</td>
<td>Mild</td>
<td>Moderate</td>
<td>IQ 79</td>
<td>Mild</td>
</tr>
<tr>
<td>Was amenorrhea present?</td>
<td>No</td>
<td>Yes</td>
<td>?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Was co-morbid depression present?</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Was there accompanying behaviour disturbance?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Was there a co-morbid schizo-affective disorder?</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Did the person show perceptual distortions of body shape?</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Was there evidence of planned vomiting or over-exercising?</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Were anti-depressants used in the treatment?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>?</td>
<td>?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Was behaviour therapy a central part of the treatment?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Was individual or family or milieu therapy part of treatment?</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Length of treatment.</td>
<td>4 months</td>
<td>1 month</td>
<td>21 month</td>
<td>5 month</td>
<td>15 month</td>
<td>5 month</td>
<td>2 month</td>
</tr>
</tbody>
</table>
REFERENCES.


SECTION TWO.

CLINICAL DOSSIER SECTION.

AN ACCOUNT OF CONTINUING PROFESSIONAL DEVELOPMENT UNDERTaken TOWARDS THE DOCTORATE OF PSYCHOLOGY.
INTRODUCTION

The purpose of this review is to provide an account of my professional development during the nine years since qualifying for my M. Psych. Science (Clinical). Family allegiances committed me to remaining within the same psychology department, but far from restricting my development, this continuity has given me the freedom to develop expertise and carry through a range of projects without interruption.

Many of the personal and departmental developments outlined below also represent national developments in psychology and health services. Greater emphasis on community care approaches in learning disability are reflected in five of my own applied research projects. A national emphasis on the auditing process is reflected in the computerised databases which I developed in my department, and in the way these have been used to inform, analyse and change our departmental practices. Changing structures in multi-disciplinary work and supervisory work are also reflected in my own career development outlined below. The national trend towards greatly increased rights of the service users, increased freedom of information and a partnership in decision making is also strongly reflected in the final project reported in this section.

All the projects were motivated by practical concerns or questions which came out of my work. Ten of the studies were formally commissioned by management or services within the health board, and often reflected concerns and questions at national level as well as at local level. For example, in six of the studies an underlying question was, “How are community care policies working in practice?”.

I have tried to relate theory to practice through the work outlined below, and bring to my role as clinical psychologist an approach of open enquiry, planned and structured change, and constant monitoring of progress.
PERSONAL DEVELOPMENT AS A CLINICAL PSYCHOLOGIST

My development as a psychologist can be described under five main headings.

1) Pre-Clinical Course psychologist work experience.
2) Post-Clinical Course clinical, senior level and organisational work.
3) Learning Disability specialist work.
4) Information Technology Development.
5) Research Studies.


For eight years from 1978 to 1986 I worked as a basic grade psychologist. At that time the clinical qualification was not obligatory in S. Ireland. During these years I was able to gain through experience a good grounding in most of the generic work of a clinical psychologist. From 1986 to 1988 I went on to complete the M. Psych. Science (Clinical) course at University College Dublin, which was and remains a B.P.S. accredited clinical course. My experience prior to this course is outlined below.

Areas of involvement as a basic grade psychologist - 1978 to 1986.

Psychometric assessments. For the first three years of my work as a psychologist much of my work consisted of carrying out psychometric assessments on children with learning difficulties or disabilities, along with some adult assessments and some therapy work.

Child psychotherapy. As both my experience and the nature of the department's referrals broadened, I became much more involved in therapeutic interventions, and the range of
problems included behaviour management, anxiety problems, school-related problems, grief reactions, enuresis and encopresis.

**Adolescent work.** This included problems of parental control, offending behaviour, emerging sexual or sexual-identification problems and vocational assessments.

**Adult psychotherapy.** From about 1981 an increasing proportion of my work was with adults, treating people for depression, anxiety, phobic and obsessional states, relationship and sexual problems, bereavement, post-marital separation traumas and personality disorders, for example.

**Adults with learning disabilities.** Because I had developed over the years a thorough familiarity with all the learning disability services within the region, many referrals for assessment/placement or for treatment/intervention with people with disabilities came my way. I built up a good working relationship with the National Rehabilitation Bureau who often used my services, and from 1980 onwards I carried out a great deal of specialist work within area community day centres, workshops and residential centres.

**Lectures.** For four years I gave a regular series of psychology lectures to nursing students and psychiatric nursing students, and in addition there have always been frequent requests for public talks to parents' or other groups, or local radio. Subject topics have included psychology for nurses, parenting courses, dealing with bullying, the needs of children with learning disability, adults with learning disability living in the community, problems associated with separation and divorce, and a sensible approach to homework.

**Child sexual abuse, non-accidental injury and court work.** Since 1985 there was an enormous increase in this area, and about a quarter of my clinical work has always been taken up with this kind of work, even to date. As one of the few males within the psychology department in Sligo over the last decade, I have had considerable experience with adult and adolescent perpetrators, with or without learning disabilities or other complications.
Other generic work. This has included work in the area of fostering and adoption, work with children over whom there are custody and access disputes, neuropsychological assessments, multi-problem families and substance abuse. My outside clinics have been held in all parts of County Sligo and County Leitrim.

Adults with learning disabilities. The group homes programme. In 1988 and 1989 there was a large transfer of clients out of the old psychiatric hospital and in to group homes in the community, and in to specialist learning disability services, day centres in particular. I became heavily involved in this area, working in staff training and support, assessment of overall client needs, reviews of progress, individual programme planning, and dealing with challenging behaviour and psycho-social problems. This phase of my work led naturally into my promotion to the post of Senior Psychologist with responsibility for learning disability, which commenced in 1989 and is dealt with in more detail below.

My development has been somewhat atypical insofar as I had been working as a psychologist for eight years prior to gaining this professional qualification, and a great deal of the experience which many psychologists gain in the next three to five years post qualification had already been gained by myself prior to the course. But I was able to use the course itself to great effect in developing my skills, reading, studying and learning, and using my clinical placements to maximum advantage as I already had a good grounding in the basics.

2) POST-CLINICAL COURSE CLINICAL, SENIOR LEVEL AND ORGANISATIONAL WORK.

After one year following clinical training I was promoted to senior grade for a specialist learning disabilities position, and this work is outlined below.
During the last eight years my generic clinical skills have been consolidated through experience and refreshed through conference/workshop attendances (see pages 108-111 covering this). Inevitably a greater proportion of my time is now taken up with cases which demand a high level of general expertise or responsibility, such as serious abuse and sexual offence cases, preparing reports for court and giving expert witness testimony, and advising on internal Health Board and Psychology Department procedures in cases where there may be a question of complaint, professional competency or serious risk management.

**Supervision.** Ongoing clinical supervision of basic grade and trainee psychologists has always been an important priority within our department, and at any typical period during recent years I would have been supervising about four psychologists. I receive regular general supervision from a colleague and I would very frequently look to other psychologist colleagues for supervision in specialist areas. Supervision is a two way process and can provide a valuable forum for information to be received as well as imparted, and for theories or approaches to be examined and tested out. Case formulation seems to be a skill which definitely becomes refined by experience.

**Acting Head of Department.** Over the last six years there have been regular periods during a year when I served as acting Head of Department, and I worked closely with the Head of Department. The Sligo Psychology Department has a staff complement of between seven and ten psychologists, depending on availability, and there is a healthy system of delegation of responsibilities. I am thoroughly familiar with all the procedures and practices within the department, from ordering paper clips to consideration of training needs, and I would frequently attend and participate in higher committee meetings within the Health Board representing our department on matters such as quality management, child care, service developments and supervisory responsibilities.

**B.P.S. chartership.** In 1995, as a precursor to applying for the Surrey Clinical Doctorate Conversion course, I applied for British Psychological Society (B.P.S.) chartership and this was granted in November 1995:- previously I had been a member of the Psychological
Society of Ireland (P.S.I).

In 1997 I commenced working as Acting Principal Psychologist (this grade is newly created and has not yet become a permanent position), and as Acting Head of Department, and this position will be competed for as a permanent post at some stage probably in 1998.

**Service Planning.** Through my applied research projects and involvement in meetings on service demands I have been involved at many levels in service planning. Psychologists, including myself, tend to have a reputation for being relatively well-informed about national and international developments in service development, and usually know a great deal from their reading and conference attendances about which particular developments have been found to be beneficial and which have not. My specialist area of research is in learning disability, and my applied research projects and service planning surveys are covered in detail in the Research Studies section below.

**Organisational and Multi-disciplinary Work.** My senior specialist position within the area of learning disabilities has fostered considerable experience in liaising with other departments and professions, as well as independent agencies outside the Health Board, including the Gardai (police), voluntary bodies and private agencies, and parents' and friends' pressure groups which are very active and influential in our area.

Over the years I have developed considerable experience in taking the initiative in arranging meetings, case conferences and reviews both for individuals and groups of clients. Much of my work has been pro-active, involving anticipation of future needs as well as everyday and crisis work.

**Responsibilities at inter-agency level and with senior management.** My present position has involved a good deal of communication with agencies outside the Health Board such as the National Rehabilitation Board, Cregg House (a large voluntary body learning disability agency), Rehabilitation Industries, other voluntary bodies and the
Department of Education. In situations where there has been ongoing negotiations and liaising with these agencies I have held a position of trust with higher management in the Health Board, often as a kind of special advisor. During 1991 and 1992 I successfully completed the three modules and research project comprising the I.P.A. Skills Development Course for First Line Managers, funded by the Health Board.

3) LEARNING DISABILITY SPECIALIST WORK.

Assessment and therapy. Over the last 18 years I have gained considerable experience in most aspects of assessment and therapy for people with learning disabilities. This work has included psychometric assessment, individual programme planning, behavioural work within residential units as well as within the home, assessment of social competence, working with clients who present with especially challenging behaviour often at a level involving risk management and environmental manipulations, vocational assessment and placement work, and the training of others in assessment and therapeutic procedures.

Counselling and therapy work has included working in the area of sexual abuse both with victims and offenders, clients with a dual diagnosis i.e. who suffer from schizophrenia, depression or other psychiatric disorders as well as their learning disability, and I have also provided counselling for parents or other caregivers. In most cases the client could only be seen in the context of the family, residential unit, school or day centre.

Service Planning. The Health Board has always been very keen to encourage the kind of practical and applied research which I have undertaken, and which is outlined below. Because of experience of working at many levels and in a number of different roles, I have enjoyed a great deal of trust and responsibility in this aspect of my work. A psychologist can have the advantage of knowing a great deal at the level of individual clients, being trusted and accepted by other professionals such as nurse carers, knowing research methods and having a good grasp of organisations and future planning requirements. This makes psychologists particularly suitable for being involved in the service planning
process. The specific projects which I have carried out are detailed in the next section.

**Other areas within learning disability.** Other areas of involvement include establishing a psychology database covering people with learning disabilities (see separate section on this), providing statistical returns for the Health Board and other government agencies, sitting on the Parents and Friends Advisory Board which meets with the Health Board and represents groups such as the Down Syndrome Association. I have always retained a continuing involvement with all the workshops, day centres and training centres in our area. For some years I was involved in the "Home-to-Home Scheme" which is a holiday/respite care scheme in which children with learning difficulties can be hosted by volunteer families for a period, usually during the summer.

4) INFORMATION TECHNOLOGY DEVELOPMENT.

During my two years clinical training I overcame a resistance to using computers by learning their usefulness and receiving hands-on experience. In 1992 our department acquired a computer and I became familiar with database development and of course word-processing.

**Learning disability database.** As there are no educational psychologists at primary level in our area, our own clinical department carries out all the assessment and school placement work in the area of learning difficulties, and has done so for the last twenty years. A leaky manual system had been in operation for separating out psycho educational and learning difficulty cases from the rest, but because of numbers this was very difficult to maintain.

During 1993 I developed a psychology database system for children with learning difficulties which was later expanded to include adults as well. Apart from basic demographic data (name, address, D.O.B., sex) the database included level of disability, diagnoses such as Down Syndrome, other special needs, school or day service attendance, residential or respite services and some other technical information such as psychology file
number and identification number.

One immediate use this database was put to was to establish how many children with learning difficulties lived within a defined rural area where there were no special educational facilities. Armed with this working list we met with inspectors from the Department of Education and we established provisional acceptance for a special class to be set up in a village school where there was a sufficient number of children with special needs in the surrounding area. The next step was to go back to the parents and children with concrete offers of placement in the proposed integrated special class and most took up the offer. This process led to a special class being set up in one village and other rural areas are under consideration, using the same process.

Database development and proper use of information analysed in this way can help psychologists to move up from the individual level of analysis to a group or macro level of analysis. Information so obtained can inform service planning, indicate trends, show up gaps or anomalies in service delivery and provide an overview analysis.

Some other specific uses and benefits of our learning disability database are briefly listed below.

1) The database informed us of how much educational and disability work we were actually involved in. In 1995 this constituted 32% of all our referrals. As a clinical psychology department our policy is to move out of educational work as and when educational psychologists come on stream.

2) We were able to inform and cross reference with a National Database (for learning disabilities) which was being developed from 1994, and this became essentially an auditing process.

3) In the absence of a "statementing" system, our Health Board is developing a 'Key Stage Review System" in which parents participate fully at key decision stages such as
starting or leaving school. Psychology is the only department involved with all children in the region with acknowledged significant learning disabilities, and so our database can form the procedural core of this review system. A maintained database is excellent for indicating review dates, reminders for action, numbers involved and repeated information.

4) Department of Health funds became available in 1995 specifically for people with autistic features, and our database was able to pinpoint these potential recipients very quickly and efficiently.

**Psychology Throughput Database.** This database was developed from a manual system called "The Red Book", in which all new referrals were entered. The columns in the Red Book became the columns in the database, and comprised File No., Name, Address, D.O.B., Sex, Clinic where seen, Date of Referral, Referring Agent, Psychologist who was allocated, attendance, and Referral Problems as defined by the psychologist. This last column is the most controversial because a psychologist has to be responsible for this information, which could be examined by the client through the Data Protection Act (1988). But to exclude this information would leave the database impoverished of any clinical information at all.

A key word system like that used in academic journals was selected because this was felt to be more adaptable, user friendly and heuristic than a medical diagnostic system such as D.S.M.-4. This database system, although very basic and simple at this stage, has had enormous clinical impact within the department, and has led to significant changes and adjustments some of which are outlined below.

**Caseloads.** Some psychologists were seeing nearly twice as many new clients in a year than other psychologists, with no apparent differences in their respective loadings or weightings for the type of client/problem seen. Such analyses of individual caseloads can indicate very clearly and powerfully whether a psychologist is "holding on to clients", working too hard or too little, not working effectively, or unwittingly receiving an unfair distribution of allocated cases.
Most of these problems are as much the responsibility of the head of department or senior supervising psychologist including myself, and when these issues are addressed during supervision, it is far easier to say, "This is what the database analysis shows." rather than offering an unsubstantiated impression. As a result of this process, caseloads have been evened out to some extent and problems have been addressed before becoming crises.

**Analyses of the nature of our work.** By carrying out creative queries on the data within our database, several interesting analyses have emerged and are brought up for discussion periodically at staff meetings. Some of these findings are listed below.

a) Many more boys were referred to our department than girls: over 50% more boys were seen than girls. But for adults the reverse was the case. There were more than twice as many women seen by our department than men. A more detailed analysis revealed that it was General Practitioners who were mainly responsible for the referral pattern among adults. G.P.s were found to have referred nearly four times as many women to our department than men. Of the adult self-referrers, 30% were male and 70% were female. Perhaps there is a background state of psychotherapy being more acceptable to women than to men, but this trend becomes accentuated by medical referral tendencies. There would be scope for a student project to further elucidate these findings.

b) During recent years there has been a continuing high level of referrals from social workers and other referral agents for people suffering the effects of abuse, including physical abuse, emotional abuse and neglect as well as sexual abuse. When adult victim survivors of abuse were included, the total number of referrals for abuse-related problems constituted 20.4% of all referrals. Accurately documenting this aspect of our work through the database enabled our department to make a case for availing of funds which became available as a result of implementation of the final sections of the Child Care Act (1991).

c) Preparing department statistics for the annual service plan used to take about 40 hours of clinical and admin. time, but now takes just 4 hours to produce far more detailed and
sophisticated analyses.

Under current active consideration are proposals to add in a great deal of further information on each client referred and seen by our department. These might include outcome statistics, attendance pattern, more demographic information on the client and finer distinctions between, for example, problem as defined by client or referral agent as opposed to case formulations by the psychologist. Such developments would introduce more poignantly the issues of confidentiality, responsibility for accuracy of information, compliance with the Data Protection Act (1988) in spirit as well as to the letter, need-to-know issues and respect for the rights of the client.

5) RESEARCH STUDIES.

The two year clinical course was invaluable in providing me with the skills and supports for carrying out research studies and since qualifying I have been completing between one and three studies per year. The studies are very briefly listed below, followed by an overview analysis of their content, and then one particular study is cited in some detail to illustrate how theory and research can inform clinical practice.

LIST OF RESEARCH PROJECTS, SURVEYS AND DISCUSSION PAPERS.

All the projects outlined below were commissioned or supported by senior management in the North Western Health Board.


Questionnaire Survey of 200 neighbours or potential neighbours of group homes. Completed as the research study in partial fulfilment of the M. Psych. Science (Clinical)
professional qualification. This study is included as part of the present portfolio.


This paper represented an internal North Western Health Board review of the setting-up of seven community group homes within the first six months of this development. It involved examining the progress of some 30 people in terms of quality of life, social and family contacts, health and community involvement.


These two projects involved assessments of some 60 people who were in need of a day service. They were examined with a specific view to their sheltered workshop, training or day care needs, so that the appropriate service could be designed around these needs. A new unit, the Resource Centre was opened in 1990 to meet these needs and currently caters for 25 people in Sligo Town.


This was a discussion document on the particular requirements of a group with very special needs as a result of severe psychiatric, social, personality and behavioural problems in addition to their intellectual disabilities. This study was based on a critical review of the literature and linkage of those general findings to the local service conditions and my own professional experience.
Sixteen representative cases were used as exemplars of the challenge to the services presented by people with dual diagnosis. Some of the recommendations made in this document have since been taken up, including the establishment of a high-support group home.


This was a highly sensitive project to examine whether the sheltered day care/workshop needs of clients were being met in a certain workshop, because the Health Board had received a number of complaints from parents of clients attending this workshop. A stratified sample of twenty people and their parents were interviewed. Recommendations for improving the quality of care were made.


This was a major study examining more than 100 clients with a significant level of behaviour disturbance. A proposal for a Treatment Unit had been put before the North Western Health Board. They commissioned this study to examine whether there really a need or demand for such a treatment unit, and if not, what would be the alternative approaches. It emerged that treatment of the problems in situ would be far more appropriate to the clients' needs rather than concentrating together in one treatment unit a number of people with quite disparate needs and service demands.


This was a brief review summarising the trend towards increased referrals to the Group
Homes Programme of young adults with social problems.

8. 20th August 1991. Project completed on establishing whether there was a demand for a new Day Centre in South Leitrim: 5 pages of summarised statistics.

This project involved contacting families or carers of over 75 adult clients. It was found that because this county was very sparsely populated, geographical distance and travel times mitigated against attendance at a day centre for a significant proportion of people. Alternative services such as carer support, home help, respite care and individual programmes should be considered.


This piece of research was submitted as a project for the Institute of Public Administration (I.P.A.) Skills Development Course for First Line Managers.

Three groups of 20 subjects, balanced for age, sex level of disability and social competence were compared with each other for levels of disturbed behaviour. The first group were located in Disturbed Behaviour Units, the second group were in large residential centres, and the third group lived in community group homes.

We found that recent policy trends had resulted in a concentration of people with behaviour disturbance in the larger mental handicap centres.


This survey covered all of the children with a recognised learning disability in one county.
in the west of Ireland and was very comprehensive. It detailed age, prevalence rate, syndrome or disability type, residential and educational placements, degree of disability and future service requirements. This information formed the basis for a database which was developed by myself within the psychology department, which is outlined above in the Information Technology Development section.

11. **14th September, 1992 "The needs of People with a Severe Mental Handicap who are living at Home:-Parents' Requirements"**

This project, a copy of which was forwarded to the Department of Health, looked at the individual needs of a representative group of families caring for a severely or profoundly disabled child. A semi-structured interview technique was used to elicit parents' real priorities, which did not necessarily correspond with traditional service provisions.

It was found that these families did not want more counselling, nor did they require more day service provision. Instead they showed highly individual and varied needs including transport or special taxi facility, “baby sitting” services, specialist equipment, immediate or drop-in respite care services and flexible financial allowances.

12. **30th August, 1993 "A Statistical Profile of the People in the Residential Care of the N.W.H.B. Sligo/Leitrim Mental Handicap Services." 43 Pages**

This study represented the start of a computerised database on all the people in residential care within the Mental Handicap Services, and has since been expanded to cover all people known to the Psychology Department who have a learning disability. It covered basic demographic information as well as levels of disability, levels of behaviour disturbance, levels of social competence, history of care and sensory or other disabilities. The database which this report covered is outlined above in the Information Technology Development section.

The information on those people in the residential care of this health board area, which
was collected on the basis of assessments carried out by myself, formed the core of the demographic data on the population under study in what became my main research study for the Surrey Doctorate Conversion Course, described in the research section of this portfolio- ‘Family Contacts of People with Learning Disability who are in Residential Care’.


This study, in which I was closely involved, used the database information from the previous study no. 12 to compare the leisure activities of those in residential care with those who live at home. A further comparison was made between those receiving a day care service and those who had no such service. Four stratified groups of 15 subjects made up the total sample of 60. The amount, type and quality of leisure activities was examined in depth.

Ability level was found to be unrelated to hours of leisure activity, but more able people had more varied leisure activities. Older people (over 30 years) had significantly less leisure participation than younger people, and attendance at a day service significantly improved a person’s leisure opportunities. 72% of all leisure activities took place in the company and supervision of caregivers.


Our survey covered the following areas:-
Terminology used for describing learning disabilities, and disturbed behaviour.
Assessment styles and approaches e.g. tests and scales used, other methods. Styles of report-writing :-what is included and what is excluded.
Decision-making styles and practices, access by parents to key meetings, reviews and to reports, especially with regard to placement decisions.
Attitudes to service evaluations.
Attitudes to database registers held by services on clients.

The implications of this study for informing clinical practice are dealt with in the final section of this clinical dossier.

15. 15th June 1995. "Customer feedback survey for the psychology department" carried out by Michele Ni Dhuill and Marese Monaghan and supervised by myself. The findings of this study were presented at a "Quality Initiative" Health Board meeting seminar later in the year.

16. 20th June 1997. “Family contacts of people with learning disability who are in residential care.” 100 pages. This research thesis was in part fulfilment for the Clinical Doctorate Conversion Course (University of Surrey). This study is presented below in the research section of this portfolio.

THEMES COVERED IN THE RESEARCH STUDIES.

Applied psychological studies are probably at their strongest when they are specific, relevant to services and focused on particular questions. In my own work I have tried to relate theory to practice by carrying out research studies which are directed typically at our own local services but which reflect theoretical issues at the macro level.

Community Care: Residential Services for people with learning disability.
Community contacts and family contacts.
Research Study no. (1), on community contacts and neighbours' experience of group homes for people with mental handicap, indicated that the potential fears felt by neighbours at the prospect of a group home being established in their street were not
realised in practice.

In two neighbourhoods where group homes had been established, a significant proportion of neighbours were unaware of the existence of the group home in their street, or that it was for mentally handicapped people. Residents and staff of the group homes appeared to have little interaction with their immediate neighbours. Only 14.5% of neighbours had any kind of regular contact with the mentally handicapped people in the group homes. Implications for community care policies were discussed. Being located in the community did not mean that group home residents were necessarily part of the community. Some neighbours within the community, particularly those who had a history of doing voluntary work or who themselves had a disabled relative, expressed a potential willingness to help out and get involved with the group home.

Project no. 16 (the main research study for this portfolio) examined family contacts of people in residential care and found a similarly disappointingly low level of involvement. The development of the theme of what living in residential care means for community and family contacts is considered in more depth within that study.

**Group homes. Progress review. Developing acceptance. Quality audit.**

Projects nos. (2), (7), (9) and (12), which were carried out between 1989 and 1993, dealt with the impact of the trend for people with learning disabilities who were in larger residential units moving out into group homes in the community. Broad findings from our local area were that, despite initial extreme resistance from the public, parents and political representatives to the community care policy, within two to five years there was broad acceptance and appreciation of the group homes. For those who were able to cope with community living, quality of life did seem to improve, but probably more as a result of smaller unit size than location within the community per se.

**Community Day Centres. Small, local, homely and personalised services are best.**
Studies nos. (3), (5), (8) and (11) covered the development of community day care facilities for people with disabilities, which occurred in the N.W. of Ireland about 10 years later than in most parts of the U.K., and hence the Irish services were able to take advantage of previous experiences. The findings documented in my own studies were that families preferred small-scale and local facilities for their disabled family member. They valued quality of care, varied programmes and "homeliness", and they did not appreciate or want conditions similar to real factories or workplaces, despite the principle of normalisation.

Families caring for people with very severe disabilities had quite different and more individualised service needs. They certainly did not want or appreciate more counselling, and in contrast they did want practical supports such as a specialist "baby-sitting" facility in order to get out, mobility allowances or grants, and respite care. These findings can prevent a Health Board wasting scarce resources on services which are not wanted. The studies represent examples of applied science informing practice.

The needs of people with behavioural problems, social problems and mental health problems.

Studies (4), (6), (7) and (9) focused on the service difficulties and responses to people with dual diagnosis i.e. both learning disability and challenging behaviour. From these studies it was concluded that it would not be a good idea to develop a large specialist treatment unit for people with challenging behaviour. Treatment units inevitably develop into residential units and it is bad policy to concentrate together in one location people with disparate but significant behaviour problems. However, small scale specific responses were appropriate to the needs of people with challenging behaviour, and a high support group home was developed in 1990 to cater for people who might not otherwise be able to live in the community.

In three of these studies the referral and placement trends over a five year period were closely documented. It was found that a concentration of the more behaviourally disturbed
people within the larger residential centre resulted from the move into group homes as a result of a community care policy. Furthermore, there was a tendency for specific learning disability group home placements to be taken up by people who had quite other needs, such as victims of abuse, people with social problems, people who offend and people with specific mental health problems. Documenting any such trends can prove to be the best way to advise policy and inform alternative decisions.

The next study, which is presented in some greater detail, represented an example of how the writer attempted to relate a small research project to personal and departmental practices.
A STUDY INDICATING THE INTERACTION BETWEEN RESEARCH AND PRACTICE, undertaken by the writer and Emmet Murray in 1995.

SURVEY OF THE TERMINOLOGY USED, ASSESSMENT STYLES AND THE CURRENT WORKING PRACTICES OF PSYCHOLOGISTS WORKING WITH LEARNING DISABILITY.

BACKGROUND AND INTRODUCTION.

The survey, the results of which are outlined below, was initiated because a number of key issues had arisen in the area of working practices of psychologists in the learning disability services.

Terminology. At the basic level of terminology, psychologists in our department had expressed confusion about the appropriateness of different terms for learning disability which were currently in use, and even whether it was appropriate to use any term which might label a person. Different category terms for mild moderate and severe degrees of disability were in use by psychologists who were unsure whether to use the Dept. of Health recommended terms, the World Health Organisation (WHO) system, the UK current terms or some other terminology. In similar vein psychologists were unsure whether to use the term ‘behaviour disturbance’ or ‘challenging behaviour’. It is of note that for three years prior to this study a working group of the Psychology Society of Ireland had been trying to establish agreed recommended terminology for learning disability, but was having difficulty in achieving consensus.

The Department of Education used the terms “mild, moderate and severe mental handicap”, and was making no moves to change. The term “learning difficulty” was
gaining increased currency in S. Ireland because of the prevalence of its use in the UK. The Irish Department of Health recommended the term “intellectual disability” but preliminary impressions before the survey were that psychologists baulked at using the word “intellectual”.

**Professional practices.** A second area of confusion was in the professional relationship of the psychologist towards the person with learning disability and their parents. Background ideologies and assumptions have changed considerably in the last two decades, and professionals can be unsure whether to relate to the person with learning disability as a child, or as a patient, or as a client, or as a consumer/customer or as an equal partner. Depending on that primary relationship, even more confusion can be experienced in how to define the professional relationship with the parents or guardians of the person with learning disability. This confusion can be expressed in divergent working practices among psychologists:- some always give psychological reports to the family, others rarely do so:- some always invite parents to case conferences, others rarely do so:- some use traditional IQ assessment and feedback practices, others use different approaches.

**Parents’ pressure groups.** During 1995 an agreement was hammered out between the N.W.Health Board and the parents' umbrella organisation called Parents' Action Group, whereby a Key Stage Review system would be implemented. The main features of this development were that at key stages of a child's life, such as starting or finishing school, there would be a formal meeting of the health professionals involved with the child and the child's parents. Review reports were to be available at or before the meeting to facilitate the fullest involvement of parents in any placement decision. This system began in January 1996 with the compliance of most health professionals. It was felt important to determine what were the practices of psychologists before implementation of the new key stage procedures and how they felt about issues such as parents’ access to reports, attendance at case conferences and the respective roles of parents, psychologists and other professionals in decision-making about appropriate placements and services.
**Freedom of information.** Another background issue which influenced the initiation of the survey outlined below was the future implications which would follow from implementation of the Freedom of Information Act (1997) which will come into force in 1998 for Health Boards, and which will accord more rights of access to information than corresponding legislation in the UK or the U.S.A. It was felt important to examine what the current procedures were for psychologists working in learning disability specialisation with regard to giving parents or clients psychological reports, details of IQ scores and other such test results, minutes to case conferences and access to the files themselves.

**General aim.** A more general objective in carrying out this survey was to provide a picture of the current pattern and styles of psychologists' work within the area of learning disability. Within the last fifteen years there have been enormous changes in the area of learning disability, with general philosophies influencing policies, and policies in their turn influencing working practices. Psychology as a profession has been at the forefront of many of these developments, and arguably has been the quickest to change and adapt to new policies and practices. Impressions were that new developments have occurred in a patchy, uneven fashion, and that there is often not a "standard practice" in any particular work area.

**Key questions.** The key questions were, how closely did psychologists' working practices in learning disability conform to a common standard? Was there even any conformity on the basic terminology for learning disability? What general methods did psychologists employ in their assessments of people with learning disability, and how much concordance was there in the perceived appropriateness of different styles of assessment?

Because we assumed that there was a trend towards greater rights of access by service users to information and the decision making process, we wanted to find out what current practices were in this regard. Were there any differences between recommended practice policies and actual practice?

The approach in this study was to ask, through interview schedule, a representative group
of working psychologists about the terms they use, their working practices and assessment styles within the area of learning disability.

**BRIEF OUTLINE OF METHOD AND PROCEDURE.**

Our target group consisted of psychologists who worked for a significant proportion of their time in the area of mental handicap. In fact, over half of our sample worked full-time in the area of mental handicap. Selection was on the basis of a stratified sampling from the known broad distribution of characteristics of psychologists working in S. Ireland, and psychologists were recruited into the study by initial phone contact followed by arrangement to meet for interview. Two nominated contacts dropped out for reasons of inconvenience.

The sample size was 30 psychologists, and strong efforts were made to achieve a good representational balance. The age range was from early twenties to late fifties, and there were 16 females and 14 males. Of our sample, 53% worked within a Health Board setting, 40% worked within a Voluntary Body setting, and 7% worked in some other setting. Experience in the area of mental handicap ranged from about 1 year to 35 years, but a majority had 5 to 15 years experience. As there are an estimated 180 psychologists in S. Ireland who work for a significant proportion of their time in the area of learning disability, our sample represents an approximate 1 in 6 of the total.

Since this study is presented briefly here, principally to illustrate the interaction between research and clinical practice, the study itself is not reported on in any great detail.

Each psychologist respondent was given an interview schedule lasting from 50 minutes to 90 minutes, and divided into themes such as terminology used for mental handicap, approach and style of assessment, report-writing, and case conferencing practices. The format within each theme was a combination of open questions for free responses, followed by a number of closed questionnaire-style questions. The open questions typically began with the words, “Can I ask for your thoughts and opinions about......”,
The interviews were carried out by myself and Emmet Murray, co-author of this study. The broad nature of the study was explained to the participating psychologists. Detailed handwritten notation was taken by one or other of the authors of all verbal responses of a subject, as well as notes about shrugs or laughs, for the open-ended free response questions. At data analysis stage, where responses required categorisation, the authors carried this out separately and then compared the results to provide an inter-rater reliability measure.

**BRIEF SUMMARY OF RESULTS.**

**TERMS USED FOR LEARNING DISABILITY.**

The main finding in this study as a whole was that there is a great range and variety of work practices, approaches and attitudes among psychologists working in the area of mental handicap. There was also considerable range and variety in the basic terms psychologists use to talk about learning disabilities.

Psychologists were asked specifically to say what was their most preferred term to describe people with a mental handicap. Knowing that most psychologists use more than one term, we also asked for the 'second preference' terms which psychologists used.
Table 1. Showing 1st and 2nd preference terms used by psychologists for mental handicap/learning disability.

<table>
<thead>
<tr>
<th>First preference</th>
<th>Second preference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning difficulty.</td>
<td>53%</td>
</tr>
<tr>
<td>Learning disability.</td>
<td>13%</td>
</tr>
<tr>
<td>Mental handicap.</td>
<td>30%</td>
</tr>
<tr>
<td>Intellectual disability or</td>
<td>0%</td>
</tr>
<tr>
<td>difficulty.</td>
<td></td>
</tr>
<tr>
<td>Other e.g. special needs.</td>
<td>4%</td>
</tr>
</tbody>
</table>

The preferred term for the majority of psychologists (53%) was learning difficulty. A further 13% had learning disability as their first preference term. Many psychologists used the terms 'learning difficulty' and 'learning disability' quite interchangeably, and if these two terms are added together, a clear majority of 67% now prefer to use the terms 'learning difficulty' or 'learning disability', but a sizeable minority (30%) use the term mental handicap as their first preference term and the remainder (4%) used some other terminology.

The results of the less structured and more open-ended section of the interview schedule with psychologists indicated the following main findings:-

A majority were careful to use phrases indicating that the disability was something secondary to the individual, e.g. 'People with learning difficulties', or 'John is a 30 year old man who has a severe learning disability.' Conversely though, phrases including the words person or persons seem to be going out of style and use, with less than a third of our sample ever using this particular form.
A majority of psychologists (83%) were uncomfortable with the term profound insofar as they never mentioned this particular category term in their responses about terminology (inter-rater reliability - 93%). But one or two spontaneously and stoutly defended the term profound as being a particularly important distinction for planning within large services.

A number of respondents mentioned spontaneously that they would avoid any disability label for young children, preferring a term such as developmental delay.

Incidentally, not one single respondent ever used the term challenged, as in 'intellectually challenged' in the context of terminology for learning difficulties.

Respondents were asked specifically whether they tended to use different terminology according to who they were communicating with, and whether it was by spoken word or by written report. Two thirds of respondents claimed that they used the same language and terminology no matter who they were speaking with, whereas the other third admitted they would tend to use more abbreviated and category terms when speaking with other professionals.

When writing reports, a majority of respondents said they might use different terms to those they would use when speaking. The most frequently cited reason given was that the Department of Education (and to a lesser extent other service or unit heads) might require a traditional category label such as 'mild mental handicap' for placement purposes.

A majority of our sample seemed to be still quite comfortable with using some categorising or labelling system for distinguishing different levels of learning disability, whereas a sizeable minority of 37% expressed a desire to move away from categorisation (inter-rater reliability - 89%).

Many psychologists (57% - inter-rater reliability 91%) expressed something in their interview answers which indicated they were moving towards a needs-based description.
in their assessments and reports. Within this grouping we included two or three who focused more on the client's lifestyle and quality needs.

**TERMINOLOGY FOR BEHAVIOUR DISTURBANCE.**

In this section we examined psychologists' preferred terminology for behaviour disturbance, again asking for first and second preferences.

Table 2 below lists the first and second preference terms for behaviour disturbance, using the same interview procedure as for terminology for learning disability.

**Table 2. Showing psychologists 1st and 2nd preference terms used to describe disturbed behaviour.**

<table>
<thead>
<tr>
<th></th>
<th>1st preference.</th>
<th>2nd preference.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Challenging behaviour.</td>
<td>50%</td>
<td>20%</td>
</tr>
<tr>
<td>Natural language descriptions.</td>
<td>27%</td>
<td>20%</td>
</tr>
<tr>
<td>Behaviour disturbance or disturbed beh.</td>
<td>13%</td>
<td>27%</td>
</tr>
<tr>
<td>Other terms or specific diagnosis.</td>
<td>10%</td>
<td>33%</td>
</tr>
</tbody>
</table>

As can be seen from the table above, the term *challenging behaviour* is clearly the most preferred term among our sample, but as for learning disability terms, there is a significant and probably growing number who want to avoid any labelling terms, and so choose to use natural language descriptions.

This trend was reflected in the qualifications, comments and reservations psychologists made during the open-ended interview section, and which we recorded. Of our total sample, 17% disapproved of the word 'challenging', 10% mentioned their dislike of any labelling terms, and 7% disapproved of behavioural-style language.
ASSESSMENT STYLES AND APPROACHES.

The main finding concerning assessment styles was that psychologists use a great variety of approaches to assessment, use of tests and style of reporting. Even if two psychologists were using the same tests and assessing similar client groups, the resulting assessment reports could be very markedly different in style, focus and content. We tried to focus here on some of the more easily measured aspects of assessment, such as tests used, length of report, and whether mental ages or levels of handicap were reported, but this research approach cannot do proper justice to expressing the range and subtlety of changing styles of psychological assessment in the area of learning difficulties.

TESTS USED.

The detailed results of the most frequently used tests used by psychologists in the area of learning disability can be found in the Appendices (page 117). The old and new versions of the Wechsler Adult and Child Intellectual Scales, and the old and new versions of the Stanford-Binet Scales, and the Griffiths Scales, together accounted for 69% of the most frequently used tests for psychometric assessment. The other 31% of most frequently used tests was taken up by the Bayley Scales, the Psyche Cattell, the New Vineland Test, the Merrill Palmer Scales, the British Ability Scales the Leiter Test and others.

For assessment of social competence, we found that 30% of respondents used no formal test or scale at all. Instead this 30% relied on informal methods such as a sample of questions to parents or care staff, or observation during testing. The other 70% who used more formal measurement of social competence indicated that Vineland Social Competence Scales (old or new versions) together with the Adaptive Behaviour Scales (American Association on Mental Deficiency) were the two most frequently used social competence scales. The details of scales of social competence frequently used by psychologists are on page 118 in the Appendices.

Despite expressing misgivings and reservations about assessments of intellectual ability
and social competence, no psychologists in our sample said that they never carried out such assessments. But a number emphasised that they used other assessment approaches, and these are listed below in order of frequency of mention, in a free response answer to the question “Do you use other methods with significant frequency?” (other than assessments of IQ and social competence).

Table 3. Showing categories of assessment approaches (other than IQ and Social Competence measures) used with significant frequency by psychologists.

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>OBSERVATION (e.g. of play, or at home)</td>
<td>41%</td>
</tr>
<tr>
<td>BEHAVIOURAL (e.g. functional analysis)</td>
<td>20%</td>
</tr>
<tr>
<td>ENQUIRY (e.g. with school, care staff or parents)</td>
<td>20%</td>
</tr>
<tr>
<td>OTHER (e.g. by drawings, Gentle Teaching)</td>
<td>14%</td>
</tr>
<tr>
<td>LIFESTYLE (quality of life assessment)</td>
<td>5%</td>
</tr>
</tbody>
</table>

(Inter-rater reliability 83%)

For general assessments, not including ongoing support and counselling, psychologists were asked how many appointments they would usually and typically give to each client.

The mean number of appointments for an assessment was 2.6 appointments.

The range was from 1 to 5 appointments (as usual practice) and the mode was 3.
REPORT-WRITING.

Having established the main approaches to assessment, and some of the tools and techniques which are used in the process, we were also interested in the practices in writing up the psychological reports produced on the basis of these assessments. We asked how long they were, whether IQ figures, Mental Ages or levels of handicap were quoted, and how much background information was provided.

Based on respondents own estimates of their typical and usual reports, the mean length of a psychological assessment report about someone with learning difficulties was 2.2 sides of A4 paper. The range of usual report length was from 1.5 to 3.5 sides, bearing in mind that a psychologist might still produce a much longer report in unusual circumstances e.g. for court. The mode was 2 sides of A4 paper.

The mean number of headings or sections within a report was 3.9 sections. The range was from 2 to 7 sections and the mode was 3 sections.

For background history and introductory information in reports, 37% of respondents said they included a good deal of background information, 60% said they included some background information, and the only psychologist who said he included no background information explained that a social work report always accompanied his own report in his service.

Only two psychologists in our sample quoted I.Q.s in their reports with any frequency, giving a freedom of information rationale for so doing. There were nearly a third who would typically tend to quote a Mental Age or Developmental Index in their reports, whilst over two thirds would not quote Mental Ages in their reports.

A solid majority of 87% of psychologists usually do quote a level of disability in their reports. A minority would not quote levels of disability any more in their reports.
Reports have become longer. An examination of 30 psychological reports on people with learning difficulties from 7 to 12 years ago in the N.W. of Ireland Health Board region revealed that **the average length of report used to be 1.3 sides of A4. Now, the average length is 2.2 sides of A4**.

A final open-ended question within this section was to ask what direction respondents were moving in and could they predict what assessment style or approach they might be using in five years time. The results to free response answers to this question indicated that 17% did not know in which direction their assessment practices were heading, or they thought it would be the same as at present. But 23% gave a response indicating they were moving towards a needs-based style of assessment and report. A further 40% of respondents gave a response along the lines of assessing/considering the client in the context of the family or society or specific environment, and/or focusing on lifestyle and quality of life. Another 20% gave a response which we can only classify as "Other", e.g. greater awareness of litigation, becoming more concise, aspiring to improve. (Inter-rater reliability - 87%).

**TRENDS.**

Some trends emerged quite clearly from our data. Increasing numbers of psychologists are uncomfortable with stated measurement and categorisation of their clients' (dis)abilities. At the same time, some form of assessment of clients' social competence has become fairly prevalent. A majority of psychologists themselves were saying that they were moving towards an approach which considered the client in terms of their needs within a specific environment or context. General impressions were that reports are tending to become longer, more descriptive and less categorical in both senses.

Despite this the information on current practice indicates that psychologists are not yet
rejecting traditional approaches which measure a person’s abilities, though it is possible these methods are being broadened and adapted to current perceived needs.

ACCESS TO REPORTS.

In this section the aim was to find out what our psychologist-respondents' practices and attitudes were on the question of clients' access, or more typically, parents' access to psychology reports, assessment results, files and case conference minutes. On the first item, psychology reports, Table 4 below shows the percentages of different frequencies of access.

Table 4. Percentages of psychologists who provide parents with reports, at the frequency level stated.

<table>
<thead>
<tr>
<th>Psychologists who routinely or nearly always give access to report.</th>
<th>30 %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychologists who frequently give access to psychology report</td>
<td>30 %</td>
</tr>
<tr>
<td>Psychologists who rarely give access to psychology report</td>
<td>13 %</td>
</tr>
<tr>
<td>Psychologists who never give access to psychology report</td>
<td>27 %</td>
</tr>
</tbody>
</table>

(Inter-rater reliability - (97%))

This issue seems to split psychologists between the 60% who frequently or routinely give psychological reports to parents, as against 40% who rarely or never do so.
There were 44 free response comments about access to psychological reports, of which 23% concerned how increased access would affect the way they would be written, 20% mentioned the need for departmental or service consensus before greater access could be given: a further 18% mentioned access as a right or entitlement of the client or parent, and 9% mentioned strong reservations about report access in the cases of abuse or neglect. The remaining comments were 'other' amounting to 30%, and including the following, "Future access is scary", "Everyone is in favour of open access", "There's a need to be flexible". (Inter-rater reliability for the above - 83%)

When asked about trends, 87% of respondents indicated that they were moving towards a greater degree of access to psychological reports, whereas 13% did not feel that they were (inter-rater reliability - 93%).

**Assessment results.** Assessment results were taken to mean broad disability category and explanation of its significance: hardly any psychologists made available the actual test score results in any form.

All psychologists said they gave parents verbal feedback on assessment results to the parents, and just under half said they also gave written feedback in that parents were usually given a copy of the psychological report.

**Access to psychology file.** Only one psychologist said she would willingly make available a child's psychology file to parents, but 40% said they would do this by special request. At the time the survey was carried out, the Freedom of Information Act 1997 was still two years away, so people were unaware that they might be obliged to provide access on request.

**Minutes to case conferences/reviews.**
Here again professional practice and service policy seemed to be split on whether to provide parents and clients with minutes to case conferences and reviews. Just under half said that they rarely or never provided case conference minutes, and just over half said
they frequently or routinely provided case conference minutes. Three points mentioned in the free responses to this question were:

1) that it might depend on whether the parents or client attended the case conference.
2) that any decision about provision of minutes was rarely within the remit of the psychologist alone.
3) that in cases of abuse or neglect there might be legal issues about written minutes going to the subjects of an enquiry.

**Attendance at case conferences/ reviews/ placement meetings.**

On this issue we were aware that there can easily be a discrepancy between a psychologist's opinion on the matter and the actual reality in their service, so we asked two questions:

1) What did the psychologist believe should happen with regard to client/parent attendance at case conferences? and,
2) What was the actual current practice in their service? The responses are summarised in Table 5 below.

**Table 5. Discrepancy between who should attend and who actually does attend.**

<table>
<thead>
<tr>
<th>% response to the question “Should clients/parents attend case conferences?”</th>
<th>% response to the question “Do parents/clients actually attend case conferences?”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attendance SHOULD BE routine 77%</td>
<td>ACTUALLY IS routine 30%</td>
</tr>
<tr>
<td>Attendance SHOULD BE frequently 20%</td>
<td>ACTUALLY IS frequently 17%</td>
</tr>
<tr>
<td>Attendance SHOULD BE seldom 3%</td>
<td>ACTUALLY IS seldom 53%</td>
</tr>
</tbody>
</table>

(Inter-rater reliability - 93% and 100%)
Clearly, there was a discrepancy between what psychologists would like to have seen happening, and what was actually happening currently in their services.

One third of respondents mentioned at some point in their free responses that the professionals had rights to have their own meetings, or needed time and space to discuss a case. At the same time, three quarters of respondents had said that parent/client attendance at meetings should happen routinely.

We went on to ask about the process of decision-making especially with regard to the placement of a child or adult client. Again we made a distinction between how psychologists thought such decisions should be made, and how they felt such decisions were actually made. The table below shows psychologists' perceptions on this.

**Table 6a. Showing respondents opinion about who should be the main decision-maker(s) ?**

| Professionals' team and parents and client through discussion. | 53% |
| Professionals' team should have the main say. | 13% |
| Parents or clients should have the main say. | 34% |

(Inter-rater reliability - 93%)
Table 6b. Showing respondents’ opinion about who actually seemed to be the main decision-maker(s) ?

| Professionals' team actually had the main say. | 42% |
| Professionals' team and parents/clients actually had main say. | 29% |
| Professionals' team and service directors or school board. | 29% |

(Inter-rater reliability - 97%)

As for attendance at case conferences, there is a discrepancy between psychologists’ opinions about how placements decisions really should be made and how they perceive decisions are actually made. For both work practices the difference is in the direction of parents and clients having less involvement in these processes than they should have, in psychologists’ opinion. It is speculated that psychologists may feel constrained by the agencies within which they work, or by systems which accord more power to professionals than should be the case. But it is also possible that psychologists themselves bear an equal responsibility for this discrepancy between what should be and what actually is perceived to be the decision making process.

Respondents were asked to predict how their working practice would be in five years time with regard to parent/client involvement.

**Overall 63% of psychologists anticipated that in five years time there would be greater involvement of parents and clients in the case conference and decision-making process.** (Inter-rater reliability 93%)
If this is a reliable finding and prediction, it might indicate that psychologists are on the right track in believing there should be more consumer involvement than is actually the case.

Some representative quotes of respondents on these issues are listed below.
"The psychologists' role is not to decide, but to give clear information."
"The psychologists' role is not to make decisions, but to present choices and support parents' choices."
"The psychologist's role is as a facilitator."
"The psychologist's role is like a consultant."
"Our role will depend on fitting in with increased parent/client power."

DATABASE REGISTERS.

In answer to the question "What is your opinion about clients being listed on a mental handicap database register?" the psychologists could be categorised into three broad groups on the basis of their responses:- 1) Broadly positive towards database registers- 27%, 2) Mildly positive towards database registers, but holding one or more major reservation- 60%, and 3) Negative, being against the holding of learning disability database registers- 13%.

This issue elicited a total of 64 comments which we have summarised below, having split them first into either broadly positive or broadly negative comments.
Table 7. Disadvantages or Reservations about Databases

<table>
<thead>
<tr>
<th>Concern</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concern about client CONFIDENTIALITY</td>
<td>35%</td>
</tr>
<tr>
<td>The aspect of client or parental CHOICE about being on a database</td>
<td>14%</td>
</tr>
<tr>
<td>Concern over ILLEGITIMATE USE of database information</td>
<td>11%</td>
</tr>
<tr>
<td>Concern over CRITERIA OF INCLUSION in a database especially re those with only mild learning difficulties</td>
<td>11%</td>
</tr>
<tr>
<td>BIG BROTHER is watching you concerns</td>
<td>5%</td>
</tr>
<tr>
<td>OTHER CONCERNS e.g. monitoring it, a form of labelling</td>
<td>22%</td>
</tr>
</tbody>
</table>

(Inter-rater reliability 83%)

Table 8. Advantages or benefits of a database

<table>
<thead>
<tr>
<th>Advantage</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>SERVICE NEEDS and even rights e.g. to be able to PLAN</td>
<td>63%</td>
</tr>
<tr>
<td>Indirect BENEFITS TO THE CLIENT</td>
<td>15%</td>
</tr>
<tr>
<td>OTHER ADVANTAGES e.g. research, budgeting</td>
<td>22%</td>
</tr>
</tbody>
</table>

(Inter-rater reliability 90%)
SERVICE EVALUATION.

In answer to the question, "What is your opinion about service evaluation in the mental handicap service? In particular, what do you think about evaluating the input of psychologists in this area?" all the psychologists but one were broadly positive about evaluation. Half were strongly positive and half were mildly positive, holding one or more major reservation about evaluation. Some reservations are quoted below.

"Mental handicap is too emotive an area for evaluation."
"Management can abuse it." (evaluation)
"You tend to get output getting measured instead of quality."
"People with learning disability don't get better so how can you measure outcomes?"

GENERAL CONCLUSIONS AND TRENDS.

One general conclusion can be made at the start, from taking all the findings together, and it is that there is a very great range and variability in terminology, work practices, attitudes and philosophies. It is felt that this will make the psychology profession better able to respond to changing times and changing needs and demands from the service users.

A significant percentage of psychologists are moving towards a more needs-based approach to assessment and intervention, with a greater focus on strengths and lifestyle, and many psychologists are moving away from the traditional diagnostic and categorical approach. Psychology assessments and reports have become longer and may be becoming more descriptive and less categorical. There may be increasing ambivalence about use of IQ figures and Mental Ages, but there are no signs of rejection of the assessment process itself. It is speculated that there is more diversity of approaches and no single prevailing
model of learning disability.

Psychologists may be moving faster than their employing agencies in the direction of providing clients with more access to reports, information, meetings and the whole decision-making process, but there remains a good deal of ambivalence and reservations about this trend.

There is also acceptance with reservations about some of the service trends of the last decade, including service evaluations and the use of computer databases.

**HOW THE RESEARCH INFLUENCED CLINICAL PRACTICE.**

The findings of this study were presented over two sessions at the monthly staff meetings of the Psychology Department where I work, and this stimulated discussion and thoughts on the issues covered. The study was also presented over a full morning at a one-day workshop attended by about forty psychologists at a conference arranged by the Psychological Society of Ireland Mental Handicap Group, and it was received with great interest there. A written summary of the main findings was circulated to all thirty participants in the study, and a further forty or so copies went to other interested parties on request. The way this study influenced working practices is necessarily impressionistic, but some of the developments that occurred are outlined below.

**Terminology for mental handicap and challenging behaviour.**

Within our own psychology department most psychologists had already been moving away from the term "mental handicap" towards the terms "learning disability" or "learning difficulty", and our research findings seemed to speed up this process. Paradoxically, at the same time it seemed to influence our staff into feeling confident about using a wider variety of terms, including natural language descriptions, because the survey had indicated that there was no "gold standard" for mental handicap terminology.
When we presented our findings to the Psychological Society of Ireland (P.S.I.) Mental Handicap Interest Group there were representatives of the P.S.I. sub-committee for developing agreed recommended terminology in mental handicap. Our findings made their job harder, because we had found wide diversity of terms used and a reluctance among psychologists to be restricted by guidelines in this area.

Six months later, this sub-committee decided that they would abandon the attempt to develop recommended terminology because it was acknowledged that any terms might become quickly out-dated in a period of rapid change.

It is harder to assess how the findings on assessment styles and approach influenced psychological practice. For myself, the results revealed that the very diversity of practices made it more acceptable for me to try out new and different approaches. In particular, I became interested in an approach focusing on lifestyle and quality of life in my work with adults with learning disability. It also made me question why some practices are kept up routinely when there may be little purpose. For example, in my department there was a system of yearly review assessments of older children with significant learning difficulties, often for no clear reasons, and adopting a system of less frequent but more purposeful reviews has led to an improvement in service.

Upon feedback of these results within my own psychology department, the most frequent feeling expressed was one of some reassurance that practices in our own department were reasonably representative of practices in the rest of the country. There had been a perception that practices within the specialist learning disability agencies were more progressive than practices in generic Health Board settings, because the specialist agencies dealt full time with learning disability, carried out more research and seemed to have better facilities. In fact the present study indicated there were very few differences between generic and specialist services in their psychologists’ work practices.

For myself the findings validated my own preference for direct and clearly understood terms such as "disability" and "behaviour disturbance", but also heightened my awareness
that a majority of professionals now prefer the gentler, more sensitive terms such as "learning difficulty" and "challenging behaviour". I now use a greater variety of terms than before.

**Partnership with parents of children with learning disability.**

Within our three-county health board area there had been increasing pressure from parents' groups such as Down Syndrome Association for greater involvement in the assessment and decision-making process for provision of specialist services for children. Specifically, parents wanted copies of psychological reports and they wanted to be present at any important case conferences or placement meetings concerning their children. As outlined in the Introduction, a Key Stage Review system was developed in which parents attended a case conference on their child at a key stage such as start or end of schooling, and a full psychological report was prepared for such a conference and given to parents.

At the start psychologists in our department were ambivalent and apprehensive about complying with a Key Stage Review system because there had been no tradition of giving psychology reports to parents and no tradition of parents attending case conferences, even though most psychologists were in favour of such practices in principle.

Our survey indicated that practices according greater rights to parents were operating in other parts of the country with no obvious ill effects, and this made the acceptance of such practices easier within our own department.

The research findings also indicated, to myself at least, that the psychologist's role in decision-making for placements ought to be more circumscribed. It is still usually necessary to have a psychology report recommendation before a person with learning disability may be placed within special education or a special day/training placement. But psychologists tend to believe in greater client/parent rights in both the assessment process and the decision making. These findings have influenced myself towards taking a role in which I provide more
general advice, more supportive partnership and less powerful recommendations.

**Service Evaluation and Database Development.**

In our own department service evaluation and database development have gone hand in hand. The databases have provided us with the means for a more efficient and clear analysis of our work, and this in turn has facilitated service evaluation projects such as a customer feedback survey which two psychologists in our department undertook in 1995, and which I supervised (see page 79).

The present research findings indicated that, despite reservations, psychologists around the country were broadly in favour of such developments. These general findings helped to overcome potential resistance or inertia in our own department and facilitated a feeling that we were "on the right track". Knowledge about the real concerns and reservations psychologists had about database registers and service evaluation has enabled these issues to be raised at my own psychology department meetings, where they have been debated openly. There are not always definitive answers to every concern expressed, but open knowledge and debate of the issues helps to put into perspective some of the exaggerated fears.

**Diversity of Practices and Attitudes.**

Finally, the survey in its entirety indicated that there was a wide diversity of clinical practice and attitudes among psychologists in the area of learning disabilities. But it was not the case that "Anything goes". There were clear and strong ethical principles underlying this apparent diversity. The main observable principle was respect for the person with disability, even though this might lead to varied styles of expressing that respect. It is suggested that psychologists may be trying to reach a balance between direct openness about all information and sensitivity towards the needs and feelings of their clients. This tension is reflected in use of terms which range from clinical diagnostic category terms, through more sensitive terms, to a rejection of the use of any terms at all.
which might label a person.

We believe the general diversity found in this study is good and healthy, and will make the psychology profession better able to respond to changing times and changing needs and demands from our customers.

These findings have influenced me to continue questioning my own practice, and to examine the implicit philosophy underlying any particular working model.

In the next section is an outline of most of the courses, workshops, training events and conferences which I attended during the nine year period between my Clinical Masters degree and the present Doctorate of Psychology degree.
<table>
<thead>
<tr>
<th>YEAR</th>
<th>VENUE</th>
<th>COURSE TITLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1988</td>
<td>UCD</td>
<td>Completed M. Psych. Science (Clinical) professional qualification, and returned to my Clinical Psychologist post in NW Health Board, Sligo.</td>
</tr>
<tr>
<td>1988</td>
<td>Portlaoise</td>
<td>Psychological Society of Ireland Annual Conference. I attend the annual conference every year to keep up with developments and meet with friends and colleagues from around the country. 3 day conference.</td>
</tr>
<tr>
<td>1989</td>
<td>St. Patrick's</td>
<td>Workshop on Child Sexual Abuse for psychologists and social workers. Procedures, guidelines, therapy issues and good practices. 5 days.</td>
</tr>
<tr>
<td>1989</td>
<td>Dublin</td>
<td>The Sexual Abuse of People with Learning Disabilities. 1 day workshop.</td>
</tr>
<tr>
<td>1989</td>
<td>Athlone</td>
<td>Psychological Society of Ireland Annual Conference. 2 days.</td>
</tr>
<tr>
<td>1990</td>
<td>Sligo</td>
<td>In service Workshop and Training Course conducted by Tony Humphries covering, Family Therapy, Depression, Stress Management, Relaxation Techniques, and &quot;The Clinical Psychologist at Work&quot;. 1st day.</td>
</tr>
<tr>
<td>1990</td>
<td>Sligo</td>
<td>Tony Humphries Workshop. (See above) 2nd day.</td>
</tr>
<tr>
<td>1990</td>
<td>Sligo</td>
<td>Tony Humphries Workshop. 3rd day.</td>
</tr>
<tr>
<td>1990</td>
<td>Dublin</td>
<td>Workshop on Death and Bereavement. 2 days</td>
</tr>
<tr>
<td>1990</td>
<td>Sligo</td>
<td>Tony Humphries Workshop. 4th day.</td>
</tr>
<tr>
<td>1990</td>
<td>Sligo</td>
<td>Tony Humphries Workshop. 5th day.</td>
</tr>
<tr>
<td>20 Apr</td>
<td>Sligo</td>
<td>Tony Humphries Workshop. 6th day.</td>
</tr>
<tr>
<td>18 May</td>
<td>Sligo</td>
<td>Tony Humphries Workshop. 7th day.</td>
</tr>
<tr>
<td>1 Jun</td>
<td>Sligo</td>
<td>Tony Humphries Workshop. 8th day.</td>
</tr>
<tr>
<td>1990</td>
<td>Dublin</td>
<td>Issues in the Care of People with Learning Difficulties. 1 day.</td>
</tr>
<tr>
<td>1990</td>
<td>Kilkenny</td>
<td>Psychological Society of Ireland Annual Conference. 3 days.</td>
</tr>
<tr>
<td>1991</td>
<td>Dublin</td>
<td>Training Course in use of The Griffiths Scales, and Assessments of Infants</td>
</tr>
<tr>
<td>Date</td>
<td>Location</td>
<td>Event Description</td>
</tr>
<tr>
<td>------------</td>
<td>----------</td>
<td>-----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>20 Feb</td>
<td>NRB</td>
<td>and Children with Special Disabilities. 3 days.</td>
</tr>
<tr>
<td>1991 Sligo</td>
<td>31 May</td>
<td>Communication Skills with Parents, with special reference to the Hanen Programme. 1 day</td>
</tr>
<tr>
<td>1991 Galway</td>
<td>8 Nov</td>
<td>Psychological Society of Ireland Annual Conference. 3 days.</td>
</tr>
<tr>
<td>1992 Derry</td>
<td>27 Mar</td>
<td>Comparison of U.K. Social Services and Learning Disability Services with our Southern Ireland Equivalents. 1 day.</td>
</tr>
<tr>
<td>1992 Donegal</td>
<td>7 May</td>
<td>Family Law. 1 day.</td>
</tr>
<tr>
<td>1992 Dublin</td>
<td>14 May</td>
<td>Neuropsychology. Theory and Assessment Practice. 2 days</td>
</tr>
<tr>
<td>1992 Galway</td>
<td>22 Sep</td>
<td>Recognising Needs and Abilities with People who have a Mental Handicap.</td>
</tr>
<tr>
<td>1993 Donegal</td>
<td>20 Jan</td>
<td>Child Care Act Conference.</td>
</tr>
<tr>
<td>1993 Sligo</td>
<td>13 May</td>
<td>Quality Care. Half day.</td>
</tr>
<tr>
<td>1993 Sligo</td>
<td>11 Jun</td>
<td>Quality Care. Half day.</td>
</tr>
<tr>
<td>1993 Sligo</td>
<td>9 Aug</td>
<td>Computer Training. Word Processing, Databases and Spreadsheets. 5 days.</td>
</tr>
<tr>
<td>1993 Limerick</td>
<td></td>
<td>Empowering People in Services for People with Intellectual Disability.</td>
</tr>
</tbody>
</table>
13 Sep 3 days.

1993 Sligo Research Workshop for Professionals currently engaged in Research within the North Western Health Board. (Organised by myself) 1day.

25 Nov 1993 Dublin Sex Matters. 1 day

22 Apr 1994 Dublin Clinical Audits, Outcome and Output Studies and Service Quality. 1 day.


16 Sep 1994 Killarney Psychological Society of Ireland Annual Conference. 3 days.

25 Nov 1994 Dublin The Philosophy of Learning Disability. 1 day.


10 Mar 1995 Sligo Costing the Halo. Issues of Care for Parents who have a Child with a Disability. Half day.


19 Apr 1995 Dublin Supervisors' Workshop. (Supervision of Clinical Psychologist Trainees) and Clinical Case Formulation.

24 May UCD 1995 Bundoran Psychological Society of Ireland Annual Conference. 3 days.

10 Nov 1996 Donegal Supervisors' Workshop. (Supervision Issues in Child Care and Protection. 2 days.

13 May 1996 Donegal Outputs and Outcome Statistics for Health Professionals. 1 day.

26 Jun 1996 Donegal Quality of Service Workshop. 2 days.
<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 Oct</td>
<td>Waterford</td>
<td>Psychological Society of Ireland Annual Conference. 3 days.</td>
</tr>
<tr>
<td>8 Nov</td>
<td>Dublin</td>
<td>Seminar on Statistical Regression Techniques. 1 day.</td>
</tr>
<tr>
<td>15 Nov</td>
<td>Sligo</td>
<td>Workshop on Qualitative Research. 2 days.</td>
</tr>
<tr>
<td>15 May</td>
<td>Derry</td>
<td>International Conference on Personality Disorder. 2 days.</td>
</tr>
<tr>
<td>23 Sept</td>
<td>Ennis</td>
<td>Psychological Society of Ireland Annual Conference. 3 days.</td>
</tr>
</tbody>
</table>
Question 1

Theme: Terminology

Open Question: What terms for mental handicap do you habitually use? If you use more than one term, could you give both your first and second preference terms.

Probe: Do these terms differ if you are communicating with the following:

(a) Parents or the clients themselves
(b) Other Psychologists
(c) Nurses or teachers
(d) Written report form
(e) Other

Open Question: Do you have any general comments to make about your use of terms for learning disability/mental handicap?

Open Question: Do you feel you are moving/have moved in any particular direction in your use of terms?

Key Code:

Person : with (a) : General : Learning Difficulty
People : has (a) : Mild : Learning Disability
Sean : is : Significant : Mental Handicap
Mary : scored as : Moderate : Intellectual Disability

:Severe

:Profound
**Question 2**  Maximum 4 minutes

**Theme:**  **Challenging Behaviour or Behaviour Disturbance**

**Closed Question:**  What terminology do you prefer to use in this area of disturbed or challenging behaviour? If you use more than one term, please give your first and second preference terms.

**Open Question:**  Do you have any general comments to make about your use of terms for challenging/disturbed behaviour?

**Open Question?**  Do you feel you are moving/have moved in any particular direction in your use of terms?

**Key Code**

(1)  Person with challenging behaviour  
(2a)  Person with disturbed behaviour  
(2a)  Person with behaviour disturbance  
(3)  No term at all. Describe behaviour.  
(4)  Other

**Question 3**  Maximum 6 minutes

**Theme:**  **Style and Content of Assessment and Reports**

**Open Question:**  Could you tell me about your usual or typical style of assessment and report in the context of intellectual disability/mental handicap?

**Probe & Key: - Assessment**

a)  Do you use standard I.Q. tests (W.A.I.S-R, S-B)?
b)  Do you usually examine level of social competence? If so, how?  
c)  Do you typically assess within a behavioural framework  
d)  Do you typically examine for degree of behaviour disturbance or challenging behaviour?  
e)  Do you use other methods with significant frequency e.g. assessment by observation or through play or by work skills

Number of appointments or sessions for assessment purposes?  
Parents usually present or absent?  
Usually do you include visit to School/Day Centre/Workplace or home.

**Probe & Key: - Reports**
Do you typically include a) a good bit of background information
b) more than 3 sections (Background Assessment Recommendations)
c) Level of handicap/disability 
   i) by special needs only
   ii) by broad level of handicap (No I.Q or M.A)
   iii) by level of handicap including I.Q. figures or M.A
   iv) Some other method

Length of report: How many sides of double spaced A4 sides?

Open Question Are you moving in any particular direction in your style or practice of carrying out assessments and writing reports?

Question 4 Maximum 5 minutes

Theme: Access to reports, files, security,
Confidentiality and being on a register

Open Question 1: Please tell me where you stand on the issue of clients and/or parents having access to their own files, psychology reports, assessment results and minutes of case conferences or reviews.

Key Code 1 ROUTINE ACCESS BY ACCESS OTHER
             ACCESS REQUEST ONLY DENIED

Psychology file
Psychological Report
Assessment Results
Verbal feedback
Copy of Minutes

Other
(a) Distinction made between those with a moderate, severe or profound disability as against those with a mild, borderline or specific learning disability?
(b) Distinction between subjects real opinion as against dept, policy and their own practice.

Open Question 2: What is your opinion about clients being listed on a mental handicap register?

Key Code (1) No Mental Handicap register should be kept
            (2) Clients should have choice to be listed or unlisted
(3) Boards or agencies should have right to compile register

Does your agency have such a register?

**Question 5:** Maximum 6 minutes

**Theme:** Clients and/or Parents attending case conferences, reviews, placement meetings, and degree of involvement in the decision making

**Open Question 1:** Could you explain roughly where you stand on the issue of parents and/or clients attending case conferences, reviews or placement meetings?

**Open Question 2:** Where do you stand on the issue of parents or clients rights to decide on or choose the placement, as against professionals duty to select the most appropriate placement or services for the client? How should decisions get made?

**Open Question 3:** How do decisions actually get made in your services?

**Code Key:** QI

ROUTINELY ATTEND RARELY
INVITED TO BY NEED OR NEVER INVITED
ATTEND OR REQUEST INVITED

Case Conferences
Placement Meetings

Review Meetings
Programme Planning

a) Distinction between procedures for children as against procedures for adult clients?

**Open Question** Are you moving in any particular direction with regard to the case-conferencing and decision-making process? How do you think your practice will be in five years time?

**Question 6:** Maximum 4 minutes
Theme: Service Evaluation Quality Control, Clinical evaluation of psychologists' input

Open Question: What is your opinion about service evaluation and quality control in mental handicap services? In particular what do you think about evaluating the input of psychologists in this area?

Probe/Coding key:

Is there any service evaluation or quality control being carried out where you work?

General attitude: Broadly positive, mildly positive, broadly rejecting, mildly rejecting, Other e.g. no knowledge of.

Number of problems mentioned:-

e.g. Who would do it? Some things can't be measured
     Haven't the time. What would you evaluate?
Table 9. Ability Tests in frequent use by psychologists.

<table>
<thead>
<tr>
<th>TEST INSTRUMENT</th>
<th>Percentage of total no. of times mentioned</th>
</tr>
</thead>
<tbody>
<tr>
<td>W.A.I.S. (R) or W.I.S.C. (R) or III</td>
<td>27 %</td>
</tr>
<tr>
<td>Stanford-Binet (L-M)</td>
<td>24 %</td>
</tr>
<tr>
<td>Griffiths MDS</td>
<td>13 %</td>
</tr>
<tr>
<td>Bayley Scales</td>
<td>6 %</td>
</tr>
<tr>
<td>Cattell</td>
<td>5 %</td>
</tr>
<tr>
<td>Stanford-Binet (1988)</td>
<td>5%</td>
</tr>
<tr>
<td>New Vineland</td>
<td>5%</td>
</tr>
<tr>
<td>Merrill Palmer</td>
<td>4%</td>
</tr>
<tr>
<td>B.A.S.</td>
<td>4%</td>
</tr>
<tr>
<td>Other e.g. Leiter</td>
<td>6%</td>
</tr>
</tbody>
</table>
Table 10. Social competence scales in frequent use by psychologists.

<table>
<thead>
<tr>
<th>Social Competence Scale</th>
<th>% of total no. of times mentioned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vineland old or new</td>
<td>35 %</td>
</tr>
<tr>
<td>Adaptive Behaviour Scales (A.A.M.D.)</td>
<td>18 %</td>
</tr>
<tr>
<td>Pathways to Independence</td>
<td>9 %</td>
</tr>
<tr>
<td>P.I.P. charts</td>
<td>9 %</td>
</tr>
<tr>
<td>P.A.C.</td>
<td>9 %</td>
</tr>
<tr>
<td>Others</td>
<td>18 %</td>
</tr>
</tbody>
</table>
SECTION THREE.

RESEARCH STUDY ONE.

COMMUNITY CONTACTS AND NEIGHBOURS’ EXPERIENCE OF GROUP HOMES FOR PEOPLE WITH MENTAL HANDICAP.

National University of Ireland.
University College Dublin,
Belfield, Dublin 4.
Department of Psychology.

Thesis submitted in part fulfilment for the degree of
Master of Psychological Science (by clinical specialisation)


M. Psych. Sci. (Clinical) Course Organiser:
Therese Brady, Department of Psychology.
Community Contacts and Neighbours' Experience of
Group Homes for People with a Mental Handicap

Stephen Ronald Clarke

SUMMARY

In this doorstep questionnaire survey 200 people were interviewed in four housing estates in Dublin to investigate community contacts and neighbours' attitudes towards group homes for people with a mental handicap. Two areas had had such a group home for two or more years and two were treated as "prospective" areas for opening a group home. Areas of private housing were compared with corporation estates, and basic demographic information was obtained.

Neighbours were questioned about their involvement in the community, knowledge of the group home, contact with people with a mental handicap, group home contacts, experience or anticipation of problems and benefits from the group home, willingness to become more involved and attitudes towards community care policy.

A significant proportion of respondents were unaware of the existence of the group home, or that it was for mentally handicapped people.

The "prospective" areas anticipated many more problems than the actual group home areas had experienced. Neighbours expressed more concern for the welfare of the mentally handicapped residents than for the neighbours themselves.

Residents and staff of the group homes appeared to have little interaction with their immediate neighbours, but 25% of neighbours expressed an interest in becoming more involved.

Personal characteristics, such as age, sex and education, did not seem to be related to attitudes towards the group homes, but people with previous experience of voluntary work especially with mentally handicapped people were more likely to offer help.

The implications of the study were considered in the light of the implementation of community care policy.
FOREWORD

This project was initiated on the suggestion of Dr. Roy McConkey who has been working in the field of attitudes towards people with a mental handicap for some years. I had been determined to do my research thesis in an applied area which would be of practical use and interest to an agency, and so had approached St. Michael's House asking how I could be of use to them rather than vice versa.

Of the charity bodies operating in Ireland, St. Michael's House is the largest agency in the field of mental handicap, and was able to provide me with nearly all the necessary resources which included computer access, specialist library and photocopying facilities. The co-operation of the professional staff of St. Michael's House at all levels greatly facilitated the progress of this project.

The survey described in this thesis was confined to four housing areas within Dublin because of constraints on my time and residence, but from the outset Dr. McConkey was keen that it could be extended to include rural and provincial town locations both in the South and in Northern Ireland. In fact, this came about through the help of other agencies and volunteers to the extent that it became a nationwide survey with over 1,500 respondents. The broad pattern of results of this nationwide survey seemed to be very similar to my own findings from the Dublin data, but the nationwide results cannot be given here as I was not directly involved in that work.
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INTRODUCTION

Deinstitutionalisation Movement

Over the last two decades the main trend in residential facilities for people with mental illness or mental handicap has been away from the ward setting within institutions and towards smaller hostels or group homes. This process of deinstitutionalisation can be traced historically in terms of the changing relationship between hospital and society during the 1930s to the 1950s, during which time the barriers became more permeable (Bennett and Morris 1983). Day care and outpatient facilities became established in this period, the population of psychiatric hospitals started to decline, and acute patients spent briefer spells of time in hospital.

During the 1960s and 1970s this process was accelerated by the influence of the work of Goffman (1961), Wolfensberger (1972), Blatt and Kaplan (1966) and Morris (1969) who described the negative features of institutions and the impact of the institutional regime on those who live in them. During the 1960s day-care attendances for those with a mental illness or mental handicap rose in Britain by 250% between 1963 and 1970, and the number of patients in extramural community care rose by 280% (Bennett and Morris 1983).

Quality of Life and Group Homes

There is strong evidence that individuals who change from a larger institutional setting to a group home environment do indeed show marked improvements in a variety of adaptive skills including receptive language, domestic skills, appropriateness of behaviour, meaningful activity and community orientation (Felce et al. 1985, Thompson and Carey 1980, Alexander, Huganir and Zigler 1985). These studies lend qualified support for the claim that group homes provide better "quality of life" for residents than do larger institutions, the qualification being, it depends on how you define quality of life.
The Campaign for Mentally Handicapped People have used a 25-item checklist (Tyne 1981) examining aspects such as basic daily requirements, special requirements, personal identity including culture, surroundings, rights of privacy, relationships, activities and communication. The P.A.S.S. analysis of Wolfensberger and Glenn (1975) is probably the most widely known method of critically examining the quality of services using normalisation criteria.

The umbrella term "normalisation" refers to the assumption that the more normal the environment is, the more normal the pattern of life will be, and the more satisfying the quality of life will be for the individual. Measures of normalisation, though difficult, are still much easier to obtain than, for example, measures of individual contentment or personal fulfilment. Not surprisingly, using normalisation criteria, group homes emerge as preferable to larger institutions, but in some ways this still begs the question about quality of life.

Community Care

The changes in terms of quality of life which occurred within institutions during the 1960s were welcomed as progressive and beneficial. But they still did not come up to the requirements of the principles of normalisation (Wolfensberger 1972) and the aims of the community care movement which were being more clearly formulated in the early 1970s. The assumption and expectation of the community care movement is that the environments of people with handicaps should, as far as possible, reflect normal community life, and that forms of institutional care that segregate them are unacceptable.

It should be noted that among professionals who do understand the meaning of and implications of community care, there is not total acceptance of the advisability of severely and multiply handicapped individuals living in the community. Some professionals (e.g. Ellis et al. 1981) maintain that community placement does not necessarily
enhance the behavioural skill development of people with a mental handicap, nor significantly improve their quality of life. They fear community placement may constitute a "serious injustice" to residents' safety and well-being, with conditions that could be as restrictive as those in the institution.

Some confusion has arisen from the tendency to equate community care with the location of residential facilities in the community. Obviously a good model needs to specify the nature and objectives of the care to be provided. It cannot be assumed that hostels or group homes will provide an acceptable quality of life for their residents merely by being located in the community. Nor does location within the community necessarily imply being part of the community.

The term "community" is often used loosely in the literature within the field of mental handicap. To many sociologists it implies a cohesive interactive group holding common values, interests and beliefs (Okolo and Guskin 1984), and within this narrower definition many group home residents could not claim to be part of the community. Within this study a broader use of the term community will be used to embrace location, all residents and facilities, and their interactions and attitudes.

There is evidence that the public's knowledge of and attitude towards community care has lagged behind the actual developments that have taken place within the professional field. The U.K. government report, "Better Services for the Mentally Handicapped" was issued in 1971 and stressed the need to shift the care of people with a mental handicap from the hospital to the community by providing support for those still within their family or by establishing small group homes. Locker, Rao and Weddell (1979) found that only 39% of their sample had heard of the term "community care" in 1977. In a follow-up survey in 1980 this figure had increased to 50% but only an average of 30% of respondents could provide an adequate definition of community care in both surveys (Locker, Rao and Weddell 1981).
Attitudes to People with a Mental Handicap

One of the first points to note is that there is a lot of confusion between mental handicap and mental illness. In one recent study (Watson 1987) an alarming 50% of respondents felt that "mentally ill" was a suitable alternative to "mental handicap", and other studies have found a lot of indirect evidence for widespread confusion between mental illness and mental handicap (Weir 1981, MENCAP 1982). This may be surprising to those of us who have spent a long time working within these fields, but most people have had very little contact with either mentally ill or mentally handicapped individuals (Welsh 1986). In an abstract way there is a lot of public sympathy for people with mental handicap and most feelings towards them are positive (MENCAP 1982). In that study, "70% were sympathetic towards the mentally handicapped (and, indeed, the mentally ill), and nearly half felt acceptance, friendliness and kindness towards them". (p.ii). Women, more than men, tended to see them as child-like, affectionate, happy and strong.

Those from social class group A and B and those who had a relative with a mental handicap tended to be more aware of the realistic problems that people with a mental handicap face, but they were also more positive about their ability to work, manage on their own, their emotional needs and their legal rights.

Altman (1981) reviewed evidence that people with disabilities are in general often stereotyped as isolated, dependent, depressed and emotionally unstable, and the confusion of mental handicap and mental illness has given rise to a strong association of unpredictability, instability and dangerous behaviour with mental handicap. Many of these confused stereotypes are just as unfair to those with a mental illness, of course.

Furnham and Pendred (1983) examined lay people's attitudes towards those who have a disability as a function of whether it was observable (visible) or not. People's attitudes were consistently more
positive towards physical disability and they speculated that unfamiliarity, fear, difficulty in empathy and lack of understanding contributed towards negative attitudes to people who have a mental handicap.

Contact with People who have a Mental Handicap

In Ireland roughly 4 per 1,000 adults have a mental handicap so that in a town of 15,000 population there might be expected to be 60 adults with mental handicap (McConkey, Walsh and Mulcahy, 1982). About half of the population have never met a disabled person and about three-quarters have never met a mentally handicapped person (McConkey 1987). Only about 8% reported being in regular contact with a mentally handicapped person compared with about 15% who had regular contact with a disabled person.

In 1981 in Ireland roughly half of all adults with mental handicap were still living in institutional settings, which probably decreases the chances of contact within the community (Mulcahy et al. 1983). In one survey, where two areas were chosen deliberately because a service for people with mental handicap was located in each, over half the neighbourhood residents did not know of the existence of the day centre (McConkey 1987).

Most studies support the common assumption that the more exposure to or contact with people who have a mental handicap the more favourable the attitudes, but some research has found no such connection (Furnham and Pendred 1983, Sendler and Robinson, 1981). Two studies examining professional staff’s attitudes found that contact with handicapped people prior to training was an important factor in promoting favourable attitudes (Bell 1962, Whitby 1986).

Most studies involving children have found that more contact leads to more positive attitudes (Voeltz 1980) but McConkey and McCormack (1983) and Gottlieb (1975) note that the quality of contact in terms of successful interactions is more critical than the quantity.
of contact.

Contact has been examined in terms of neighbours' distance from a group home, but with equivocal or contradictory results, and much seems to depend on the nature of the group home and the actual experience of the neighbours, whether close or distant (Okolo and Guskin 1984).

McConkey (1987) summarises studies which suggest that the public at large tend to avoid more personal contact with people who have a mental handicap, but are more tolerant of impersonal contact such as seeing them in the neighbourhood. The other way of looking at contact is from the point of view of the people with mental handicap. McConkey, Walsh and Mulcahy (1982) looked at the life styles of adults with mental handicap living within the community, in most cases with their own family, most of whom were capable of looking after all their personal needs. But their general life style, their leisure pursuits and their community contacts were very limited. It was concluded that to a large extent they were "home and family" bound and that this hardly counted as community care.

In a further study McConkey, Naughton and Nugent (1983) examined the community contacts of adults attending day workshops for people with mental handicap. The number of community contacts seemed initially encouraging, with most occurring in the local neighbourhood, fewer in the city and least of all at home. But there were only three groups of people with whom the majority had recent contact – local shopkeepers, bus conductors and chemists. Furthermore, most contacts were made either alone or accompanied by a family member, but rarely with a friend or within a social group. Community living did not seem to be very meaningful for the majority of respondents in this survey.

Attitudes towards Community Care of People with Mental Handicap

Given that the world trend in services for people with a mental handicap is towards normalisation and community placement, what are the attitudes and reactions of the community on this issue? The answer seems to be, it depends on who you ask, which community, how you
frame the question and a number of other factors which are considered below.

A distinction can be drawn between a general attitude a person may hold in favour of people with mental handicap living in the community and a specific attitude that the same person may hold about people with mental handicap living in his neighbourhood or his street. Agreement to a general principle does not necessarily imply agreement to its implementation if seen to threaten an individual's own living space or sphere of operation. This raises the question of the tenuous relationship between attitudes and behaviour and the question of cognitive consistency as against "opinion molecules" (Bem 1970, Festinger 1957).

Most survey polls carried out in the last fifteen years have reported between 60% and 95% of the population being in favour of people with mental handicap living in the community (President's Committee on Mental Retardation (1975), Kastner et al. (1979) MENCAP (1982)). Some of the differences in percentage reflect differences in wording, number of alternatives or the presence of a "don't know" category.

A few studies have compared a control group with a "threat" group in order to establish the relationship between theoretical agreement and actual agreement. In one such study (Kastner et al. 1979) the threat group consisted of 5 to 12 households close to a house that was actually for sale, and respondents were asked for their views on community placement if the Group Home was established in the sale house. A control group matched the threat group on basic demographic variables. Modest but significant differences were found. For example, 90% of the control group said they would not object to a group home in their neighbourhood but this was dropped to 81% for the threat group. Kastner et al. speculated that this figure might have dropped further if respondents in the threat group had been told that the house for sale would definitely become a group home.

Two other studies in the States used a realistic "threat" condition, this being whether landlords would accept mentally handicapped
tenants (Trippi, Michael, Colao and Alvarez 1978), Margolis and Charitonidis 1981). In both studies an initial phone call established that an apartment was available for rent and a subsequent call half an hour later was made in which the landlord was told that the interested tenant was "a mentally retarded adult who had just completed training and was ready for independent living". In the 1978 study (Trippi et al.) only 1% of landlords proved willing to rent whereas in the 1981 replication (Margolis and Charitonidis) in a different part of the county 72.5% were willing to accept a mentally retarded tenant.

These dramatically different results probably did not so much reflect attitudes becoming more favourable during 3 years, but probably did reflect enormous differences in regional and neighbourhood variables, changes in the housing market and wording and presentation of the questions.

But there is some evidence that attitudes towards people with mental handicap and community care have become significantly more positive. Locker Hao and Weddell (1979) examined community reaction to a group home in 1977 3 months before it opened, and then compared the results with a follow-up survey in 1980, reported in Locker et al. 1981. In 1977 more respondents assumed that the best form of care consisted of a quiet, peaceful atmosphere preferably in the country and had been opposed to community placement, believing it inappropriate. The 1980 survey revealed that, whilst the respondents' knowledge of mental handicap had not changed, their attitude towards community care had become more favourable. More had heard of the term community care and the experience of having a group home in their neighbourhood had allayed a lot of the initial fears and apprehensions that had existed before the group home opened.

Actual contact with the mentally handicapped residents had been minimal in the Locker et al. study (1981). Only 6% had visited the group home and only 2% had been visited at home by a mentally handicapped resident, though many expressed a willingness for more contact. It
seemed that the mere presence of people with a mental handicap in the community has a positive educational effect.

In the MENCAP study (1982) 62% of the public believed that people with mental handicap should be cared for in the community rather than in special homes or hospitals (23%). Those who favoured community care consisted of more younger (67%) than older people (56%) and more of those who knew a person with mental handicap (67%) than those who did not (58%). But it is important to note that respondents were given a choice in this survey between community care and special centres. If the wording had been "Would you have any objections to a person with a mental handicap living in the community?" it is likely that a much higher percentage would seem to have been positive about community care.

But overall the evidence suggests that a majority of the public are in favour of community care for adults with a mental handicap, even though many are unable to give an adequate definition of community care (Locker et al. 1982) and many are confused about mental handicap (MENCAP 1982).

But at the same time a significant, and sometimes very influential, minority are opposed to group homes in the community, and many of those in favour still have fears, apprehensions and concerns both for themselves and their family and for the adults with a handicap.

Concerns, Risk and Problems:—Real and Perceived

The MENCAP survey (1982) showed that despite a broad, pro-community care attitude, the public are a little concerned about the impact that mentally handicapped neighbours might have. Interestingly, they showed more concern for the mentally handicapped people themselves rather than the problems they might cause, and this may reflect a general sympathetic and paternalistic attitude towards people with mental handicap.

An earlier study in the States provides a flavour of some of the concerns of residents who had opposed the setting up of a group
home (Berdiansky and Parker 1977). Opposition was attributed to one or more of the following factors: (1) perceived danger of group home residents to the community, (2) fear of sexual deviance, (3) potential decreases in property values, (4) lack of supervision of group home residents, and (5) sexual racial composition of the home. Other studies in the States have indicated neighbourhood concerns, often related to misconceptions and prejudice about persons with mental handicap, such as fears about sexual deviance, crime and violence, and abnormal or grossly inappropriate behaviour (Lauber and Bangs 1974, Segal and Avarim 1978). Many of these concerns have no substance or are simply wrong. For example, Edgerton (1983) adduces evidence to suggest that people with mental handicap are more likely to be the victims than perpetrators of crime.

It will be noted that most of the concerns of neighbours in the studies from the U.S.A. revolve around problems that the neighbours themselves might experience whereas in the English MENCAP survey over half the concerns related to problems the mentally handicapped residents might experience. Because of differences in time, area, social class and methodologies a real comparison is not possible, but it is tempting to conclude that attitudes towards group homes are more sympathetic and paternalistic this side of the Atlantic, and that perceived threats are less.

Below we outline some of the problems and apprehensions most often cited in previous studies. The first four headings subsume primarily concerns for the people with a handicap and the next six, concerns for neighbours, but there is considerable overlap and the headings basically represent a structured way of looking at the concerns, rather than discrete categorisation.

Concerns for the People with a Mental Handicap

Concern over supervision, care standards and safety

Concern over care and supervision represents one of the most frequently expressed concerns and is also one of the more realistic concerns.
Significantly, it is one of the biggest fears of the parents of handicapped adults due to move into the community (Connecticut Association for Retarded Citizens V. Mansfield Training School, 1979). In another study (Meyer 1980) of those parents who favoured an institutional setting for their handicapped children, 37% mentioned the need for 24-hour care and supervision.

Perhaps both parents and concerned citizens have understandable fears about "deinstitutionalised" people being thrust onto the community without adequate back-up services. The history and record for ex psychiatric hospital residents being returned to the "community" in Britain over the last 15 years has left many people with a lot of doubts and misgivings about the wisdom of this policy (Wallace 1987).

In the MENCAP poll respondents were asked, "If two mentally handicapped adults moved in next door to you please would you tell me whether you think each of the following would be a major concern, a minor concern, or no concern at all to you." A list of the possible concerns followed. As no mention of care or supervisory staff is mentioned, even on a visiting basis, respondents are probably left with the impression that the mentally handicapped adults would be left to fend for themselves. Not surprisingly, then, nearly three quarters of the respondents were at least a little concerned that the mentally handicapped neighbours might not receive enough professional care. The other side of this fear was reflected in the fact that 44% were concerned that they (the public) might have to help look after them.

In our own survey we asked how people would feel in regard to concerns and risks if a group home with 4 to 6 mentally handicapped adults, with one or two care staff, was set up in their neighbourhood. This was, in fact, or would be the structure of such group homes in Dublin.
Concerns about mentally handicapped residents being lonely and isolated

Again, this is a very realistic concern, as there is a lot of evidence reviewed above and elsewhere to indicate that mentally handicapped people do in fact tend to be isolated from the community even when living within it (McConkey, Walsh and Mulcahy 1982). In the MENCAP poll 68% of respondents felt at least some concern that mentally handicapped neighbours might feel isolated, and in the Irish poll this was also a frequently mentioned point of concern.

A number of studies have looked at this aspect of social isolation in terms of degree of participation in community activities (O'Connor 1976, Baker et al. 1977) and showing an overall modest or low level of participation. In one or two studies there were indications that there might be a lot more goodwill and untapped potential for greater neighbourly contact than was actually taken advantage of (McConkey 1987, Locker et al. 1979).

As our own study was focussing on neighbours' attitudes we decided to include a section asking just how much commitment for further contact there might be in the community.

Concerns about being ridiculed, teased or made fun of.

This was the most frequently mentioned concern in both the Irish poll and the MENCAP poll. In the MENCAP poll 82% thought that mentally handicapped adult neighbours might be made fun of by local people or children. It is a little difficult to guage how realistic a fear this is. Most of the American literature focusses more on the hostility element in surveys of existing group homes (Okolo and Gaskin 1984) and other references to ridicule tend to be impressionistic or prescriptive.

In our own survey we felt it was a worthwhile question to inquire whether there was much actual experience of ridicule being an ongoing problem for the mentally handicapped residents where there
was a group home. This could be compared with the public's perception of this being a risk problem in the areas where there was in fact no group home yet.

Concerns about being victimised or taken advantage of

These concerns are closely allied to the fear of ridicule, and can tend to reflect characteristics of the neighbourhood itself as much as the people with mental handicap. This was the second most frequently cited concern in the Irish poll, but was not included as a separate issue in the MENCAP poll, though it was partially reflected in the concern about the need for professional care.

Concerns for Effects on the Neighbourhood

Perceived risk of danger to children

This was the most frequently cited potential problem in a number of American studies (Berdiansky and Parker 1977, Wehbring and Ogren 1975), and English studies (MENCAP 1982, Lock et al. 1979) as well as the Irish poll (McConkey 1987) and an Israeli study (Cnaan et al. 1986). It is worth pointing out there is no evidence for a higher incidence of aggressive deviance among people with mental handicap than among the population at large. They are probably more often victims than perpetrators of crimes, and Sitkei (1976) found that fewer than 1½% of 1804 mentally handicapped residents living within the community had been in custody of the law over a 2 year period.

Nevertheless, in the MENCAP poll 46% of respondents were concerned over the issue of possible harm to local children or people.

Embarrassment or uncomfortableness

This is another perceived problem which says as much about the respondent as about a handicapped individual but it was frequently cited in both the English and Irish polls.

O'Connor (1981) found that embarrassment was more of a problem for younger people - the under 24 age group - and that there was a tendency for this to decrease in direct proportion to age.
Another way of looking at embarrassment is in terms of willingness to meet or have more contact with people who have mental handicap, and we included a section on this in our own questionnaire.

Perceived risk of violence, unpredictability or lack of responsibility

These fears seem to figure more in the American literature (e.g. Berdiansky and Parker 1977) but also were mentioned fairly often in one form or another in the English and Irish polls.

Property might be devalued

Again, this seems to be more of a fear in the U.S. and comes fairly low in the list of perceived risks in the English and Irish studies. There is no evidence for devaluation of property surrounding group homes, but there is some evidence for it increasing (Segal and Aviram 1978). Nor has there been any evidence for increased turnover rates for houses close to group homes (Okolo and Guskin 1984).

Notwithstanding the evidence, the perceived threat of house devaluation has very often been a powerful factor in cases where community opposition prevented group homes opening in the U.S. (Berdiansky and Parker 1977). It is possible that the devaluation threat is popular because it appears, quite spuriously, as if this was an important and unprejudiced objection. Or it may be because it touches on a subject close to most people's hearts - money.

Other fears and vague uneasiness

Other perceived risks that have been suggested in previous studies include fears of pets being harmed, increase in traffic, noisiness and vandalism. In the Locker et al. study (1979) 17% of respondents thought there would be disadvantages but were unable to specify them. It seems possible that some people have vague fears such as, "You wouldn't know what might happen", and this might account for some of the agreement to the more obscure concerns, such as harming of pets, in the MENCAP poll.
Advantages and Benefits

An obvious point is that if you ask about problems you will get answers in terms of problems even though few may be mentioned spontaneously. Too few studies have made any attempt to redress this imbalance by enquiring about possible advantages or benefits, but the Locker et al. studies (1979 and 1981) provide a notable exception. They asked respondents if they thought there were advantages or disadvantages to the community in having a group home in the area. One third thought that there would be advantages to the community compared with a quarter who thought there would be disadvantages.

Of those mentioning advantages, the most popular spontaneous response was that the group home would have an educational effect, promoting awareness and understanding of mental handicap. Thirteen per cent mentioned advantages to the mentally handicapped people and their families, 10% mentioned employment and voluntary work opportunities and 8% thought it would create and enhance community feeling.

To counterbalance any tendency to only consider problems, a question was included in our own survey on possible advantages and benefits that a neighbourhood group home might bring about.

Demographic and respondent variables

Sex

Most studies that do show any difference indicate that females have more accepting and favourable attitudes to mentally handicapped people than do males. For example, Gottwald (1970) and Sheare (1974) found that females were more positive, more accepting of and more nurturant towards mentally handicapped people, and females tended to be more likely to respond in a socially desirable way.

McConkey, McCormack and Naughton (1983) found that female school students were more willing to become involved in voluntary work with handicapped people than males, and that this sex variable seemed to be
stronger than the variable of previous contact. Females with no
previous contact were more willing than males who had prior contact.

But other studies have shown no significant difference between
males and females (Johnson and Beditz 1981, Furnham and Pendred, 1983).

**Social Class and education**

It is safest to agree with Okolo and Guskin (1984) that few
conclusions can be reliably stated about socio-educational class and
attitudes towards mentally handicapped people. But where correlations
have been found, it tends to be in the direction of higher levels of income
and education being associated with more positive and liberal attitudes
(Gottwald 1970, MENCAP 1982).

But a number of studies have found no association between
attitudes and socio-economic class (McConkey et al. 1983, Johnson and
1981) seemed to show unskilled working people to be more tolerant than
middle class people, but the criterion of tolerance was whether or not
respondents thought it "a good idea if their son or daughter or close
friend said they were going to marry a person who was mentally handicapped".
It is probable that the middle class respondents were simply more realistic
on this issue rather than less tolerant in general.

Education is difficult to separate out from social class in
questionnaire surveys, but one study claimed to demonstrate that residents
with low income but high educational attainment were more accepting of
group homes within the neighbourhood (Segal, Baumohl and Moyles, 1980) and
McConkey et al. (1983) found vocational school students tended to be more
in favour of social integration than fee-paying school students.

Whilst social and educational backgrounds are probably important
determiners of attitudes in some general ways, there is not enough
consistent evidence for these factors being good predictors of specific
attitudes towards mentally handicapped people, or group homes.
Other demographic and respondent variables

Area and neighbourhood are variables which are very much confounded with socio-economic class but some attempts have been made to compare urban versus rural differences. McConkey et al. (1983) found that amongst 15 and 16 year olds in Ireland 30% of rural as opposed to 23% of city dwellers had meetings with mentally handicapped people. Sinson (1983) found urban mothers more accepting of social integration of people with mental handicap, but not educational integration. Rural mothers were more openly opposed to either idea. But many studies find no significant difference or no clear direction in the data on this variable.

Weir (1981) quotes a number of small attitudinal differences in regard to disability according to region, voting preferences and social class, but notes that the results are probably not generalisable beyond that survey itself.

Age is a factor which has often been examined but it is safest to conclude, as do Furnham and Pendred (1983), and Siller and Chipman (1964), that there are no clear-cut patterns of age determining attitudes towards disability. There may be a slight trend detectable for the under 18's and the elderly to be both less knowledgeable of and less favourable towards people with mental handicap than are people within the middle range of age.

Understanding of the term "mental handicap" has itself been found to be a significant variable (Locker et al. 1979), and this study also indicated that "neighbourliness" also seemed to be a significant factor in regard to attitudes towards a group home. Those who had lived longer in a neighbourhood and had more community contacts knew more about the group home than comparative newcomers to the area.

Time itself seems to be a significant factor in the acceptance of a group home. Baker et al. (1977) examined community attitudes
over time to 17 group homes in seven states and reported that in all facilities opposition had decreased over time. Interestingly, they found no relation between opposition and the actual size of the group home facility, and no relation between opposition and the severity of the handicap of the group home residents.

But other studies have found that both the nature and degree of disability, and the age of the handicapped person are significant determinants of attitude (Furnham and Pendred 1983, Gollay et al. 1978), though not in a simple or consistent way.

Outstanding Issues: the Aim and Scope of our Survey

There were a number of key issues which we wanted to focus on in our study. There was the natural question of whether attitudes in Ireland, as opposed to any other country, were any more favourable towards people with a mental handicap and their integration into the community. This question was not just academic or of cultural interest: the policy of community care has really only taken off in the mid 1980's in terms of community integration of people with a mental illness or a mental handicap. It is important to know if this policy has broad acceptance by the public, and particularly whether group homes are accepted by the local community.

Within this general question, a number of specific issues needed to be addressed. The impression is that in Ireland local community contacts are closer, that there is more general tolerance and that there is a stronger tradition of charitable behaviour than in most Western countries. Although it might be difficult to validate this impression in a general sense, we were interested to know, specifically in relation to group homes (a) whether there really was a high level of general neighbourly contact, (b) how this related to contact with a group home in a neighbourhood and (c) whether there was acceptance of group homes.

We also wished to know whether there were any problems either anticipated or experienced, with regard to people with a mental handicap living in a neighbourhood group home, or indeed any benefits.
Again, this was not merely an academic question: actual policy and style of implementation could depend on what answers we received.

In addition, we wanted to know whether there were any untapped community resources in terms of local people who might be keen to become involved or help out in connection with group homes. Again, this was not just of academic interest. If there are people who are ready and willing to promote community integration of their mentally handicapped neighbours in a real sense, then we want to know who they are.

Obviously, then, we also wished to obtain basic information on the demographic variables of our survey population in order to try to answer questions such as what sort of people have most contacts, who perceives problems and who might be willing to lend a hand.

Finally we had the aim of providing feedback on the results of our survey to the mental handicap service managers, other policy-makers and involved agents, and to the care staff of the group homes, so that any implications from our study would be seriously considered. In fact a large meeting took place for precisely this purpose on November 25th, 1987, and written feedback was also circulated internally within the St. Michael's House service and externally to interested parties.
METHODOLOGY

Attitudes

The concept of attitudes can present difficulties in definition, and the relationship of attitudes to behaviour is by no means a simple one (Festinger 1957, Fazio and Zanna 1981). The term "attitudes" will be used in a broad sense to include all reactions by others to mentally handicapped people being placed within the community, and to group homes and the individual residents, as well as related issues. Altman (1981) summarises the current research methodologies in the study of attitudes to people with mental handicap. He outlined three broad approaches: (a) picture-ranking (b) sociometric methods and (c) pencil and paper surveys. Other methods include interviews, semi-structure open-ended questions, content analysis of radio, T.V. and newspaper items and examination of actual decision-making and policy-making.

There was a need for our survey method to be repeatable since there was a good chance of it being broadened to include other areas in Ireland, forming part of a larger scale study undertaken by Roy McConkey. In fact, this came about, and other research assistants carried out parallel surveys of group home neighbourhoods in several towns and rural neighbourhoods both in the Rep. of Ireland and Northern Ireland.

A structured questionnaire method was chosen as other methods, such as picture-ranking or semantic differential techniques seemed either inappropriate or too involved to adapt to our task. But within the chosen questionnaire method a number of choices had to be made.

We rejected the possibility of a postal questionnaire because this can have a high non-response rate. As the immediate neighbours of the group home were a focus of our interest, we could not risk losing information from them.

A structured or semi-structured open-ended interview technique could have been used. The advantage of this method is that a lot of useful
qualitative information may be elicited. Some fine distinctions can be brought out when respondents are allowed to express in their own words their attitudes, experience and feelings on a topic. But one disadvantage is that this method can be comparatively more susceptible to response bias factors such as social desirability. Another drawback is that incomplete, inadequate or less articulate responses can result in a great loss of potential information. Open-ended answers can also present problems of interpretation, categorisation and experimenter bias.

Nevertheless, we decided to include three or four open-ended questions in our survey, but within a context of a majority of closed questions.

Comparing experience with no experience

One essential aim was to examine the actual experience and attitudes of neighbours in an area with an existing group home in comparison with the attitudes of neighbours with no such experience. It would have been preferable to look at attitudes before a group home was set up, and then, one or two years later, measure the attitudes of the same respondents in the light of their actual experience. Time restrictions for this study ruled out that option.

It was decided instead to compare two areas which had an existing group home with two similar areas with no group home in terms of perception of problems, real or potential, and in terms of benefits.

Degree of Contact

A major area of interest was how much contact there was between residents and staff of group homes and their neighbours in the vicinity. For comparison purposes we would also need to know how much contact a respondent had with any other neighbours, so it was decided to include a section designed to measure "neighbourliness" and community involvement in general.
Willingness to help

Because finally we were concerned with practical ways of improving community integration we wanted to obtain a measure of how much potential help and involvement there was in the community. So we decided to include a section, both for group homes with and without group homes, asking in some detail how much, if any, commitment they might be prepared to give if they were asked to provide company or assistance for their mentally handicapped neighbours.

Comparing Private with Corporation Housing

It is a practical policy question whether group homes should be provided within the corporation housing stock or as private houses. There are advantages and disadvantages to both, and in Dublin both types of group home operate. Whilst the type of housing was predicted to be an important factor underlying attitudes and contact, it could be expected to co-vary with social economic and educational class. Despite difficulties of teasing these out we had the type of housing, corporation or private, as one of our main variables.

Deciding which group homes and the scope of the study

Finding two neighbourhoods with typical group homes, one in a corporation estate and one in a private estate, did not present any serious problems in Dublin. We had two meetings with the service managers and explained the broad aims and nature of the survey, and a lot of interest was shown in our study.

It was decided that our group homes should be ones where the residents were severely mentally handicapped rather than mildly mentally handicapped for several reasons. First, to the general public a severely handicapped individual is more instantly visible and definable than a mildly mentally handicapped person. This should exclude any possible confusion over terms. Second, the survey results are more likely to be capable of being extrapolated from severe handicap to mild handicap than vice versa. If we had used group homes for people with
mild mental handicap the obvious qualification could be made that more problems could arise with more severely handicapped residents.

Some apprehension was felt about our asking about problems in case this might stir up ill-feeling. But most of these misgivings dissipated when it came to examining the actual question frames. For obvious reasons there should be no questions which could reflect personally on individual residents or staff in the group homes.

As a result of these discussions some questions were added or amended. For example, it was pointed out that it would be highly relevant to enquire not only about neighbours' contact with the group home residents but also with the staff.

The staff of the group homes were consulted before beginning the survey, and asked for any comments, additions or objections, and we promised to provide full feedback of the results of the survey. In fact, there were no objections but great interest was expressed in knowing the survey results. Ideally, for the no-group-home areas we would have liked two locations, one corporation and one private, where group homes were actually planned to be opened. In the event this presented problems of matching criteria with the existing group home neighbourhoods, as well as resistance to providing permission for the survey in case it stirred up potential opposition.

The "Threat" Condition

But we reasoned, as did Kastner et al. (1979) that it would be enough for neighbours to think that a group home may be set up near their own home for this to represent a realistic condition. Two neighbourhoods were chosen that matched the group home neighbourhoods in terms of either private or corporation housing, and as similar as possible in terms of general area location, age of houses and social composition. Respondents in these areas were to be asked about their attitudes, "if a house for three or four mentally handicapped people with one or two care staff started up in your neighbourhood, for
example, at that house over there/down the road/round the corner, which is vacant".

Sample size

Although the terms neighbourhood and area have been used interchangeably a discrimination can be made between the immediate neighbourhood of a specific house and the wider area or district. The immediate neighbourhood could, for example, be defined as the 4 closest houses or the 10 closest. The area might be defined in terms of housing estate, postal area or parish.

We wanted a sample of neighbourhood attitudes that would reflect both the area, for example, in terms of corporation estate, and those houses in the immediate vicinity of the actual or potential group home within that area. It should include those houses that, due to their proximity, might be expected to have heard about the group home's existence.

Sampling only immediate neighbours' attitudes would be too restrictive and unrepresentative. Taking the 100 most proximate households would certainly provide a comprehensive sample of both neighbourhood and area, but the more outlying houses might over-represent those households having minimal contact with the group home. As there were also constraints on time and energy a sample size of 50 per neighbourhood was chosen as the optimal number. Since we were examining 4 neighbourhoods in all, this would make for a reasonably respectable total sample size of 200.

Sampling Method

A preliminary visit was made to all 4 neighbourhoods to check the "lie of the land" and maps were made of the streets and house numbers in the vicinity of the target home. On the maps a circle or ellipse was drawn to include the specific 62 houses closest to the group home. Allowing for a 20% rate of refusals and non-contactables this was expected to come down to a figure of 50 respondents per neighbourhood.

From the electoral register a list was made of all occupants of
these 62 houses. It was decided to take only one respondent from each house(hold) on the assumption that a great deal of influence and contamination would result if two or more respondents from the same family were used.

It was felt preferable to have a named respondent, chosen randomly from the electoral register, to avoid biases of the sample. Taking the first person to answer the door can result in too many unemployed people or mothers working at home being included in the sample. Our sample then included only those over the age of 18 years who were on the electoral register and who were still living at home.

A random selection method was used to identify each named respondent from each household. If this person was not at home on our first visit we made an appointment to call again at a time expected to be convenient. If, after the second visit to the house, our named respondent was still not in we asked for the person in the house closest in age to our named respondent to complete the questionnaire for us.

If no-one answered the door two further visits were made before counting this as a non-contactable. If the named respondent refused point blank to complete the questionnaire this household was perforce excluded from the survey. Fortunately this was rare.

If the named respondent had moved from the area the person in the house closest in age to our named respondent was asked to complete the questionnaire for us. Again, this was rare.

In fact we had a fairly friendly reception overall, most respondents being quite happy about doing the survey once they found out what it was about. In one typical area, Lorcan Avenue, we encountered two direct refusals, one empty house for sale, four non-contactables, and seven cases where the closest in age was substituted for the named respondent who was unavailable. More often than not it took two or three visits before we found our named respondents.
Each respondent was given a "thank-you sheet", copies of which appear on this page. The "thank-you sheet" for the areas with no group home has an extra explanatory debriefing section, and verbal debriefing was also given after each questionnaire had been fully completed.

"Thank-you sheet" for areas with no group home

THANK-YOU

We are very grateful to you for your help with our study. The findings will be used to plan better services for mentally handicapped people in the Dublin area. There are many hundreds living with aging parents and there is an urgent need to plan what will happen to them when their parents are no longer able to care for them.

WE KNOW OF NO PLANS TO OPEN A GROUP HOME IN YOUR NEIGHBOURHOOD

However, there are many such homes in all parts of Dublin, usually for between 4 to 8 mentally handicapped people under the supervision of paid members of staff.

To date there have been very few problems expressed by neighbours. For example there have been no reports of excessive noise, vandalism or violence. House prices have remained steady. Some neighbours have become regular visitors to the home. In general great efforts are made for the home to fit into the neighbourhood and whenever possible, handicapped people from that district are housed there so that they can more easily keep in touch with their family and friends.

If you would like further information about the survey or about mental handicap in general, please telephone Dublin 88 58 05 and ask to speak to Dr Roy McConkey.

Once again, many thanks for your help.

"Thank-you sheet" for areas which had a group home

THANK-YOU

We are very grateful to you for your help with our study. The findings will be used to plan better services for mentally handicapped people in
the Dublin area. There are many hundreds living with aging parents and there is an urgent need to plan what will happen to them when their parents are no longer able to care for them.

If you would like further information about the survey or what you might do to help, please telephone Dublin 88 58 05 and ask to speak to Dr Roy McConkey.

Some methodological considerations. Problems with some previous studies

The studies reviewed in the Introduction broadly conformed to standards of acceptable methodology. One which did not do so was that of Manning (1987) who asked some interesting questions about community care using a postal questionnaire survey method. Unfortunately, only 61 respondents sent back completed forms, and this represented only 19.7% of her sample population, so that the representative validity of her findings must be rejected.

In other studies less serious but still important reservations can be held about the interpretation of wording of questions. For example, in one study (Locker et al. 1979) the 30% of respondents who said they had no objections to the group home "..... were considered to be in favour of the hostel". (p.818) which is rather a qualitative leap of interpretation.

Similarly, both the President's Committee study (1975) and the Kastner et al. study (1979) interpret not objecting, or not seeing problems as being in favour of a hostel.

Researchers investigating actual or potential concerns about group homes are caught in a Catch 22 situation. If they simply restrict the question to an open-ended form such as, "Do you think there have been/would be any problems?" they might miss out on a great deal of information. Respondents may be reluctant or unable to come up with clear and detailed replies. Locker et al. (1979 and 1981) used such open-ended questions, and some of their response categories were predictably vague, such as, "it would create anxiety among the local population." Locker et al. do
not provide the exact wording of their open-ended question about problems. But an inherent difficulty with open-ended questions is the basis for classification of the responses which may depend on the interpretation and even intuition of the research worker.

At the other extreme, the MENCAP poll (1982) presented respondents with a list of 14 potential problems and required them to consider whether each and every problem might arise if two mentally handicapped adults took up residence next door. It is significant that all the respondents picked out at least one of the problems from the listing: we are all used to forms where there is something wrong if we end up with all YES's or all NO's.

In our own questionnaire we tried to circumvent some of these difficulties by first presenting an open-ended question about problems anticipated or experienced, followed up by a listing of the 9 most frequently mentioned problems which respondents were asked to consider.

Also, as a counterbalance to problems and risks, we included a question about possible benefits that might have come about from the group home, or if a group home opened in the neighbourhood.

The design and construction of the questionnaire

The areas of interest had already been defined as the degree and quality of contact with the group home and the people in it, the perception of problems, and the willingness of neighbours to become more involved. In looking at these issues we wanted to compare areas which actually had a group home with areas that did not, and in addition, to contrast areas of corporation housing with areas of private houses.

Contact: General neighbourly contacts

In order to examine contact with the group home we needed to obtain a base-line measure of the amount of contacts that respondents had within their community aside from the group home. It was hypothesised that "neighbourliness" might be a variable in its own right in determining attitudes towards group homes.

McConkey (1987) had examined this aspect of neighbourly contacts
in a previous survey concerned with knowledge of day care facilities for people with mental handicap and a number of questions used in that survey were modified for use in the present study. We defined neighbourliness in terms of how long respondents had lived there, how many members of the extended family lived in the same area, how many community activities respondents took part in, e.g. going to church or shopping locally, how many households the respondents knew by name at least, and how much contact they had with their neighbours. This theme of neighbourly contacts was covered by questions 1, 2, 3, 4 and 5 in our questionnaire. In question 6 we asked specifically about contact with disabled people in the neighbourhood and whether any were mentally handicapped.

Contact with mentally handicapped people in general, and attitudes towards Community Care policy

This was covered by questions 6, 7 and 7X which are of a general rather than specific nature. There are good grounds for expecting that a general attitude, say, in favour of community care does not necessarily lead to a specific commitment for example towards a group home in your street (Bom 1970). In any case, we wanted a general measure of respondents contact with people with mental handicap and attitude towards community care against which to set their responses to the more specific questions which follow.

Contact with Group Home or knowledge of its existence

This was covered by questions 8, 9, 10 and 11. This section was for the two areas where there was in fact a group home. The questions are quite detailed because we needed to ascertain that respondents really did know of the group home and what sort of people lived there, and exactly how much contact there was. Otherwise respondents might have been able to confuse the group home with larger mental handicap centres which existed within a two mile radius, or they might have confused a family with a mentally handicapped child for the group home.
Perceived Problems. Attitudes towards or experience of neighbourhood group homes in terms of problems or benefits

This was covered by questions 12, 13, 14, 15 and 16. Those respondents in the group home areas were asked for their actual experience whereas for those respondents in no group home areas the questions were framed in terms of: "If a house for three or four mentally handicapped people with one or two care staff started up in your neighbourhood....... do you think this would give rise to any problems in the neighbourhood?"

Only after the open-ended question were respondents asked whether they anticipated or had experienced any of the list of 9 potential problems. This list was kept reasonably short to avoid over-suggestion of possible problems but broad enough to cover most possibilities, and the selection was made on the basis of frequency of citation in the literature as well as mean frequency of its selection as a problem in the MENCAP poll (1982) and McConkey (1987).

Obviously, in this section we were particularly interested in whether people in the areas with no group homes anticipated more or less problems than were actually experienced by the people living in group home areas. Willingness to provide extra help or involvement

This was covered in the multiple question 17, though we would also be comparing answers to question 23 which asks about previous or present experience of voluntary work. This section was based on a real need to know how much potential help, contact and involvement there might be within the community.

Some care was taken in this section to try to minimise social desirability effects. Instead of just a willing or unwilling response category we included one of "Perhaps but wouldn't have the time", as an easier let-out for those who don't like to say No. Also, one item, "Helping out the staff in an emergency", was expected to allow respondents to show willing on at least this one item and so not have to refuse all items.
Basic Demographic information

Questions relating to age, sex, marital status and educational history (18, 19, 20, 21 and 22) appeared at the end because we reasoned there would be less reluctance to give this by the time the respondent realised that this really was a harmless survey concerned with mental handicap. Questions on income were excluded as they can provoke angry or suspicious responses especially in a period of high unemployment but it was felt reasonably acceptable to include age range, working status and educational history in this data.

Stages in questionnaire construction

On the basis of the defined areas of interest, previous surveys and literature, and our preliminary discussion with service managers on the scope of the study, a first draft questionnaire was constructed.

This was presented at our second meeting with service managers and concrete proposals were put forward and a detailed examination was made of the questions item by item. At this stage some re-ordering of sections, some changes of wording and some amendments were made. The point was made that, especially in the case of the no group home neighbourhoods a debriefing information leaflet was necessary. These neighbourhoods were treated as the "threat" condition ("If a group home opened at that house round the corner....."), and so it was important to explain that no such plan was in fact being considered at present. Copies of this information sheet appear in the Appendices, as well as a briefer Thank You sheet for those respondents in the group home neighbourhoods.

The Pilot Study

A pilot study was carried out in two adjacent housing locations in Taney, Goatstown Dublin. The first location was a council house area with mainly settled families most of whom had bought out their own house and there were 10 respondents from this area, 5 male and 5 female. The second location was a group of new, up-market semi-detached private houses, all being rented and there were 7 respondents, 3 male and 4 female.
There was only one refusal from the council area but 4 refusals from the private area. We encountered no real difficulties in the practical administering of the questionnaire: the questions were easily understood and the respondents found the choice of categories appropriate for their answers. The questionnaire took on average about 15 minutes to complete, allowing for those who were inclined to talk at length, but could be completed in as little as 7 minutes by those who were pressed for time.

As a result of the pilot study we made some alterations, additions and re-ordering in the questions, and these are listed below. Question numbers refer to the final version.

Question 5. The order of activities was changed from school meetings and church as the first two mentioned activities to sports or other clubs and pubs as the first two. This was to avoid giving respondents a set towards moral or socially responsible answers.

Questions 6 and 7. Question 6 was inserted because many people are aware of disabled persons, including for example physically handicapped people but might not automatically think of mentally handicapped people as such, unless asked specifically. It was also useful to distinguish between neighbourhood contact and more general contact, e.g. from work, relatives or friends.

Question 7X. All respondents in the pilot study said they thought that the national policy of having mentally handicapped people living wherever possible within the local community was on the whole a good policy. We wondered whether the alternative "on the whole this is a bad policy" was too markedly negative, and this was changed to "on the whole a not so good policy".

The supplementary open question "Why is this?" was added to allow respondents to clarify their position on this, as it could be anticipated that many people would think that "it depends......".

Questions 13 (g) and 13 (i). In the first version these had been in one condensed form "The mentally handicapped people have been
noisy, violent or irresponsible." We felt that the concepts of noisiness was too far removed from "violent or irresponsible", so this question was expanded into two forms:-(g) The mentally handicapped people have been noisy and created disturbances, and (i) the mentally handicapped people have been violent or irresponsible.

Question 14. One respondent spontaneously mentioned that we should also ask about benefits and advantages for the neighbourhood as well as sounding out about problems if a house for three or four mentally handicapped people started up in the neighbourhood.

It had also occurred to ourselves that we needed another question, in addition to Q.8, to elicit respondents potentially positive attitudes towards mentally handicapped people living in the neighbourhood, so Q.14 was added. In practice we obtained far more answers to this open-ended question about benefits than for Q.8, possibly because it is easier for respondents to consider the specific neighbourhood aspects than to consider national policy, or possibly because, by this stage in the questionnaire respondents have crystallised their thoughts and attitudes rather more closely.

Question 17 (d) This was changed from..... "come to your home on a visit or for a meal" to ..... "come to your home on a visit or for a cup of tea" because we felt that for many respondents "come for a meal" might sound too formal, unfamiliar or daunting.

Question 17 (f) The original form of this was, "Involve the handicapped person in any community events", but we felt this was too predictable - of course they would - and too vague - what counts as a community event? So we substituted the form "make a point of talking to the person....." as this probably reflected more everyday reality.

Question 24. Finally we felt it was marginally preferable to ask specifically for comments about mentally handicapped people living in the community rather than about "the survey".
Description of Sample

Our sample consisted of 40.5% male and 59.5% female respondents. This mild imbalance was created by our selection procedure for the eventuality of the named respondent being unavailable on two occasions: males seem to be out of the house more often. In fact there is also a sex imbalance in Dublin, 56% being female and 44% male which would also be reflected in our own figures.

But our selection procedures had the advantage of preserving a good age distribution. This is shown in Table 1 below and this approximated very well to the National Census distribution.

Table 1

<table>
<thead>
<tr>
<th>Age in years</th>
<th>Less than 20</th>
<th>20-39</th>
<th>40-59</th>
<th>60 +</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage</td>
<td>11.5</td>
<td>37.0</td>
<td>42.5</td>
<td>9.0</td>
</tr>
</tbody>
</table>

In terms of education, 72.5% of our sample had left school at age 15 years, 23.0% went on to sit Leaving Certificate and 4.5% had gone on to 3rd level education.

Table 2 below shows the employment status.

Table 2

<table>
<thead>
<tr>
<th>Status</th>
<th>Employed Full-time</th>
<th>Employed Part-time</th>
<th>Student</th>
<th>Unemployed</th>
<th>Housewife</th>
<th>Retire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage</td>
<td>29.0</td>
<td>6.5</td>
<td>2.5</td>
<td>16.0</td>
<td>40.5</td>
<td>5.5</td>
</tr>
</tbody>
</table>

In terms of marital status, 22.5% were single. 28.5% were married but with no children, or with grown-up children, and 49.0% were married with one or more children under the age of 16 years.

One of our main variables was whether the housing was private or public - two areas were private housing areas and two areas were corporation estates. This more or less corresponded to an owned versus
rented distinction, except that three respondents were renting houses in the private sector and two rented corporation houses were also located in the private housing areas. This meant that 52.5% of respondents were rent-payers and 47.5% were owner-occupiers.

The Four Survey Areas

The account given below is partly objective, based on some of our results data, and partly a subjective description based on the impressions of the writer. It is meant to convey a broad impression and flavour of the areas.

Maps of the location within Dublin and the detailed street and house positions can be found in the Appendices.

(1) Lorcan Avenue

Lorcan Avenue is situated in the Beechmont area of the Northside of Dublin, Grid Reference 175395 on the 1/20,000 O.S. Map of Dublin. The houses were built in 1974 and although some had been corporation houses originally, nearly all those tenants had since bought out their own house. It is essentially a settled area of private housing. 92% of respondents have been living there for over 5 years.

In appearance most houses and gardens looked well cared for and maintained and many houses displayed Neighbourhood Watch stickers. The children in the area behaved appropriately on the streets and none were "running wild".

Most houses were occupied by families where the parents were in their thirties or forties and most families had at least one wage-earner, usually the father. 14% of respondents described themselves as unemployed and this is close to the national average of about 18%, taking account that our sample didn't include the unemployed youths under 18 years.

Most families could be described as respectable working class with skilled or semi-skilled wage earners. Whilst most respondents had left school before 15 years (66%), a sizeable minority (32%) had gone on to sit leaving certificate and one respondent had gone on to 3rd level education.
(2) Elm Mount Avenue

Elm Mount Avenue and Dromawling Road are also in the Beaumont area of the North side of Dublin, Grid Reference 178 384 on the 1/20,000 O.S. Map of Dublin, and only about ½ mile away from Lorcan Avenue. These houses had always been private and were built in 1954. It is fairly quiet and very well settled neighbourhood, with 94% of respondents living there for over 5 years.

Most houses and gardens looked very well cared for. Very few children were to be seen on the streets and many respondents had grown-up children.

The number of unemployed respondents was low (2%) which is well below the national average. Most families probably fell into the lower middle-class category, but 50% of respondents had left school before the age of 15 years. 36% had done leaving certificate and 14% had gone on to 3rd level education. A number of residents commented that it really was a quiet, pleasant neighbourhood and that there was never any trouble.

(3) Dunard Estate

Dunard Estate is in the Cabra area on the north side of Dublin situated at Grid Reference 133 356 on the 1/20,000 O.S. Map of Dublin. It is a corporation estate, 96% of respondents renting their houses from the council, though one respondent said the house was rented privately (possibly against regulations) and one was buying out the house from the corporation. No-one had lived there longer than 5 years because the estate was only built in 1983, and it would count as one of the best areas of corporation housing, each house having gardens at front and back, parking space, and of quite acceptable design, built of red brick.

The playing field on the estate is used a lot for soccer and football. Children were very much in evidence, playing around the estate, but not running wild. Most houses seemed to be quite well maintained both inside and outside and many residents had already taken steps to up-grade their porch areas and windows.
Most families were probably either upper or lower working class. There were 16% of our sample of respondents who described themselves as unemployed. As we included only those who were on the electoral register, this would not take into account the very high percentage of unemployed youths between 15 and 18 years of age, of whom there were plenty to be seen on the estate.

56% of our respondents on Dunard Estate were married with one or more children under 16 years and a further 24% were married with no children. Of our sample, 78% had left school at 15 years and only 2% were involved in 3rd level education.

Overall we received a reasonably friendly response to our survey in this area.

(4) Blackhorse Grove

This small estate is very close to Dunard Estate but well separated by a railway line and an area of older private housing. It is in Cabra on the north side of Dublin situated at Grid Reference 137 355 on the 1/20,000 O.S. Lap of Dublin. Like Dunard, Blackhorse Grove is also an area of corporation housing and was built in 1980. 76% of respondents had lived there for more than 5 years, and all but one were council rent-payers.

Like Dunard, the Blackhorse Grove houses were built to a reasonable standard in red brick and the initial appearance of the estate was reasonably attractive. But within 5 minutes a visitor would notice that many houses and gardens were poorly maintained; there was broken glass in some parts of the street and many children seemed either not under adult supervision or unresponsive to it.

Some respondents seemed to be initially suspicious that we, the interviewers, were Social Welfare investigators, and many were unfriendly or reluctant to participate in the survey. A lot of respondents complained that there was not enough control over the children in the estate, and in fact during the survey a gang of children were to be seen breaking a window by throwing stones at one house.
There was extremely high unemployment in the estate with 30% describing themselves as unemployed, and only 16% of respondents admitted to being in full-time employment. The vast majority (96%) had left school at or before age 15 years.

One person who knew the area described the difference between the two corporation estates as follows: "Most people in Blackhorse Grove would rather live in Dunard Estate".
RESULTS

The data were analysed on computer using the Statistical Package for the Social Sciences (S.P.S.S. - P C) programme. Since nearly all our data were categorical we used chi-square analyses to examine the relationships between variables. Since a large number of analyses of variables had to be made, a significance level of 1% (P < 0.01) was chosen as an acceptable level at which to reject the null hypothesis.

Contact with Mentally Handicapped People

In this section we look at the amount of contact with mentally handicapped people in comparison with contact with others within the community. Many previous studies have examined contacts which the mentally handicapped individuals have within the community (McConkey et al. 1982 McConkey et al. 1983, Pelce et al. 1985). Our results reflect the amount of contact that respondents within the 4 neighbourhoods have had with mentally handicapped people.

Table 3 below shows the answers to Q.6 asking what contact respondents have had with disabled people in their neighbourhood.

Table 3 Contact with disabled people

<table>
<thead>
<tr>
<th>No contact</th>
<th>Seen them around</th>
<th>Occasional meetings</th>
<th>Regular Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>43.0%</td>
<td>36.0%</td>
<td>6.5%</td>
<td>14.5%</td>
</tr>
</tbody>
</table>

Even though two of the areas had group homes, 43% of respondents said they had had no contact with any disabled people in their neighbourhood, and a further 36% had only "seen them around".

The follow-up question asked whether any of the disabled people were mentally handicapped and 74.5% were in fact mentally handicapped whilst 25.5% had some other disability.

Question 7 asked what contact respondents had had with mentally handicapped people in general rather than just locally, and stressed
that this included children as well as adults. Table 4 shows the
results.

Table 4 General contact with mentally handicapped people

<table>
<thead>
<tr>
<th>No Contact</th>
<th>Seen them around</th>
<th>Occasional Meetings</th>
<th>Regular Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>33.5%</td>
<td>29.0%</td>
<td>15.0%</td>
<td>22.5%</td>
</tr>
</tbody>
</table>

Again, this shows a high total of 62.5% who had had either no contact
or "just seen them around". Some of the 22.5% who had had regular contact
would have had the contact in the past but not at present.

There were no statistically significant sex differences for either
contact with disabled people and/or mentally handicapped people in the
neighbourhood, nor for general contact with mentally handicapped people.

In the next section we consider how this degree of contact with
mentally handicapped people compares with other forms of community
contacts.

Community contacts and activities in general

Clearly if neighbours had no contacts with each other in any case,
the fact that they also had none with mentally handicapped residents would
mean very little. We took a number of measures of community involvement,
these being length of residency in neighbourhood, number of families known,
and whether any were relatives, a direct question on amount of neighbourly
contact, and a check-list of the number of community activities that
residents were involved in.

In all 65.5% of our sample had lived over 5 years in their neighbourhoo
and only 7.5% had lived there less than 2 years. These would all count
as settled neighbourhoods:— even in Dunard Road Estate, which was only
built 3½ years ago. 84% had lived there from the beginning and had
remained there.
A majority of our sample (58.5%) were involved in 3 or more of these activities.

Knowledge of the Group Home

Here we consider whether the neighbourhood involvement outlined in the previous section was reflected in knowledge of the group homes in the two neighbourhoods concerned. To do this we first needed to check that the two group home neighbourhoods were not atypical in terms of neighbourhood involvement and familiarity. A statistical comparison was made between the group home areas and the no group home areas on all the neighbourliness factors outlined in the previous section, i.e., length of residency, number of families known how many were related, amount of contact with neighbours and the check-list of local activities.

In fact, there were statistical differences (p < 0.01 on chi-square tests) on the factors of length of residency, number of families known, and how many were related, but these were all related to the history of Blackhorse Grove and Dunard Road which was discussed in the Methodology section. There was no significant difference between the group home areas and no group home areas in terms of the degree of contact with neighbours or in terms of the amount of local activities that people were involved in.

Over the two group home areas 75% of respondents knew that there was a group home in their neighbourhood. But there was a significant difference between the two group home areas.

Table 7. Percentage of people who knew the group homes in Dublin

|                | Knew House | Don't know | Said "None"
|----------------|------------|------------|-------------
| Lorcan Avenue  | 92%        | 4%         | 4%          |
| Dunard Road    | 56%        | 24%        | 20%         |
| Overall        | 74%        | 14%        | 12%         |

Chi = 16.86, p < 0.0002

In the Discussion the reasons for this difference are considered.
Exactly 50% of our sample knew over 15 other families within the neighbourhood. Table 5 below shows the number of neighbouring families known to the respondent.

Table 5  Number of families known

<table>
<thead>
<tr>
<th>NONE</th>
<th>1 or 2 Families</th>
<th>3 to 5 Families</th>
<th>6 to 15 Families</th>
<th>More than 15 families</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.5</td>
<td>5.5</td>
<td>16.0</td>
<td>28.0</td>
<td>50.0</td>
</tr>
</tbody>
</table>

This would seem to represent a high index of neighbourhood familiarity. This was also indirectly expressed in the finding that 21% of respondents had one or more related families living in their own neighbourhood.

In question 4 we asked respondents to self-report directly on the amount of contact they had with their neighbours. Only 15% of respondents rated themselves as "occasionally" in contact. 35% said they had some contact and 50% rated themselves as being in frequent and regular contact with their neighbours.

Our final measure of community involvement was the check-list in Question 5 where we ask what activities the respondent is regularly involved in at present within the area. These are listed below in order of popularity in Table 6.

Table 6  Percentages of respondents involved in each activity

<table>
<thead>
<tr>
<th>Activity</th>
<th>% involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Church attendance</td>
<td>77.5</td>
</tr>
<tr>
<td>Going to local pub(s)</td>
<td>41.5</td>
</tr>
<tr>
<td>Meetings at school</td>
<td>30.0</td>
</tr>
<tr>
<td>Sports or clubs</td>
<td>26.5</td>
</tr>
<tr>
<td>Reisidents' Association meetings</td>
<td>26.0</td>
</tr>
<tr>
<td>Bingo</td>
<td>14.5</td>
</tr>
<tr>
<td>Other Activities</td>
<td>20.5</td>
</tr>
</tbody>
</table>
was related to any of the independent variables, i.e. age, sex, years of education, marital status, employment status and previous involvement with voluntary work, but none of these was statistically significant. We also examined whether general neighbourly contact was related to knowing about the group homes but this was not found to be statistically significant. The criterion variables for general neighbourly contact were length of residency, number of families known by name, how many were related, amount of contact with neighbours and number of community activities respondents were involved in.

The only factor that was related to knowledge of the group home (at the 1% level of significance) was the factor of local contact with disabled people, but to the extent that some of the local disabled people were in fact the group home residents, this was another measure of the same variable.

It can be seen from Table 8 below that in Lorcan Avenue most of those who knew of the group home also knew that it was for people with a mental handicap, but in Dunard Road many of those who knew of the home did not know what sort of handicapped people lived there.

Table 8. Percentage of respondents who knew house, and that it was for mentally handicapped people.

<table>
<thead>
<tr>
<th></th>
<th>Knew House and People</th>
<th>Only knew House</th>
<th>Didn't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lorcan Avenue</td>
<td>84%</td>
<td>8%</td>
<td>8%</td>
</tr>
<tr>
<td>Dunard Road</td>
<td>34%</td>
<td>22%</td>
<td>44%</td>
</tr>
</tbody>
</table>

\( Ch = 26.32 \) \( p < 0.0000 \)

Contact with Residents and Staff from the Group Home

If respondents did know of the existence of the group home they were asked about what, if any, contact they had had with either the residents or the staff. (questions 8d, 8e and 9 and 10 a b c d e f) These were whether respondent knew any residents or staff by name, whether
respondent had just seen them around, or talked to them, visited their home or been visited in their own home or any other form of contact, and whether recent or in the past. Those who had any direct contact were asked how it came about.

Table 9 below shows the percentage figures for amount of contact for those people who did know of the existence of the Group home (N = 74)

Table 9  The local community's contact with people from the group home

<table>
<thead>
<tr>
<th></th>
<th>With Residents</th>
<th>With Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>No contact</td>
<td>8%</td>
<td>51%</td>
</tr>
<tr>
<td>Seen them around</td>
<td>90%</td>
<td>35%</td>
</tr>
<tr>
<td>Met with them</td>
<td>22%</td>
<td>14%</td>
</tr>
</tbody>
</table>

The Table shows that local people had more contacts with the mentally handicapped residents than with the staff. This is not surprising given that the staff had their own homes elsewhere in the city and slept over in the group home on a roster system.

Closer contact was so uncommon that it is best expressed in actual numbers, as in Table 10

Table 10. Further Contacts

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of respondents who had been inside the group home</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>No. of mentally handicapped people who had visited respondents' homes</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>No. of group home staff who had visited respondents' homes</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>No. of respondents who reported any other contact with group home residents</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>No. of respondents who reported any other contact with group home staff</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>No. of respondents who knew one or more names of either staff or group home residents</td>
<td>8</td>
<td></td>
</tr>
</tbody>
</table>

(N = 74)
Potential problems compared with real problems

In the areas with no group home respondents were asked first the open-ended question, did they think that opening a group home in their immediate neighbourhood would give rise to any problems (Question 15x). In the areas with group homes respondents were asked if there had been any problems or difficulties resulting from the handicapped people occupying the group home (Question 12).

Those respondents in group home areas who did not know of its existence were treated as if they were in a no group home area: as far as they knew, they were. There were 26 such cases. Of the remaining 74 respondents, aware that they were in a group home neighbourhood, not one thought there had been any problems or difficulties when asked this open question.

Of the 126 who were, or thought they were, in a no group home area, 24 thought that there could be problems if a group home opened up, i.e. 19.0%. These people were further asked to say what they thought these problems might be, and a selection of verbatim responses appears below.

Woman, mid 30s, working part-time. "Yes, I think there could be problems. They might be rowdy or noisy".
Woman, mid 40s, housewife. "Well they would have to be supervised properly".
Married woman, retired. "If it was voluntary it would be O.K. but it would need official people to look after them".
Man, mid 30s, unemployed. "The children round here would tease and laugh at them. Even our own would".
Man, early 40s, employed. "There are over a hundred kids on this estate. They would be the problem, not the handicapped".

In Table 11 below the responses are categorised into types of problem mentioned, and the number of respondents who mentioned them.
Table 11. Potential Problems mentioned spontaneously

<table>
<thead>
<tr>
<th>Type of Problem</th>
<th>People mentioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mentally handicapped would be teased/made fun of</td>
<td>9</td>
</tr>
<tr>
<td>Need for proper supervision</td>
<td>2</td>
</tr>
<tr>
<td>Need for information or greater understanding</td>
<td>2</td>
</tr>
<tr>
<td>Other people might object</td>
<td>2</td>
</tr>
<tr>
<td>Not good for neighbourhood</td>
<td>1</td>
</tr>
<tr>
<td>Might be rowdy or noisy</td>
<td>1</td>
</tr>
<tr>
<td>People could be afraid of them</td>
<td>1</td>
</tr>
<tr>
<td>They might be highly strung</td>
<td>1</td>
</tr>
<tr>
<td>They might attack children</td>
<td>1</td>
</tr>
<tr>
<td>The neighbourhood is not suitable for them</td>
<td>1</td>
</tr>
<tr>
<td>Don't know; no reason given</td>
<td>3</td>
</tr>
</tbody>
</table>

Depending a bit on interpretation, at least half of the problems mentioned spontaneously were problems for the people with mental handicap rather than problems for the neighbourhood.

But respondents could have found it difficult to consider all the possibilities on the spur of the moment. Many people might be reluctant or embarrassed about stating some problems, so we had included in our questionnaire the nine problems most frequently mentioned in previous studies. For each potential problem respondents had to consider, in the group home area, whether this had in fact been experienced as a problem, or, for the no group home area, whether respondents thought there was a risk of that problem arising if there were a group home. Again those who were unaware they were in a group home area were treated as if the were in a no group home area.

The percentage of people perceiving problems is listed below in Table 12. It will be noted that four problems are concerned with difficulties the mentally handicapped residents might experience.
and five are concerned with problems the neighbours might have.

Table 12. Percentage of people perceiving problems

<table>
<thead>
<tr>
<th>Type of problem mentioned</th>
<th>No Group Home</th>
<th>Group Home</th>
<th>Significance level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problems for mentally handicapped people</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>They would be teased/made fun of</td>
<td>55%</td>
<td>14%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>They would be victimised/picked on/taken advantage of</td>
<td>41%</td>
<td>3%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>They would be isolated/just keep to themselves</td>
<td>33%</td>
<td>22%</td>
<td>N.S.</td>
</tr>
<tr>
<td>Inadequate professional care and supervision</td>
<td>12%</td>
<td>0%</td>
<td>N.S.</td>
</tr>
<tr>
<td>Problems for the neighbours</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People would be embarrassed/wouldn't know how to react</td>
<td>34%</td>
<td>14%</td>
<td>&lt; 0.05</td>
</tr>
<tr>
<td>A danger or threat to children</td>
<td>13%</td>
<td>0%</td>
<td>&lt; 0.05</td>
</tr>
<tr>
<td>Mentally handicapped people might be violent/irresponsible</td>
<td>11%</td>
<td>3%</td>
<td>&lt; 0.05</td>
</tr>
<tr>
<td>The property value of houses would drop</td>
<td>9%</td>
<td>0%</td>
<td>N.S.</td>
</tr>
<tr>
<td>They would be noisy/create disturbances</td>
<td>7%</td>
<td>0%</td>
<td>N.S.</td>
</tr>
</tbody>
</table>

In every instance the percentage of people anticipating problems was greater among those with no group home experience than among those who did know of their local group home.

Table 13 below shows the percentage of respondents perceiving one or more problems for the mentally handicapped people, corresponding to the first four problems in Table 12 as compared with problems for the neighbours, corresponding to the last five problems in Table 12.

Table 13

<table>
<thead>
<tr>
<th>Class of Problem</th>
<th>No Group Home</th>
<th>Group Home</th>
<th>Significance level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problems for the mentally handicapped people</td>
<td>68%</td>
<td>34%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Problems for the neighbours</td>
<td>46%</td>
<td>15%</td>
<td>&lt; 0.001</td>
</tr>
</tbody>
</table>
Apart from the main difference between No group home and group home, it is also clear that people tend to express or anticipate more concerns for the mentally handicapped people than problems for themselves or their neighbours.

We analysed the data to see whether any of the independent variables were associated with perception of problems. Only two characteristics emerged as significant at the 1% level (chi-square), these being educational history and type of estate (corporation or private). The education differences were in the direction of those who had left school at 15 years perceiving more problems for the mentally handicapped people rather than for neighbours whereas those who had Leaving Certificate or better tended to be just as much concerned about problems for themselves and neighbours as for the mentally handicapped people.

In a very similar pattern, those who lived in corporation estates perceived more potential problems for the mentally handicapped people rather than neighbours, whereas those living in private estates tended to be just as much concerned about problems for themselves and neighbours as for the mentally handicapped people.

Benefits and Policy

In Question 7x of the questionnaire we asked respondents for their opinion on the policy of community care with regard to people with mental handicap. As well as stating whether they thought it was a good policy, or not so good, we asked respondents to give a reason for their opinion. In fact, the question was not very discriminating because the great majority of respondents either thought it was a good policy or had no opinion one way or the other. Possibly for educational reasons, more people in the corporation estates chose the "no opinion" option.
Table 14. Percentage of people in favour of Community Care policy

<table>
<thead>
<tr>
<th></th>
<th>Private Housing</th>
<th>Corporation Housing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes: A good policy</td>
<td>92</td>
<td>74</td>
</tr>
<tr>
<td>No opinion</td>
<td>6</td>
<td>23</td>
</tr>
<tr>
<td>No: Not such a good policy</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

(N = 200    chi = 18.73    Sig. at < 0.005)

None of those who thought it was not a good policy stated their reason why, but nearly half of those who thought it was a good policy gave a reason. These reasons were categorised as shown in Table 15 below, which is presented as a qualitative summary of the replies. Because of some arbitrariness and overlap of the categories it would probably not be legitimate to offer statistical analyses, but it seems clear that reasons of normalisation, human rights, and awareness are the main reasons why people approve of community care as a policy. A significant proportion wanted to make a qualification, such as: "It depends on the degree of handicap."
Table 15. Reasons for pro Community Care attitudes

<table>
<thead>
<tr>
<th>Type of Reason</th>
<th>Number who gave this reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>Integration, Normalisation. Deinstitutionalisation Community care principle. Why</td>
<td>24</td>
</tr>
<tr>
<td>shouldn't they live in community? Disadvantages of institutions.</td>
<td></td>
</tr>
<tr>
<td>Promotes awareness and understanding.</td>
<td>13</td>
</tr>
<tr>
<td>Human rights. Humanitarian reasons. Dignity and self-respect. Should be treated</td>
<td>9</td>
</tr>
<tr>
<td>the same as everyone.</td>
<td></td>
</tr>
<tr>
<td>Promotes Independence</td>
<td>5</td>
</tr>
<tr>
<td>They need sympathy, care, be looked after</td>
<td>5</td>
</tr>
<tr>
<td>General and other reasons</td>
<td>6</td>
</tr>
<tr>
<td>With qualification</td>
<td>14</td>
</tr>
<tr>
<td>Don't know. No reason offered or no opinion</td>
<td>119</td>
</tr>
</tbody>
</table>

Our results support those of Locker et al. (1981) in finding the vast majority of people to be in favour of a policy of people with a mental handicap living in the community. But Locker et al. (1981) also claimed that only half of their sample had heard of the term Community Care, and less than a third could define it. Whilst our results are not directly comparable - we asked for no definitions, for example - the impression was that most people did understand the term, and many gave quite acceptable reasons for endorsing it, using concepts of integration, normalisation, human rights and general awareness.

But an important qualification to both our study and that of Locker et al. (1981) is that endorsement of Community Care policy in a
general sense is not directly related to particular attitudes about existing or potential group homes.

We examined the data to see whether any of the attitudes or experiences covered in the survey were related to each other. For example, was perception of problems related to perception of benefits, or to willingness to help, or to approval of community care policy? In fact, no significant associations between these attitudes were found.

Perceived Benefits

In question 12 or 16 (depending on the presence of the group home) we enquired about perceived benefits for the neighbourhood in having a group home. This question was more discriminating than the Policy question: - 48% of the total sample did perceive benefits. In fact, the presence or absence of a group home was not a significant factor in determining perceived benefits. The data were examined to see whether different types of benefits might be perceived according to whether or not respondents had a group home in their area, but again no statistically significant pattern of differences was found.

The types of benefits were categorised from the open-ended responses to the question, "What might (these benefits) be?" and these appear in Table 16 below. Of the 96 respondents who said, "Yes, there might be benefits," 81 (84%) were able to state what benefit there might be. Raw figures are provided in Table 16, and, again, with the caveat that these categories of response overlap to some extent and are arbitrary.
Table 16. Number of people perceiving benefits

<table>
<thead>
<tr>
<th>Type of benefit mentioned</th>
<th>Number who mentioned it</th>
</tr>
</thead>
<tbody>
<tr>
<td>Makes public more aware/bring about better understanding/helps us cope with mentally</td>
<td>24</td>
</tr>
<tr>
<td>handicapped people</td>
<td></td>
</tr>
<tr>
<td>Good for the children to mix, learn, know about</td>
<td>19</td>
</tr>
<tr>
<td>Makes you appreciate what you have/ helps you see what life is like for others</td>
<td>8</td>
</tr>
<tr>
<td>Brings the community together/provides a purpose/brings services to the area</td>
<td>11</td>
</tr>
<tr>
<td>General comments</td>
<td>13</td>
</tr>
<tr>
<td>Other comments</td>
<td>6</td>
</tr>
<tr>
<td>Don't know</td>
<td>15</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>96</strong></td>
</tr>
</tbody>
</table>

The data was analysed to see if there were any characteristics such as age, sex, education, contact etc. which distinguished those who perceived benefits from those who didn't. At the 1\% level of significance only one factor emerged as important: whether or not the respondent had ever done voluntary work involved in the area of mental handicap: 70\% of those who had done voluntary work involving mental handicap could perceive benefits, as against 41\% of those with no experience of voluntary work.

At the 5\% level of significance there was some evidence that the following characteristics were associated with perceiving benefits: living in a private housing area, having previous contact with mentally
handicapped people, and having more years of education. It is possible that a larger total sample size might have confirmed these as significant factors at the 1% level.

We went on to analyse the (on the face of it) reasonable hypothesis that those who saw benefits were less likely to perceive problems, but no significant association between the two variables was found.

**Willingness to become more involved**

In Question 17 we enquired into respondents' willingness to help, have contact or become more involved in the group home. Respondents who were in a group home area (and were aware of it) were asked, "As you know, handicapped people can do with some extra help. If you were asked, would you be interested in -" followed by a list of 6 possible ways of helping out.

Respondents from the areas with no group home were given the more hypothetical introductory form, "As you know, handicapped people can do with some extra help. If a group of mentally handicapped people were to move into your area and the staff living with them asked you for help, would you be interested in -" followed by the same 6 possible ways of helping out.

For each of the 6 ways of helping respondents could choose one of three possible answers, namely "Very interested"; "Perhaps but wouldn't have the time" or "Prefer not".

Table 17 below shows the percentage of people selecting the "Very interested" option for each type of involvement. As can be seen, for all 6 types of involvement, more willingness was expressed by respondents in the No Group Home areas (including those in a group home area but who were unaware of its existence) than by respondents who knew they were in a group home area. This cumulative difference was significant at the \( p = < 0.001 \) level (chi-square), and the individual significance levels appear in the right hand column.
Table 17. Percentage of people "Very Interested" in helping

<table>
<thead>
<tr>
<th>Type of involvement</th>
<th>Knew of Group home</th>
<th>No Group Home</th>
<th>Significance Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help out in an emergency</td>
<td>79.7</td>
<td>82.5</td>
<td>Not sig.</td>
</tr>
<tr>
<td>Make a point of talking to them</td>
<td>54.1</td>
<td>84.9</td>
<td>$&lt; 0.001$</td>
</tr>
<tr>
<td>Go along to an open day or coffee evening</td>
<td>51.4</td>
<td>69.0</td>
<td>$&lt; 0.05$</td>
</tr>
<tr>
<td>Have a handicapped person visit my home</td>
<td>28.4</td>
<td>54.0</td>
<td>$&lt; 0.01$</td>
</tr>
<tr>
<td>Go once a week to the home to visit them</td>
<td>23.0</td>
<td>43.7</td>
<td>$&lt; 0.01$</td>
</tr>
<tr>
<td>Take a handicapped person on an outing once in a while e.g. the church, shopping etc.</td>
<td>21.6</td>
<td>39.7</td>
<td>$&lt; 0.01$</td>
</tr>
</tbody>
</table>

The 6 types of involvement vary in degree and quality of contact. The first three in Table 17 consist of a relatively small amount of commitment and personal involvement and could be described as Impersonal, whereas the last three would constitute more personal commitment and time, and could be described as Personal.

The data was analysed in terms of those respondents unwilling to give any help, those only willing to commit themselves to one, two or all three items of impersonal help, those willing to commit themselves to one or more personal types of help (as well as impersonal) and those willing to help on all six items. Again, respondents from group home areas were compared with no group home area respondents, and the results are presented in Table 18 below.
### Table 18 Type of help willing to give by presence or absence of group home. Percentages.

<table>
<thead>
<tr>
<th>Amount of help</th>
<th>None</th>
<th>Impersonal only</th>
<th>Some Personal help</th>
<th>All six types of help</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Group Home</td>
<td>27.0</td>
<td>13.5</td>
<td>34.9</td>
<td>26.4</td>
</tr>
<tr>
<td>Group Home</td>
<td>25.7</td>
<td>29.7</td>
<td>29.7</td>
<td>14.9</td>
</tr>
</tbody>
</table>

Chi-Square = 8.82  Significance = 0.032

Although the differences in Table 18 do not each an acceptable level of significance overall, there does appear to be a meaningful pattern to the results. Considering those who are unwilling to give any help, there is no difference between those in group home or no group home areas. Presumably to those who don't want to help it doesn't matter whether there is an opportunity to do so or not.

Considering those offering impersonal help only, there are more in the Group Home areas than in the no group home areas, by a factor of more than two. This probably reflects the reluctance of many of those in the group home areas to commit themselves to any more than this degree of impersonal help, in case they were taken up on their offers. The differences between groups in the category of those offering some personal help are too small to comment on.

Considering those willing to commit themselves to all six types of help, there are more of these individuals in the group home areas, probably because these people knew there was less chance of their offers being taken up.
Discussion and Implications

A stated aim of community care policy is promotion of integration of people with mental handicap into the community. If this policy is working it should be reflected both in the amount of contact mentally handicapped people have with others in the community, and in the amount of contact a representative sample of the community has with mentally handicapped people.

In our survey the respondents in the group home areas could be expected to have more than average contact with mentally handicapped people – they were actually local neighbours. But one of the most striking results of our survey was just how little meaningful contact there was between the group home residents and their neighbours. Only 22% of those who were, in the first place, aware of the group home's existence had ever met or talked with their mentally handicapped neighbours. Of these, only 9 people had ever been inside the group home and there were only 5 cases of a mentally handicapped person visiting a neighbour's home. For the vast majority there had been no contact at all beyond seeing them around or occasionally saying hello in the street.

This is in the context of quite a high level of general community involvement: 50% knew more than 15 other households in their neighbourhood 58.5% were involved in 3 or more community activities and 50% rated themselves as having frequent and regular contact with their neighbours.

It should be noted that our survey results do not measure the total amount of contact of the group home residents within the community. Both staff and the mentally handicapped residents would report many more contacts within the broader community, including shops, pub and workshop.

Our survey focuses on the impact of group homes from the neighbourhood's point of view.

The very limited amount of personal contact between the mentally handicapped residents and their neighbours found in our survey corresponds closely with the findings of the Locker et al. study (1981) in London.
Only 6% of their respondents had visited the group home and only 2% had been visited by a mentally handicapped resident.

But a majority of respondents (74%) did at least know of the existence of the group home though some of these did not know exactly what kind of people lived there. There was a large and significant difference between the 92% who knew of the group home in Lorcan Avenue and the 56% in Dunard Road. Apart from the difference between Private and Corporation housing areas there are two other factors which may underlie this difference. First, the Lorcan Avenue group home had been established about 2 years earlier than the Dunard Road home, so neighbours would obviously have had more time to get to know of its existence. Against this is the fact that there were no significant differences between the two areas in terms of degree of contact with other neighbours or the number of community activities people were involved in. Second, a glance at the two detailed street maps in the Appendix shows that, whereas in Lorcan Avenue many local residents would pass the group home, in Dunard Road, the fact that the group home is in a corner of the whole estate means that many people would never pass by the house on their way to work or shops or other destinations.

The results imply that it is worth taking this sort of detail into great consideration in the choice of a group home in the first place. Main roads, quiet locations and large frontages may function as barriers to closer community contacts, whereas proximity to shops, central location and open access may facilitate contacts.

The fact that neighbours' contact with the group home staff was even less than with the mentally handicapped residents probably relates to the staff having their own homes elsewhere in the city. They would sleep over in the group home on a roster system, but this by itself does not seem sufficient to be part of the community. Only 3 respondents knew one or more names of the staff, compared with 50% who knew the names of 15 or more other families in the area.
On the positive side, the fact that most respondents had had hardly any contact with the group home apart from seeing them around does in itself indicate there had been no negative involvement, and no active complaints. When asked the open-ended question, not one single person thought there had been any problems or difficulties associated with the group home, of those respondents actually in the two group home areas.

Most of these people, quite rightly, seemed to interpret the open question about problems in a general sense, and probably as "no significant problems". When we went on to ask about the nine specific areas of potential problems, both for the handicapped people and the neighbours themselves, there was no contradiction in people agreeing to some of these problems even though they had denied them in a general sense.

In contrast, of those not in a group home area (including those who thought they were not) 19% did say that they would anticipate problems if a group home was opened up in their neighbourhood. This contrast was also evident in the list of 9 possible problem areas for respondents to consider. For all 9 problems people in the no group home condition anticipated a higher potential incidence of the problem than did the respondents in the actual group home condition. Clearly the fear or threat of a group home opening up is worse than the actuality.

It is tempting to conclude that this also indicates that contact with a group home makes people more favourably disposed towards them. But as we have already seen, the overall level of contact with the group homes was very low. It is safer to conclude it is the knowing of the existence of the group home and also knowing that no neighbourhood problems have arisen from it makes people more favourably disposed towards them, and this is in line with related research showing the decrease of objection and unfavourable attitudes with time (Locker et al. 1981, Baker et al. 1977).

Both the group home and the no group home conditions perceived more problems for the mentally handicapped people than for the neighbourhood.
Whilst this probably reflects genuine concern for the needs of people with mental handicap it is also possible that a social acceptability factor was operating here. If a person has some resistance to group homes it is easier to couch objections in terms of the neighbourhood not being right for the mentally handicapped people rather than vice versa.

It would be interesting to know how closely the actual or potential problems for mentally handicapped residents as perceived by neighbours actually relates to the problems perceived by the mentally handicapped residents themselves. Whilst neighbours put teasing and victimisation at the top of the list we would guess that isolation and loneliness would present as more significant problems for people with a mental handicap.

In this study we found very few independent variables related to the attitudes under examination. For perceived problems, there was a tendency for those with more education and those living in private housing to express as much concern for problems affecting themselves as for problems affecting the mentally handicapped residents. Those living in corporation estates and those with less education tended to express more concern for the mentally handicapped people. It may be that more educated people have fewer inhibitions about expressing more self-concern. Another reason might be that those in the corporation estates genuinely felt this was a tougher environment for a handicapped person to survive within.

The fact that neither age, sex, marital status, or employment status was related to perceived problems is not really surprising. Previous studies have failed to show any consistent pattern for these variables or else have shwon no significant differences (Okola and Guskin 1984, Furnham and Pendred 1983).

Similarly, there were hardly any reliable characteristics found to be related to perception of benefits of people with a mental handicap living in the community, or to approval of general community care policy.
A majority of those who had done voluntary work involving mental handicap could perceive benefits. There was a slight tendency for those with previous contact to perceive more benefits of mentally handicapped people living in the community, but these associations only reached a 5% level of statistical significance.

Whilst these associations have some face validity and are in the expected direction, it is recognised that a 5% level of significance is unacceptable for making any conclusions - one in twenty such associations would be found to be significant from chance effects alone and we made in the region of 300 such comparisons in the whole study.

Our question on whether community care was a good policy proved to be not very discriminating. Only 2.5% thought it was not such a good policy. This finding can be taken as evidence to support the evidence of Locker et al. (1981) that there has been increasing public support for community care. Most national surveys (MENCAP 1982, Presidents Committee on Mental Retardation 1975, Weir 1981) have confined themselves to such general attitude questions as our one on policy. There is only limited usefulness to this approach. General questions can only produce vague and general answers.

The big disadvantage is that being generally favourably disposed towards people with mental handicap and approving of community care does not predict how a person will feel about having a group home set up in the house next door but one. A generally favourable attitude towards handicapped people is not likely to be a good predictor of contact with handicapped people, willingness to become more involved, or perceptions of problems.

For these reasons our own survey was very specific. Our sample consisted not only of those who actually lived in a group home but also those who were asked for their attitudes "if a group home was set up in that vacant house down the road". In the group home areas we asked how much specific contact there had been, and neighbours...
actual experience of problems or benefits and about anticipated problems or benefits in the areas with no group homes. In both areas we went on to ask in detail about how prepared respondents would be to have further contact with handicapped people, or how willing they might be to help out.

In many ways this provided a measure of practical commitment to the stated attitudes of respondents. Despite an inevitable tendency towards socially desirable answers, people in the group home areas in particular were observed to think fairly carefully before committing themselves to practical help and involvement. They knew that they might be called upon to fulfil any promises they made.

This difference is mainly reflected in the three items of personal help or contact in Table 18. Fewer people in the group home areas were willing to commit themselves to visits or accompanying on outings than in the no group home areas. For more impersonal help, such as saying hello in the street, or going to an open day, this difference was not so marked. Presumably for all kinds of help, those in the no group areas thought that it was still more of a hypothetical question, or still a long way off before there was any chance of being taken up on their offers.

These results do indicate the very real difference between a general favourable attitude and a specific favourable commitment. It is likely that if those who said they were prepared to visit a handicapped person were given the opportunity to do this in the following week, there would be an even greater falling off.

Nevertheless, even if the figures are looked at conservatively and with qualifications, there does seem to be a lot of untapped good will and specific commitment within the community towards people with mental handicap. Considering the group home areas, even if only half of those who said they were prepared to help in some personal ways actually did so when given the opportunity, there would be roughly
1 in 8 of the neighbours available to provide this kind of support. Even two or three such people can make a considerable difference to the quality of social life of a handicapped person.

General Conclusions and Implications

This survey was carried out in Dublin city and there may be differences between rural Ireland and the major cities. It was also restricted to two group home areas and two further control areas, and whilst these were selected as being representative a larger survey might produce qualifications or additions to the present findings. Nevertheless, some broad conclusions are permissible.

First, there seems to be comparatively little meaningful contact between the residents and staff of the group homes and their immediate neighbours within the community. This was recognised as a major concern for the mentally handicapped residents by their neighboursː they thought the people in the group home were isolated.

Second, people had not experienced any serious problems for themselves as a result of the group home, but they were more concerned for problems experienced by the mentally handicapped residents, especially being teased and feeling isolated.

Third, there are many more problems, both for neighbours and for people with a mental handicap, that are anticipated by those in no group home areas than are actually experienced by those in the group home areas.

Fourth, the public at large appear to show favourable general attitudes towards people with mental handicap living within the community.

Fifth, there appears to be some willingness to help or become more involved among a significant proportion of the population, and this resource is under exploited.

Some obvious implications emerge from these findings. More community contact might arise if the staff were local people, or if fostering or adoptive families replaced group homes. In some
circumstances a combination of these alternatives might be possible, such as care staff being based, during daytime and evenings perhaps, in the home of a fostering family.

Otherwise, if the basic group home system is preserved, it would appear that a conscious effort is needed to promote more local involvement. Whilst this initiative probably needs to come from the service agencies, the evidence suggests that a significant proportion of neighbours would welcome the opportunity for closer contact and involvement. The apprehension that contacting and sounding out neighbours might stir up opposition does not seem to be warranted.

This point would apply also at the stage of setting up a group home. In selecting the house and neighbourhood two approaches may be discerned; the Machiavellian approach and the collaborative approach. (Okolo and Guskin 1984).

The Machiavellian approach, recommended by Sigelman (1976) involves group homes being established with a minimum of publicity and advance notice, under the rationale that this minimises the chance for potential objectors to organise opposition. Problems should be taken as they come, without looking for possible difficulties in advance.

In contrast those supporting a collaborative approach argue that community awareness and involvement form an integral component at every stage of any community placement programme. There is some evidence that failure to involve local residents in the planning stages of establishing group homes has been the cause of later opposition (Berdiansky and Parker 1977, Okolo and Guskin 1984).

Rather than withhold information for fear of arousing antagonism, it would be preferable to reassure potential neighbours beforehand about some of the problems that they do not need to worry about. McConkey (1987) has suggested that one effective way of countering community opposition is for critics to meet with residents from comparable areas where a group home already exists.
Finally, whilst good will and favourable attitudes exist at present for people with a mental handicap living in the community, it is important to monitor this situation in future years. The reality is that increasing numbers of both people with a mental handicap and people with a mental illness will be placed within the community. It is important to check that this policy is actually working in the best interests of everyone, and that the aim is properly pursued that people with a handicap become part of the community rather than merely located in the community.
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GROUP HOME QUESTIONNAIRE

NAME .......................... Address .......................... Code ........

SEX .......................... Interviewer .......................... Date ........

Date of previous calls ..........................

I'm from the University and we are carrying out a survey into disabled people living in this neighbourhood. Can I have about 5 minutes of your time to answer some simple questions?

1. How long have you been living in the neighbourhood?
   1) Less than 1 year  2) 1-2 years  3) 3-5 years  4) over 5 years

2. How many families would you know by name within 15 minutes walking distance of your house?
   1) None  2) 1 or 2  3) 3 to 5  4) 6 to 15  5) 16+

3. How many of these families are related to you?
   1) None  2) 1 or 2  3) 3 to 5  4) 6 to 15  5) 16+

4. Would you say that, in general, you have:
   1) only occasional contact with your neighbours (1)
   2) Some contact now and again with your neighbours (2)
   3) Frequent and regular contact with your neighbours (3)

5. What activities are you regularly involved in at present within this area, that is you could walk to them within 15 minutes. To you go to
   NO YES
   a) any sports or other clubs in this area ........................(1)  (2)
   b) any pubs in this area ...........................................(1)  (2)
   c) bingo or dances ...................................................(1)  (2)
   d) any churches in the area ...........................................(1)  (2)
   e) any meetings at school..............................................(1)  (2)
   f) Residents' association or Neighbourhood Watch ..................(1)  (2)
   g) any other activities ...............................................(1)  (2)

(please specify)

6. Can I ask what contact you have had with disabled people in your neighbourhood -
   1) No contact  2) Seen them around  3) Occasional meetings  4) Regular contact

   Are they mentally handicapped people?  1) NO  2) YES

7. Thinking of mentally handicapped people in general, can I ask what contact you have had with mentally handicapped children or adults -
   1) No real contact  2) Just seen them around  3) Met and talked with them  4) Regular contact

7X. There is now a national policy of having mentally handicapped people living wherever possible within the local community. Do you think that -
   1) on the whole this is a good policy  2) ... a not so good policy

   3) you have no opinion one way or the other - Go to (x)

   If answers 1 or 2; then ask - Why is this?
Is there a house that is occupied by a group of handicapped people in this neighbourhood.
1) YES, there is  2)I don't know  3)NO, there is not - Section 3

Whereabouts is it? If not the house ask 8b
Any others? 
What sort of handicapped people live there?

How many of the PEOPLE would you know by name?

How many of the STAFF would you know by name?

What contact have you had with the handicapped people from the home?
For example,

a) Have you seen them around the neighbourhood
b) Have you talked to them outside
c) Have you been into their home?
d) Have any been into your house?
e) Have you had any other contact

How was the contact made -
1) you approached the handicapped person 2) they approached you
3) introduced by staff 4) other/can't recall

What contact have you had with the STAFF who work in the home?
For example,

a) Have you seen them around the neighbourhood
b) Have you talked to them outside
c) Have you been into their home?
d) Have any been into your house?
e) Have you had any other contact

How was the contact made -
1) you approached the staff person 2) they approached you
3) introduced by handicapped person 4) other/can't recall

Has anyone else in your household had contact with people from the group home? 1) No 2) Yes
If YES: Who? 
What contact have they had?

Do you think that there have been any problems or difficulties in the neighbourhood resulting from handicapped people occupying that house?
No (1) Yes (2)
What problems have there been?
Probes: Any others?
13. Can I just check some (other) problems that other people have suggested in previous surveys. I'd like to know if you have found any of these things to be a problem with regard to the home for mentally handicapped persons in your neighbourhood.

N.B. 1 = Yes, that has been a bit of a problem
2 = No problem that I am aware of (3 = Can't decide)

a) The mentally handicapped people being teased, made fun of or jeered at. 1 2 3
b) The M.H. people not receiving adequate prof. care and supervision. 1 2 3
c) They have been isolated and just kept to themselves 1 2 3
d) They have been victimised, picked on or taken advantage of 1 2 3
e) They have been a danger or threat to children. 1 2 3
f) They have made people embarrassed. People haven't known what to say to them or how to react to them. 1 2 3
g) The M.H. people have been noisy and created disturbances 1 2 3
h) The property value of neighbourhood houses has dropped or the tone of the area has been lowered. 1 2 3
i) The M.H. people have been violent or irresponsible. 1 2 3

14. Do you think there has been any benefits for the neighbourhood in having these people living in your area?
1) None that you can think of 2) Yes there have been

Can you say what these are -

GO TO SECTION 4

SECTION 3 : (Areas with NO group home)

15X. If a house for three or four mentally handicapped people with one or two care staff started up in your neighbourhood, for example, at that house over there/down the road/round the corner which is vacant, do you think that this would give rise to any problems in the neighbourhood?

No, it wouldn't (1) Yes it would (2)

What might these problems be?

Probe: Any others?

Can I check some (other) problems that other people have suggested in previous surveys. See if you think there would be a risk of that problem arising in your neighbourhood.

N.B. 1 = That could be a risk in this neighbourhood
2 = No risk that you can think of (3 = Can't decide)
15 a) The M.H. people would be teased, made fun of or jeered at. 1 2 3
b) The M.H. people might not receive adequate professional care and supervision. 1 2 3
c) They might feel isolated and just keep to themselves. 1 2 3
d) They might be victimised, picked on or taken advantage of. 1 2 3
e) They would be a danger or threat to children. 1 2 3
f) They would make people embarrassed. People would not know what to say to them or how to react to them. 1 2 3
g) The M.H. people would be noisy and create disturbances. 1 2 3
h) The property value of neighbourhood houses would drop and the tone of the neighbourhood would be lowered. 1 2 3
i) The M.H. people would be violent or irresponsible. 1 2 3

16 Do you think there could be any benefits for the neighbourhood if a group of mentally handicapped people moved in to the area.
1) None, that you can think of 2) Yes there might.
Can you say what these might be?

SECTION 4

17. AREAS WITH GROUP HOME: As you know handicapped people can do with some extra help. If you were asked, would you be interested in -

AREAS WITH NO GROUP HOME: As you know, handicapped people can do with some extra help. If a group of mentally handicapped people were to move into your area and the staff living with them asked you for help, would you be interested in

N.B. 1. Very Interested : 2. Perhaps but wouldn't have the time 3: Prefer not

a) Taking a handicapped person from the home along with you on an outing once in a while, e.g. to church, shopping 1 2 3
b) Go once a week to the home to visit them 1 2 3
c) Helping out the staff in an emergency 1 2 3
d) Having a handicapped person come to your home on a visit or for a cup of tea 1 2 3
e) Go along to an Open Day or Coffee evening in the house 1 2 3
f) Make a point of talking to the person if you saw them around the neighbourhood or when shopping etc. 1 2 3
FINALLY CAN I ASK SOME QUESTIONS ABOUT YOURSELF?

16 Are you aged: 1) Less than 20  2) 20-39  3) 40-59  4) 60+

19 Did you leave school at 1) 15 years
       2) go on to leaving cert
       3) go on to 3rd level

20 Are you - 1) working full-time  2) part-time  3) full-time student
       4) unemployed  5) housewife  6) retired

21 Are you single (1)  Married (2)
      Have you a child under 16 years?  1) No  2) yes

22 Is your house/accommodation 1) rented  2) Owned/Bought out by you
      Is it (1) private  2) Corporation

23 Have you ever been involved in any form of voluntary work?
      1) No  2) Yes, in the past  3) Yes, at present

      If YES: Did/does it involve any contact with mentally handicapped people?
      1) No  2) Yes

H. B. HAND-OVER THANK-YOU SHEET AND EXPLAIN

24 Any further comments you would like to make about mentally handicapped people living in the community?
SECTION THREE

RESEARCH STUDY TWO.

DOCTORATE RESEARCH STUDY.

1997.

FAMILY CONTACTS OF PEOPLE WITH LEARNING DISABILITY WHO ARE IN RESIDENTIAL CARE.
ABSTRACT.

Family contacts of a representative sample of 179 people with learning disability who are in residential care were examined in a correlational study which included the variables of years in residential care, family members who are left, distance between family and residential unit, type of residential unit, and the client characteristics of age, sex, I.Q., degree of social competence, behaviour disturbance and presence of additional psychiatric difficulties.

Overall low rates of family visitation were found. Half the people had had no overnight stays with family and less than 6 visits from family within the last year, and 24% had no direct family contacts at all.

The age-related factors of years spent in residential care, who is left in the family, and the client's age were all significantly negatively associated with family contacts, and distance between residential unit and family was also associated with low family contact rates. An interpretation based on lifespan development seemed best able to account for the findings.

A discriminative model based on a logistic regression analysis indicated that the age-related variables accounted for most of the variance, after which behaviour disturbance and degree of social competence also contributed to accounting for the remaining variance.

The implications of the findings for public policies which emphasise the role of the family are discussed.
CHAPTER 1.

INTRODUCTION.

In much of the literature concerned with people with learning disability who are in residential care, there is an assumption that there is a high level of involvement from their families. In this review and research thesis it is argued that family involvement cannot be taken for granted, and evidence is adduced to suggest that, despite current ideology and policies designed to promote family involvement, in practice there is a generally low rate of contact between people with learning disability in residential care and their family members. The underlying factors associated with family involvement are critically examined.

Most commentators in the area of family involvement of people with learning disability refer to two competing ideologies which have influenced policies and practices. The first ideological influence can be traced back to the deinstitutionalisation movement (Hunt, 1966; Goffman, 1961) together with acceptance of the principles of normalisation (Wolfensberger, 1972) which started in the 1960s and gained momentum in the 1970s. Together with work from Bowlby (1980) who stressed the primacy of parental nurture, the ideology states that residential care is detrimental to personal and social development, and it should be avoided or delayed until as late an age as possible. The enduring quality of family attachment is emphasised, as well as the rights of children to remain within their family and home and community. A corollary to this ideology is that if residential care becomes necessary, then it should be within the community and made as similar as possible to a family home (Dept. of Health (S. Ireland), 1990). Family involvement should be maintained at a high level throughout a person's life because of its crucial importance (Blacher and Baker, 1992).
The second ideology, which can also claim its provenance from normalisation principles, assumes that people with a learning disability, like other people, should gain independence over time and move out of the family home to develop their own lives (McConkey, 1987). They should find their own place within the community, make their own friends and relationships and develop their own interests, and their social role within the community should be valued as much as any other person’s. Smith and Brown (1992) have edited a collection of papers on current interpretations of normalisation and social role valorization, which emphasises the rights of independence for a person with learning disability. Within this view there is stress on the need for a transition from home to community in order to develop independent living skills (Hill and Bruininks, 1981).

In theory there need be no contradiction between these two influences: a person with learning disability could live at home until completion of education, then move out into a group home in the community but maintain close family ties for the rest of his life. Both these ideologies centre around the needs and rights of the person with learning disability and involve an unsubstantiated but implicit assumption that this accords with the needs and rights of the parents and other family members.

A third and much older influence can be discerned, but is rarely alluded to directly in the literature. This is the attitude that having a son or daughter with a learning disability is a misfortune and a burden for the parents, and that placement within a specialist institutional setting is the most appropriate course of action (Mayer-Gross, Slater and Roth, 1974): it is preferable for families to detach themselves from the person with learning disability in order for the remaining family members to achieve their own development and lifespan tasks. An ancillary attitude can be that the specialist learning disability services will provide for the total needs of the person with learning disability and family involvement may be upsetting or an unnecessary interference. Okolo and Guskin (1984) have noted that during the 1970s it was still very common for professionals to promote the benefits of specialist institutional care to parents on the basis of the need for 24 hour care and supervision (see also Mayer-Gross et al., 1974).
The link between current ideological influences and actual behaviour and attitudes of families who have a learning disabled close relative remains speculative. Most researchers in this area have focused on the measured behaviour and known characteristics of the people with learning disabilities and their families and only a few have examined feelings and attitudes regarding the decision to seek placement and subsequent feelings and attitudes towards involvement following placement (Blacher and Baker, 1994b; Sherman, 1988; Tausig, 1985). Only one study (Hill, Lakin, Bruininks, Amado, Anderson, and Copher, 1989) has examined the feelings of the people with learning disability regarding family contact or its absence, and they found that about half would have wanted more family contact and almost none wanted less.

The policies promoted by government departments emphasise the primacy of the family's role and their partnership in the care, development and maintenance of the person with learning disability throughout the lifespan (D.H.S.S., 1971; D.H.S.S., 1983; Dept, of Health, (Southern Ireland) 1986; Welsh Office, 1978; Welsh Office, 1983). This view is reinforced by advocacy bodies (e.g. Campaign for Mentally Handicapped People (CMH), 1980), and this view is usually reflected in the mission statements of the care provider agencies (e.g. King's Fund Centre, 1980). Kelleher, Kavanagh and McCarthy (1988) have sampled agencies' objectives which stress the partnership with family and the importance of "promoting contacts with parents, relatives and persons in the community" (p. 88). Most learning disability services in the 1990s provide training for their nursing and houseparent staff which emphasises the importance of community involvement and family contacts. A very similar emphasis is made in most of the patients' charters of people with learning disability, where the rights of access to normal community, social and family contacts are usually stressed.

These aspirations can fly in the face of evidence that in the U.S.A. a majority of people with learning disability have minimal contact with their family members, and a significant proportion have no such contact at all (Hill, Lakin, Bruininks, Amado, Anderson and Copher, 1989; Anderson, Lakin, Hill and Chen, 1992). Failure to address the issue of low family involvement with people in residential care who have learning disability can lead
to positions of confusion and hypocrisy. The primary objectives of the present study were to determine what are the current rates of family contacts for people in residential care in Southern Ireland, and to examine what factors are associated with contact rates, and to consider the implications for services.

The main body of research in this area has addressed the question of what factors determine the amount of family involvement a person in residential care receives. The factors can be considered within the following three categories:-

1. characteristics of the person with learning disability, including age, I.Q., level of social competence, degree of behaviour disturbance,
2. characteristics of the family, including socioeconomic and educational status, number of children, marital status, stressors and supports, and
3. intermediate or other factors, including distance between home and residential unit, attributes of the residential unit and the care staff, involvement in decisions about care.

**Family involvement and family contacts.**

Family involvement in the general sense of the term can include family members' feelings and attitudes toward the person in residential care, their involvement in placement and programme decisions, their visitation contacts and their indirect contacts by phone or by letters and gifts, and contacts with the staff in the residential units about the person's welfare and progress. All these forms of involvement have been examined by researchers in this field, but by far the most frequent measure of involvement has been visitation rates, usually with a distinction made between visits to the residential setting by family and visits or holidays at home with family members. Measures of visitation have the advantages that they are meaningful, direct, behavioural and they include both parties- the person in care and the family.

The most frequent and reliable finding is that overall family contact rates for people in
residential care with learning disability are very low. A representative study was carried out by Hill, Lakin, Bruininks, Amado, Anderson and Copher (1989) who found that 50% of their residential population were never visited by a family member. Some did make visits home themselves, but there were still 31% left who had no contact at all with their families. In an earlier study of 965 representative residents, Hill, Rotegard and Bruininks (1984) had found that 20% had no personal contact with any relatives (although some received letters and gifts), 60% received visits from family members, usually parents, from one to three times a year, and 20% received more frequent contact.

In their sample of older persons with learning disability Anderson et al., (1992) found that 51% were never visited by family members, but 24% of their total population had no known living family members. Willer and Intagliata (1982) also found that almost half of all residents were never visited by family members, and more recently Stoneman and Crapps (1990) found that approximately half of their residents living in family foster homes were never visited and never travelled to see their families. Lowe and de Paiva (1991) indicated that between 18% and 31% of residents in their study had no contact with their family.

This review and the present research study covers family contacts over the whole age range, but a distinction must be made between adults and children because there have been significant policy changes over the last twenty years which emphasise the primacy of the family for children and the importance of family access if a child is in care. This is reflected in the U.S. Public Law 94-142, The Education For All Handicapped Children Act, the U.K. Children Act 1989, and D.H.S.S. 1990, People First, and Southern Irish legislation (The Child Care Act 1991). A study by Anderson et al. (1975) in the 1970s did not show visitation rates for children to differ from adult rates by very much at all:- 44% of children were visited "seldom or never" by their parents. A much more recent study examined family involvement with children who (1) had learning disability, (2) had psychiatric disorder, and (3) had both learning disability and psychiatric disorder (Baker, Blacher and Pfeiffer, 1993). Sample size was 234 and the age range was from 5 to 19 years. Almost one third of the children had no family contact and about 50% had three or less contacts.
per year. Although dually diagnosed children had the lowest rates of family involvement, the visitation rates for the children with learning disability did not differ from the rates for children with a psychiatric disorder.

In one of the very few longitudinal studies Blacher and Baker (1994b) claimed, in contrast to most previous research, that there was no evidence of a decrease in family visitation or other measures of parental involvement for children who had started in residential care. There are grounds for doubting the long term validity of their claim. The sample size was only 55 and does not seem to have been representative because three quarters of parents were college educated- a characteristic that is known from other studies to predict high levels of involvement (Stoneman and Crapps, 1990). The two post-placement follow-ups took place within a period of only one year later so it is too early to predict what the pattern would be after more years.

Whilst it is probable that placement decisions and visitation habits are changing over time there is not yet enough evidence to affirm this.

There was one early published Irish study on family contacts of people in residential care, and this was one question contained in the Census of the Mentally Handicapped in the Republic of Ireland, 1974 (Mulcahy, 1976). A question about visitation was an unusual item to be contained in a national census of all 8,138 people in residential care in the country, which was designed to obtain basic demographic information (age, sex, location, length of stay, level of disability, additional incapacities and day placement). The category frequency of visits to the residential centre was asked for, and it was assumed that only family members were likely to make such visits.

Of the total residential population, 21% were never visited, and a further 20% were visited only once a year, 28% were visited occasionally (several times a year) and 31% were visited monthly or more often. Mulcahy (1976) broke these figures down into three age categories which showed that the frequency of visiting declined with the age of the resident, but no further analyses were offered. Nevertheless, this was an important and
totally representative study which indicated very low visitation rates for people who for
the most part were resident within an institutional setting at that time.

Following publication of that census most of the national newspapers seized on this one
finding of low visitation rates in a spirit of national outcry and shame that so many people
in residential care received minimal contact from family or the outside world. Perhaps this
should not have so surprising. After all, approximately 95% of the residents lived within
large scale institutions at that time and 34% were still located within large psychiatric
hospitals. In 1974 the ideological influences of normalisation and the importance of family
involvement in residential treatment had only started to percolate through to sections of
the learning disability services and the public at large could not have been expected to
have been much affected by such influences.

Another later Irish study entitled "Home Together" (Kelleher et al., 1988) examined a
population of people representative of those living in the recently established community
group homes throughout the country in 1984. So many changes in residential provision
have occurred within the 13 years since this study was carried out that it can no longer
claim to be representative:- the first cohorts of people going into group homes were
younger, including many children, and more able, and with fewer additional disorders or
disabilities. In the Kelleher study nearly half of the group homes catered for children and
only 10% of their residential population were within the severe or profound disability
range whereas the 1997 National Database (Mulcahey, 1997) indicates that currently only
6.2% of the total residential population are children, and a much higher percentage
(43.0%) are functioning within the severe or profound disability range.

There are strong grounds for believing that people currently attending group homes in
Ireland have different characteristics from those attending 13 years ago, and that the
service itself has also changed. It is for these reasons that Bratt and Johnston (1988) have
recommended evaluating "second generation" cohorts. Kelleher et al. (1988) found that
nearly half of the group home residents went home every weekend, and when other forms
of contact were included, two thirds of residents had weekly contact with family members.
These apparently very high contact rates were inflated by excluding cases where parents were deceased or their whereabouts were unknown, which constituted 22% of the total sample. Another factor explaining the very high rates for family contact was that 34% of the group homes operated on a five-day week basis:- the residents in these group homes were contracted to go home every weekend. In contrast to the high rates for visits home, Kelleher et al. (1988) found that 51% never received visits from family members, which is a figure much more in keeping with other research findings (e.g. Hill et al., 1989).

The study of Kelleher et al. (1988) illustrates some of the methodological problems and difficulties of representativeness which plague research in this area. Residential services and placement policies have changed so dramatically in most western countries over the last two or three decades that it is very difficult to make meaningful comparisons between different studies.

Methodological issues.

There are only a small number of studies which fall fully within the area of family contacts of people with learning disability who are in residential care, and two U.S.A. research teams dominate the field, one based in Minneapolis and including Hill, Lakin, Bruininks and Anderson, and the other based in California and including Baker and Blacher. In Wales some of the studies from Felce and his associates have been partially focused on family contacts within the context of community residential developments (Felce, Lunt and Kushlick, 1980; Perry and Felce, 1994; de Kock, Saxby, Thomas and Felce, 1988). In Ireland McConkey and associated workers have focused on community contacts and integration (McConkey, 1987; Kelleher et al., 1988, Clarke, 1988), but family contacts represented only a marginal aspect of these studies.

Nearly all the studies on family contacts are cross sectional and within that a majority are correlational studies. The few longitudinal studies which exist cover a whole range of behaviours and characteristics of people in residential care, and family contacts constitute
only a small section of these studies and may be dealt with only cursorily, as for example in the studies of Evans, Todd, Beyer, Felce and Perry (1994), Shalock and Lilly (1986), and Lowe and de Paiva (1991). One longitudinal study which focused primarily on family contacts (Blacher and Baker, 1994b) covered a two year period and indicated very little drop-off in contacts over this limited period. A later follow-up of this cohort could prove to be very revealing.

Most of the methodological problems fall under the headings of sample size and representativeness, clarity and objectivity of the measures, and exclusions of important variables or sections of the sample.

The studies by the Minneapolis team (Hill et al., 1989; Hill et al., 1984) are exemplary in their attention to sampling procedures, geographical representativeness and large sample size - between 200 and 1,000 subjects. In contrast Baker and Blacher have published at least three studies all based on a small and unrepresentative sample of between 55 and 63 subjects, where three quarters of the parents were college educated (Blacher and Baker, 1994a; Blacher and Baker, 1994b; Bromley and Blacher, 1991; Baker and Blacher, 1993).

In one of the few U.K. studies (de Kock, Saxby, Thomas and Felce, 1988), the sample size was small - 10 and 36 subjects in two related projects, and their families lived within a five mile radius of the residential unit, which seemed relatively very proximate compared with studies from the U.S.A. and Ireland. But this study was a valuable piece of exploratory research examining the links between community/family contacts and the characteristics of residential settings, staff factors and management policies.

Large samples are not always representative. Sherman (1988) examined the factors involved in the decision to place learning disabled family members in residential care and his findings are based on a detailed questionnaire completed by 531 families, but this represented only a 27% response rate.

Most studies of family contact have family visitation rates as their principal objective
measure of contact, but studies can be difficult to compare exactly because of different
time frames and methods of reporting, as well as different sources for the information. Of
greater concern are studies where different measures are amalgamated to make a single
family contact statistic. For example, Baker, Blacher and Pfeiffer (1993) amalgamated
measures of programme involvement, telephone contacts, family visits and child visits to
the family home in order to create a single family involvement index which they used in
a regression analysis. The involvement demonstrated by a child going home to the family
is qualitatively quite different and quantitatively far greater in time than the involvement
demonstrated by making a phone call, and such a composite index would still be of
dubious legitimacy even if a weighting system was employed.

A number of studies rely on parents' or caregivers' reports about characteristics which
should be measured independently. Blacher and Baker (1994b) relied on parents' estimates
of both level of functioning and level of behaviour disturbance, both characteristics which
can be far more objectively measured. Stoneman and Crapps (1990) in one part of their
questionnaire survey asked care providers to rate how close the client's relationship was
to the family, an estimate of the feelings of two distinct parties.

Age.

In the research literature there is frequently an assumption that younger people starting
off in residential care have relatively strong family contacts, but that this falls off with time
and age. This assumption is based on inference from the studies which have shown that
older people tend to have fewer family contacts than younger people (Mulcahy, 1976,
Willer and Intagliata, 1982; D'Onofrio et al., 1980). But other factors such as changing
policies and attitudes over time, differential mortality rates, placement changes, and
distance to travel could be responsible for reduced family contact rates among older
people.

Because residential care is often organised to specialise by age groups, a number of
studies (Baker and Blacher, 1996; Anderson et al., 1992; Blacher and Baker, 1994b;
Anderson *et al.* 1975) have subjects with a very limited age range, and very little can be concluded from such studies except that they have necessarily ignored or underestimated the factor of age. Blacher and Baker (1994b) claimed to have found that there was no evidence of a falling-off in family involvement over time, but they examined contacts only up to two years following initial placement, and their sample was small and unrepresentative.

The much more reliable study of Stoneman and Crapps (1990) included subjects over the complete age range and greater care was taken to achieve representativeness. Within a context of very low visitation rates they found that older residents were less likely to go home than younger residents, but in general there was low involvement among all age groups.

D'Onofrio *et al.* (1980) found age to be the second largest negative correlate with family contact in a multivariate correlational study, but years spent in residential care proved to be a slightly more powerful correlate.

It is probable that age is a powerful mediating variable. Although the published studies reviewed here do not quote the details of correlations between several independent variables, some studies refer in discussion to the connection between age and family members left (Anderson *et al.* 1992), age and distance (Stoneman and Crapps, 1990), and age and years in residential care (D'Onofrio *et al.*, 1980).

The speculated lifespan picture suggested by these studies is that younger persons (under 21 years) whose parents are alive start off in residential care in a setting not too distant from the family home and have relatively high family contact rates. As the years go by, more of their parents die and more of their siblings move away, and the contact rates tend to lessen. By age 50 years and over most of their parents are deceased and contact from other family members may be hampered by long distances, leading to minimal contact rates. Although this interpretation seems to fit much of the evidence, it remains speculative until expensive longitudinal studies support or disconfirm it. Even if such a
picture was broadly true, there is very little reliable evidence about when the main falling-off in contact rates occurs: it is not known whether there a gradual decrease throughout the residential lifespan or whether most of the decrease occurs within the first few years.

**Years spent in residential care.**

The younger a person is when he enters residential care the higher the correlation will be between chronological age and years spent in residential care, assuming that the person remains thereafter in residential care. Therefore it is not surprising that there is a close association between the factors of age and years in residential care as determinants of family contacts in the few studies where both these factors have reliable variance (for example, Stoneman and Crapps, 1990; D'Onofrio et al., 1980). But the greater the trend for people to enter residential care at an older age there is, the looser the association between age and years in residential care will be.

These two factors need to be considered carefully for their relative influence as determinants of family contact because they may reflect other factors such as policy and attitude changes over time. For example, it might be that in the 1970s people tended to enter residential care at a younger age and family contacts were discouraged whereas in the 1990s people tended to enter residential care at an older age and family contacts were positively encouraged.

In practice it is likely to be very difficult to tease out such differential influences because of other factors which can co-vary with age (for example, family members left, distance from home, differential mortality rates). A further factor which can be expected to interact with years spent in residential care is the number of residential placements a person has had. Hardly any study has included this factor as a potential influence on family contacts, probably because it is likely to be a very arbitrary variable: a person in one health authority area may spend 20 years in one placement whereas a person in another health authority area may have ten different placements during the same 20 year period. One study in this field (Stoneman and Crapps, 1990) produced some tentative evidence that
Frequent changes in care provider homes seemed to reduce family contacts.

**Family members left.**

In the research about family contacts of people with learning disability in residential care the issue of who exactly is left within the family has often been ignored or confused. First an examination of who constitutes a family member is needed. For non-disabled people (defined here as people who do not have a learning disability) immediate family members could include the following possible relationships: a mother, a father (including adoptive parents and step-parents), a brother, a sister, and a son or a daughter. Extended family members might include grandparents, grandchildren, aunts and uncles, nephews and nieces, brothers- and sisters-in-law, and other partners of immediate family. A majority of the non-disabled population produce children of their own, and these parents can have family contacts with their sons and daughters and perhaps with grandchildren as well.

Only a small minority of learning disabled people have children of their own, and therefore as they grow older the majority have no possible access to such family contacts. At the same time their own parents are more likely to be deceased and any adult siblings are more likely to have moved away. These lifespan factors can go a long way in explaining the decrease with age of contacts with family for people with learning disability. Anderson et al. (1992) found in a study of older people in residential care that an estimated 24% had no contact because there were no living family members left. But many studies in this area have failed to take account of the factor of who is left in the family for the person to have contact with.

A number of studies have excluded from their sample cases where there are absent or deceased family members, or where their whereabouts is unknown. Baker, Blacher and Pfeiffer (1993) excluded 32 children (12%) from their study sample because they had no families. Cases where families could not be contacted were also excluded from Baker and Blacher (1996). Stoneman and Crapps (1990) chose to treat as missing data the cases where there was no living mother or father or sibling, which necessitated them rejecting
10% of their data. D'Onofrio et al. (1980) reported that they excluded cases where there were no family members left. Anderson et al. (1975), in a study with 22 correlates of family contacts, also failed to take account of the family left variable, even though they gathered information on parents' education, marital status and financial contributions.

Having no family members left, or one or more family members left, is likely to be an important variable in itself. There is likely to be a spectrum ranging from having no family members, and through having one or two family members, to having a complete immediate family plus a large extended family. It would seem preferable to make "family left" a variable in its own right and include a total representative sample. Subsequent analyses can then be carried out to examine the family contacts of particular subsections, such as those who have both parents alive, or those who have both parents deceased but have siblings.

Partly this confusion can be explained by what the studies are focusing on. If the study is about family contacts with the focus on the family then it is reasonable to exclude cases where family members are absent or deceased. If the focus is on the person in residential care then it does not seem legitimate to exclude cases where family members are absent or deceased. But it would be preferable to treat family left as a variable in its own right and account for all contingencies in data collection and analysis.

Distance.

The distance of the residential unit from the family members has been the factor which has been found to be correlated with family contact most often and most reliably. Parents who lived far away from the residential unit were less likely to visit their children (Anderson, Schlottman and Weiner, 1975). In two recent studies of children in residential care, Baker, Blacher and Pfeiffer (1993) and Baker and Blacher (1996) also found that
distance from the residential unit was the strongest correlate of family involvement, and that distance was even more of an obstacle to visitation for children who had both learning disability and an additional psychiatric disorder. This may have been because such children would need a specialist treatment unit which would be more likely to be distant from home.

Distance from residential unit has also been found to be a very significant factor for visitation rates of older people in residential care. Anderson, Lakin, Hill and Chen (1992) found that only about one quarter of residents who had living relatives were within an hour's travel, and about 40% were more than two hours travel away.

It is likely that distance would be related to the years a person has spent in residential care and to the distribution of surviving relatives. An individual could start in residential care reasonably proximate to the parents' home, but the parents, and more especially the siblings, could move on and away. Also as and when the parents die, there is likely to be a greater distance involved for any remaining contact with siblings. Stoneman and Crapps (1990) in a study covering the complete age range of people in residential care, found results which tended to indicate such a pattern of lifespan development with regard to visitation. They found that the longer a person had been in residential care the further away both parents and siblings tended to live. Siblings visited from further away as the clients increased in age, and there was a significant negative correlation between distance and visitation rates for these siblings.

Surprisingly, distance was not mentioned very often as an important factor when parents were initially selecting a residential home for their son or daughter (Blacher and Baker, 1994a). In a multiple choice interview questionnaire only 15% said that proximity to home was a factor in selection.

But most studies of family involvement which have involved a distance measure have found a significant association between the two variables (Ballinger, 1970; Balla and Zigler, 1971; Felce, Lunt and Kushlick, 1980).
It might then be thought that the development over the last twenty years of providing community group homes designed to serve the needs of people within their own locality would increase levels of family involvement, but, as the next section shows, the evidence for this is equivocal.

**Type of residential unit and characteristics of care providers.**

Following the influence of the principle of normalisation many western countries established small group homes within the community as an alternative or replacement for the large residential units. Smaller units were presumed to be more homely and conducive to social contacts including contacts with the family. Some early studies did seem to show enhanced family visitation for people in the community group homes as against those in large institutions (Hill and Bruininks, 1981; Felce, Lunt and Kushlick, 1980).

But after community homes had become a more established form of residential care, there was a much weightier body of evidence showing no significant difference between group homes and large units (Latib, Conroy and Hess, 1984; Lowe and de Paiva, 1991; Emerson and Hatton, 1994), or that, when distance was controlled for, there was actually more family visitation in the larger units (Grimes and Vitello, 1990; Conroy and Feinstein, 1985). Because the Grimes and Vitello (1990) study examined visitation rates before relocation to community homes, and then 3 to 7 years afterwards, it might have been the factors of age and years in care which were responsible rather than the type of residential unit. It is also possible that change of residential unit itself disrupts routines of family contact.

An interaction of factors was suggested by de Kock, Saxby, Thomas and Felce (1988) who claimed that people newly admitted to group homes from their family homes maintained significantly greater family involvement than those transferred from institutions. Lowe and de Paiva (1991) suggested that family contacts did not improve after transfer to group homes if they had been poor prior to transfer, but for those who had good contacts there was evidence of some enhancement of such contacts as a result.
of transfer to group homes. Anderson, Lakin, Hill and Chen (1992) found social relationships to be negatively correlated with size of residence but there seemed to be no control for distance, and family contacts were only one part of their social relationships factor.

The safest conclusion from the literature is that when distance, age, degree of disability and behaviour disturbance factors are adequately controlled for, there is no significant difference in family contacts for people in group homes as against people in larger residential units.

In areas where fostering families for people with learning disability is a common form of service provision, the evidence also seems to indicate no significant difference in family contacts, compared with people in large residential units or small group homes (Intagliata, Crosby and Neider, 1981).

The reasons speculated by researchers for these inconclusive findings are that any benefits accrued from creating more homely settings for people in residential care can be counterbalanced by guilt or uncomfortableness felt by family members visiting their disabled relative in what can be perceived as someone else's home. Some family members may feel more secure visiting within the more anonymous and structured setting of an institution. Blacher and Baker (1992) suggested that younger staff members who believe rigidly in normalisation principles might show disapproval towards parents who have put their son or daughter into residential care, but differential staff attitudes remain under-researched in the area of family contact.

Stoneman and Crapps (1990) placed a major focus on the care providers in their study. The prevailing model of residential care in that part of the U.S.A. was for adults as well as children with learning disability to live in foster families termed family care home providers. The authors found the providers' encouragement of involvement was one of the three variables contributing unique variance among the predictors of family involvement, within a context of very low visitation rates overall. The strongest predictor was family
involvement in the placement, and subsequent analyses indicated that when a positive relationship between family and care providers had been initiated and developed, this contributed strongly to higher visitation rates, and especially so if care providers had a disabled person in their own family. The survey also revealed that 81% of care providers who had tried to involve families believed their efforts had little or no effect.

Willer and Intagliata (1982) found evidence that opportunities provided by the residential care facilities were an important determinant of family involvement.

**Level of disability and level of social competence.**

Level of disability is the most frequently quoted determinant of the decision to seek residential placement (Sherman, 1988; Tausig, 1985). In a large study (N = 531) examining characteristics of the disabled person and characteristics of the family which might be predictors of the decision to obtain residential placement, Sherman (1988) found that degree of learning disability and severity of behaviour problems were the two strongest determinants among the characteristics of the disabled person. Within that general finding there is evidence that having more severe and profound disabilities is even more likely to lead to residential placement, presumably because these people have much greater dependency needs and specialist care needs which many families feel unable to provide (Cole and Meyer, 1989; Sherman, 1988). A further refinement to that general finding was that for younger individuals (under 21) behaviour disturbance was the most important determinant, whereas for older individuals (over 21) the main determinant was I.Q. (Tausig, 1985). In similar vein, Bromley and Blacher (1991) found that level of learning disability and behaviour problems were strong contributors to the decision to place.

One recent study found that level of disability, as one of seven characteristics of the children under study, was not related to any placement experience variable (Blacher and Baker, 1994). There are grounds for doubting the general validity of this finding because their sample was small (N = 62) and not very representative (three quarters of parents in
their sample were college educated).

It is reasonable to expect that degree of disability would also be a strong determinant of family contacts after placement, when the individual is in continuing residential care. Anderson et al. (1975) found that this was indeed the case for children; those with lower I.Q. and lower social competence received less visitation from their family.

In a sample comprising the whole age range from 3 to 76 years, Stoneman and Crapps (1990) also found that more able and competent clients had closer family contacts, and these factors were more important than characteristics of the type of residential unit. Baker and Blacher (1996) also found that people with lower levels of learning disability had less family involvement.

Anderson et al. (1992) examined a sample of older people in residential care and found the factor most directly associated with low levels of general social integration was the level of learning disability, and although they did not discuss the finding, their tabulated results indicated that level of disability was also a statistically significant determinant for family contacts in particular.

In a relatively smaller scale study (N = 62) of children in residential care, Baker and Blacher (1993) found that more severely disabled children were more likely to be visited at the residential unit and less likely to be taken home, but they did not find a significant overall association of level of disability with visitation rates. But in one of this team's larger studies (N = 234) Baker, Blacher and Pfeiffer (1993) found that family involvement was greater for children with higher I.Q.s among other significant characteristics.

Very few studies in the area of family contacts included a measure of a person's social competence in addition to their level of disability, probably because the two variables are likely to be strongly correlated for a learning disabled population. One of the few that did examine social competence as one of 22 biographical and psychological variables was that of Anderson et al. (1975) who found in a regression analysis that a social competence
quotient was one of the best predictors of parental visitation for children. Anderson et al. (1975) also showed that other non-contact forms of involvement by parents, such as attending case conferences, were not related to the characteristics of the child, leading them to conclude that child characteristics such as intelligence, social maturity and behaviour disturbance are only relevant when there is actual contact with the child.

Researchers have also looked at other variables related in some way to a person's level of disability and which might be predictors of family contact, including the presence of physical anomalies- not significant (Anderson et al. 1975), mobility and sensory disabilities- significant, but not as strongly as I.Q. (Anderson, Lakin, Hill and Chen, 1992), and presence of a convulsive disorder- significant (D'Onofrio et al., 1980).

**Behaviour disturbance and additional psychiatric problems.**

Presence and degree of behaviour disturbance represent another client characteristic which has been found to be negatively associated with family involvement (Tausig, 1985; Sherman, 1988; Baker, Blacher and Pfeiffer, 1993). Stoneman and Crapps (1990) also found behaviour disturbance to be a significant factor militating against family involvement. Behaviourally disturbed people were less likely to go home to their family, but they received just as much visitation as others within the residential units.

Behaviour disturbance was found to be the most significant factor precipitating requests for residential placement for younger people (Tausig, 1985), but other family stressors also contributed significantly. Sherman (1988) also found that an interaction of behaviour disturbance with other family stressors influenced decisions to place a person in residential care.

For children who are in residential care, those who had fewer behaviour problems received more family involvement (Baker, Blacher and Pfeiffer, 1993). In their study of older
people in residential care Anderson et al. (1992) also found that aggressive behaviour was negatively associated with the family contacts a person received.

In a smaller scale study Baker and Blacher (1993) found behaviour problems to be unrelated to family involvement variables, but this non-significance may have been due to their small sample size (N = 62).

In the much larger study by this team (Baker, Blacher and Pfeiffer, 1993) where the sample size was 234, an interesting comparison was made between children in residential care because of psychiatric problems, children with learning disability alone, and children who had a dual diagnosis of learning disability together with additional psychiatric problems. This last group had the lowest rate of family involvement. A regression analysis indicated that the factors of distance from home, socioeconomic status, child's age and behaviour problems accounted for most of the variance, after which having a dual diagnosis did not significantly increase the variance explained.

This finding indicates the difficulty of assessing the relative importance of factors which are themselves inter-correlated. In that study, distance emerged as the strongest single correlate of family involvement, but this may have been a spurious statistical finding because children with behavioural and psychiatric problems are so hard to place that a suitable residential facility might be found only at some considerable distance from home (Baker et al., 1993). Also as the authors themselves observed, it is very difficult to distinguish between disturbed behaviour which is symptomatic of psychiatric problems as against disturbed behaviour which is associated with severely limited development. The authors did not comment on why the child's age was found to be a significant determinant of family involvement, but for children, age can have a simple interaction with behaviour disturbance:- an older, stronger child's behaviour can be far more disturbing than the same behaviour exhibited by a young child, especially if aggression is involved.

For adults as well it can be difficult to distinguish between primitive behaviours which can occur as a result of severe cognitive deficits and disability and behaviours which result
from emotional disorders including neuroses, psychoses and personality disorders (Holt, Kon and Bouras, 1995). This difficulty is often referred to as "diagnostic over-shadowing" where a psychiatric disorder is over-shadowed by a pervasive learning disability (Moss, Patel, Prosser, Goldberg, Simpson, Rowe and Lucchino, 1993).

**Sex, ethnicity and religion.**

Nearly all studies in the area of family involvement with people in residential care have failed to find any difference between males and females (Tausig, 1985; Anderson *et al.*, 1992), although not every study mentions that they examined this variable (for example, Baker, Blacher and Pfeiffer, 1993). One study (Stoneman and Crapps, 1990) found a significant difference in that males were found to visit the family home more often than females.

Few studies report on the ethnicity or religion of their populations, and one which did examine these factors found that whites had higher visitation rates than non-whites in the U.S.A. (Baker, Blacher and Pfeiffer, 1993).

**Characteristics of the family.**

Sherman's study (1988) focused on critical factors which predicted parents' request for residential placement for their disabled son or daughter. He found that families who had sought placement were more likely to be larger, headed by a single parent, have more stressors and disruption, and tended to have fewer client support services. Neither family income nor parents' educational level were found to differentiate those who placed their child from those at home, but the low response rate of 27% to this questionnaire survey raises questions about representativeness of sample.

Once a person has been placed in care it is likely that a similar association of family factors will influence visitation rates. Baker, Blacher and Pfeiffer (1993) found that the parents' socioeconomic status and to a lesser extent their marital status, were significant predictors
of visitation. Very similar findings came from the study by Anderson et al. (1975) who found that low economic status, and the parent with custody being divorced and remarried, were strong predictors of lack of involvement.

Baker and Blacher (1993) found that mothers who had higher educational status and fewer children tended to visit the residential unit more often. Stoneman and Crapps (1990) found that parents who had involved themselves more in the initial placement tended to maintain subsequent contacts far more, but they implicitly acknowledged that it was likely to be parents with marriage intact and more personal resources who had these characteristics.

Focus of the present study.

During the course of assessing the people in residential care in my own health authority area I had observed that family involvement levels seemed to be very low. Since no study within Ireland has focused specifically on family involvement, it seemed important to determine whether the pattern of involvement and the influences on visitation were similar to those found in research carried out in other countries. Ireland has a reputation for placing great emphasis on family values and on the care of the weak and vulnerable. Irish people have a reputation for having close ties with the immediate and extended family, but is this reputation really justified and would it be reflected in the family involvement of people with learning disability?

In common with other western countries, the Irish Dept. of Health places great emphasis on the partnership between families, service users and service providers (Dept. of Health, 1986). It is important to know what the basis is for this policy assumption.

The focus of the present study was on the people with learning disability themselves rather than on their families. The study was designed as an exploratory piece of research to determine the rates of family involvement and to investigate the principal factors associated with involvement. Previous studies had ignored or underestimated the
importance of critical factors such as who was left in the family, and the presence of behavioural and psychiatric disorders in adults. A representative study was needed to determine the main correlates in a correlational study where a number of individual factors were likely to prove significant in themselves.

Implications of the findings for service providers were considered to be important. For example, present assumptions of strong family involvement and interest in progress reviews and programme planning may prove to be unwarranted. An assumption that family members are strong advocates for the rights of their relative in residential care may also need to be questioned if those family members prove to have no involvement.

There was a twofold aim in the present study. The first was to provide a description of the rate and pattern of family contact within the context of the characteristics of people with learning disability who are currently in residential care. Strong efforts were made to provide a sample which would be representative of all people with learning disability who are in residential care in Southern Ireland.

The second aim was to determine which set of variables could best discriminate between the levels of family contact which were found. Understanding the factors associated with family contact could prevent efforts being wasted by agencies on projects which assume a high level of family involvement. If there were factors which clearly promoted or inhibited family contacts, then an understanding of these could inform services on what to encourage or avoid in the setting up of future services.

Selection of variables.

At an early stage it had been decided that this study would not focus on characteristics of the family of origin because these have been covered in other studies (Anderson et al., 1975; Sherman, 1988; Stoneman and Crapps, 1990; Baker and Blacher, 1993). Also, from preliminary impressions the researcher knew that a large proportion of people in residential care were likely to be found to have minimal contact, so it would have been
very difficult to establish co-operation and consent from people who were uninvolved in the first place.

For the same reason it was not appropriate or feasible to examine the nature and quality of family contact in this study, except for making the clear distinctions between overnight visits to family as against receiving a visit in residential care and indirect contacts by phone, letters or cards.

What might have been possible, and would certainly be a worthwhile area of interest, was to examine the importance and meaningfulness of family contact for the person in residential care. From sociological studies (reviewed in Maluccio, Fine and Olmstead, 1986) it is known that contact with birth family can be crucially important for non-disabled children who are in foster care or children's homes. But there would be some challenging and inherent difficulties in investigating this for people with learning difficulties, because most have limited verbal skills and limited ability to self-report. Even if methodological difficulties could be overcome, there would be an ethical issue in whether it would be right to ask about matters which the person with learning difficulties could find upsetting, and whether informed consent could be given for that. Asking a person with learning difficulty about what in many cases would be an absence of family contact could be insensitive.

One of the main aims of this study was to obtain a broad overview of the important main variables determining family contact, and to provide a representative baseline measure of family contacts of people with learning difficulty in residential care in S. Ireland. Important main variables included age, level of learning disability, family members who are left, and distance between residential unit and family.

In all, there were 10 factors which were capable of being examined in this study. To have gone beyond this number of factors would have made the study too large and unwieldy for present purposes. Other studies have focused in on comparatively minor factors such as educational level of parents, birth order of child, physical anomalies of child and presence of convulsive disorder (D'Onofrio et al. 1980, Blacher and Baker 1994a). But
over-inclusiveness of variables could have led to problems in the statistical analysis stage of this study. Too many variables entered into a regression model can reduce the overall reliability.

The present research was essentially a correlational study. Some good studies (Blacher and Baker, 1994b; Baker and Blacher, 1993) have examined pre-placement and post-placement conditions, and designs which take advantage of manipulation of one or more of the factors are more powerful than the more common retrospective studies such as D'Onofrio et al. (1980), Anderson et al. (1992) and Bromley and Blacher (1991). In the present study it was not possible to manipulate the conditions for obvious ethical reasons; nor was it possible to take advantage of changes which were occurring anyway, because few people enter residential care in an average year in the area under study and no major change such as transfer of residential unit was taking place.

The selection of independent variables was made mainly on the basis of their predicted importance as correlates of family contact, but ethical considerations of whose rights to what level of information were also considered important, as well as practical considerations of time availability.

**RESEARCH HYPOTHESES.**

This research was a correlational study where 10 factors were examined to determine their relative influence on family contacts. It was likely that a number of these factors would be inter-correlated with each other, and therefore a multivariate regression technique would be the most appropriate to elicit the relative importance of one factor rather than another.

Any one of the 10 factors could be found to be a significant correlate of family contacts,
but implications from previous research findings made it likely that some factors would be strong correlates, defined as showing a correlation with family contacts of 0.3 or greater, some factors would be weak correlates, defined as showing a correlation with family contacts of less than 0.3, and some factors would be unrelated to family contacts. Within this schema the hypothesised critical factors, their relative strength and the direction of the predictions are presented below.

**Strong Correlates.**

**Age.** It was hypothesised that age would be a strong correlate of family contacts. It was hypothesised that younger people would receive more family contacts than older people.

**Years in Residential Care.** It was hypothesised that the number of years spent in residential care would be a strongly associated with family contacts. It was hypothesised that people who have spent a shorter period in residential care would receive more family contacts than people who have spent a longer period in residential care.

**Family Left.** It was hypothesised that the number of immediate family members left to a person in residential care would be a strongly associated with the amount of family contact they receive. It was hypothesised that people who have more family members still alive would receive more family contacts than people who have few family members left.

**Distance.** It was hypothesised that the distance in miles between the residential unit and the person's family home would be strongly negatively associated with family contacts. It was hypothesised that people in residential units proximate to their family members would receive more family contacts than people who are living a longer distance away from their family members.

**Behaviour Disturbance.** It was hypothesised that the degree of behaviour disturbance exhibited by people in residential care would be strongly associated with family contacts. It was hypothesised that people with little or no behaviour disturbance would receive
more family contacts than people who have significant and more severe behaviour disturbance.

**Additional Psychiatric Problems.** It was hypothesised that the presence of significant additional psychiatric problems would be strongly associated with the amount of family contacts. It was hypothesised that people who have no additional psychiatric problems would receive more family contacts than people who have significant or severe additional psychiatric problems.

**Weak Correlates.**

**Level of Learning Disability.** It was hypothesised that level of learning disability would be weakly correlated with family contacts. It was hypothesised that the more severe the level of learning disability the less the amount of family contact there would be.

**Level of Social Competence.** It was hypothesised that level of social competence would be weakly correlated with family contacts. It was hypothesised that people with higher levels of social competence would receive more family contacts than people with lower levels of social competence.

**Non-correlates.**

**Sex.** It was hypothesised that there would be no difference between males and females in the amount of family contacts received.

**Type of Residential Unit.** It was hypothesised that there would be no difference between people in group homes as against people in a large sized residential unit in the amount of family contacts received.
CHAPTER 2.

METHOD.

Subjects.

There were 179 subjects in this study, all with some degree of learning disability. The subjects consisted of the entire population of people with learning disabilities who were in the residential care of a designated Health Board division. The Health Board area mainly comprises two whole counties which are on the western side of Southern Ireland, plus responsibility for two other small areas of neighbouring counties where geographical proximity to services made this more practical than adhering strictly to county divisions. The total population of the Health Board area was 80,057 in the 1991 census, but about 5,000 should be added to this figure to allow for the two small areas of neighbouring counties, making the effective Health Board area total population 85,000.

The sample of 179 subjects in this study comprised 58.1% of the total population in residential care within the designated Health Board area, the other 41.9% being in the care of voluntary bodies whose services were parallel and highly similar to the Health Board services. Of the present sample, 96.1% came from the two counties of the designated Health Board area. A detailed breakdown of the characteristics of the population sample appears in Chapter 4.

Criteria for Selection as Subjects.

The main criteria for selection as a subject were 1) having a significant learning disability, 2) being in residential care, and 3) having the consent of the main caregivers for participation in this study. Another criterion which was pragmatic more than necessary was that only people under the direct residential care of the designated Health Board division were included because the researcher worked within this division, had assessed
all the people in residential care and was familiar with all the structures and procedures necessary for such a study.

Being in residential care was defined as spending four or more nights per week in residential care, so people who mainly lived at home but had periodic or regular periods of residential placement were not included, unless this amounted to their spending more time in residential care than at home. For this reason, people who received respite care, holiday breaks or temporary care for medical/mental health needs were not included.

Nobody was excluded from the study because of age, or because of having no family to have contact with, or because there were no known parents or relatives. These are significant points because some other studies have excluded subjects on precisely these grounds (e.g. Baker, Blacher and Pfeiffer, 1993; Stoneman and Crapps, 1990).

**Brief Outline of the Data to be Collected and Rationale.**

For each individual in residential care, the aim was to obtain 15 pieces of information, which together would comprise the dataset. This required information is listed below with a brief explanation of why it was needed. The method of obtaining this information is described in more detail in the Procedure Section (Chapter 3).

**Age** of person in residential care. Age was hypothesised to be associated with family contact.

**Sex.** Although not predicted to be associated with family contact, sex is a basic demographic variable.

**County of Origin.** Although not predicted to be associated with family contact, it was important to know which county area a person came from in order to establish that the sample was representative for a defined geographical area population.
Type of Residential Unit. Although not hypothesised to be associated with family contact in this study, some earlier studies found the type or size of residential unit to be a significant factor, so it was important to include this as a variable.

Number of Residential Placements. This information was readily available and thought to be useful for a description of the sample, but the number of residential placements a person has had was not hypothesised to be related to family contact, because it would be a very arbitrary statistic and with little variation.

Years in Residential Care. This information was readily available and years in residential care was hypothesised as being associated with family contact. A wide range and variance could be expected for this factor.

Mental Age and Level of Learning Disability. Since learning disability is one of the strongest reasons for a person entering residential care in the first place, the hypothesis was that the degree of learning disability would be related to family contact. Therefore it was important to obtain a measure of learning disability in this study.

Social Competence (Dependency). Since a person's social competence (and, conversely, their dependency needs) is one of the strongest reasons for their entering residential care in the first place, a hypothesis was that degree of social competence would be related to family contact. Therefore it was important to obtain a measure of social competence in this study.

Behaviour Disturbance (Challenging Behaviour). Since the presence of behaviour disturbance is another of the strong reasons for a person having to leave home and enter residential care in the first place, the hypothesis was that presence and degree of behaviour disturbance would be related to family contact. Therefore it was important to obtain a measure of behaviour disturbance in this study.

Additional Psychiatric Disorder. For children at least, the presence of additional
psychiatric problems has been found to militate against family contacts. Therefore, for this study covering the whole age range, it was important to include presence of psychiatric problems as a variable, the hypothesis being that this would be found to be related to family contacts.

**Family Left.** Whether or not parents are alive and whether or not siblings exist and are contactable, and who is left within the family to have contact with; these were predicted to be related to family contact. A clear and simple measure of who was left in the family was hypothesised to be an important variable in this study.

**Distance (from residential unit to family).** Several studies have found distance to be strongly associated with family contacts, and it was predicted to be an important correlate in this study.

**The Measures of Family Contact.**

For the reasons detailed in the Introduction, it was decided to collect only unobtrusive category of frequency measures of family contact which would be known to the caregivers in the residential units. These measures are of visits made by the subjects to their families, visits made by family members to the subjects and the presence or absence of any other indirect contacts by phone or letters or cards.

**Overnight Stays with Family.** A measure of frequency of overnight stays with family members was theorised as being the most meaningful and important measure of family contact because a significant period of direct contact with family is implied by an overnight stay, and a serious degree of commitment is likely to be involved in such an arrangement. This variable was to be considered the primary measure of family contact.

**Visits from Family Members to the Person in Residential Care.** A category measure of the frequency of such contacts was considered to be an important secondary measure of family contacts. A visit to the person in residential care usually implies a lesser
commitment and effort than having the person staying for a period of overnights at home, but a visit to residential centre might often involve long journey times to get there.

**Indirect Contacts by Phone, Letters or Cards.** Such indirect contacts would be predicted to be far more variable and difficult to measure than a more important and memorable event of an overnight stay. Within the known context that very many people had minimal visitation rates, it was decided to make the indirect contacts a simple dichotomous variable; did the person receive *some* such contact by phone, letters or cards or *no* such contact. Anything more than this might be intrusive since caregivers do not log phone calls and the mail of people in their care, no more than natural parents would.

One objection to the method used in this study is that there was no check for the reliability of the information which the caregivers were providing. It would have been preferable to have asked alternative caregivers (for example the houseparents working the opposite shift) to provide the same information on, say, 15% of the persons in care, and then produce reliability measures between the two sets of caregivers. An alternative method would have been to seek other measures of reliability by painstaking analysis of group home diary records together with residential file records, assuming these might contain information about contacts. But these methods of reliability checks had to be rejected because in an earlier research study which the writer had supervised, a trainee psychologist had attempted precisely such a reliability check in a study on leisure pursuits of people with learning disability. The caregivers had learnt that they were being checked up on, and believed their knowledge about the people in their care was being questioned, and the whole project was put in jeopardy until this approach was abandoned and the fences mended.
CHAPTER 3.

PROCEDURE.

Subjects were 179 people in residential care. Data were collected in two distinct phases and periods of time. The first phase was over a five year period preceding the present date, during which overall psychological assessments were carried out with all the people in residential care. The second phase took place during 1996 when data were collected from caregivers specifically covering the family contacts of the people in residential care.

Phase 1. Background Information, Demographic Data and Psychological Assessments.

The researcher had carried out assessments on all the people in residential care over the preceding five years for the purposes of having accurate and relevant information for individual programme planning, for planning of future services and improving quality services and quality of life. Social and community contacts, family contacts and leisure pursuits were considered important aspects of quality of life for a person in residential care.

The formal information which the psychologist obtained during each assessment is listed below, together with notes on how this information was collected. Each person had two files, one a residential file which is started when a person first enters residential care and remains with him throughout care, even when a placement changes, and the other is a psychology file which is maintained and kept by the psychologist.

1) Date of birth, and hence age of the person in residential care. In most cases there
was accurate information in a person's residential file, but for 8 cases I needed to verify a date of birth in the Births, Marriages and Deaths Office, and for 3 people even this failed to establish a date of birth and an estimate had to be made. There were no known next of kin for these three.

2) **Sex**, male or female.

3) **County of origin.** Where the person came from was defined as where the person spent his childhood or longest period of time before entering residential care.

4) **Type of Residential Unit.** In the Health Board area under consideration this was a simple dichotomy between large residential unit and community group home. There are no fostering arrangements or sheltered housing arrangements yet in place in this area. The large scale unit houses 115 people and is a traditional institution situated in the country nine miles from the nearest town. The community group homes are situated in towns and all have one houseparent on duty at any one time, working on opposite shift to a second regular houseparent for each home, with four to eight people in any one house.

5) **Number of Residential Placements and Years in Residential Care.**

   Although these were treated as two variables in data analysis, the information was collected at one and the same time during psychological assessment. The main method was to examine closely a person's residential file which in nearly all cases contained their date of first admission into residential care and a record of all subsequent placement changes. This information was cross-checked with the current caregiver when she was being an informant for part of the assessment. In 6 cases some "detective work" had to be undertaken before accurate information could be obtained, for example, by contacting an older nurse who would remember, or by telephoning an institution to check their record of a previous placement.

6) **Mental Age and Level of Learning Disability.** Standard I.Q. assessments were carried out by myself on all the people in residential care apart from five cases where
assessments of children had been initially carried out by a psychologist colleague. The W.H.O. (World Health Organisation) classification of level of learning disability was used, based on a person's I.Q. (Borderline, Mild, Moderate, Severe or Profound). A separate record of Mental Age or equivalent Test Age was kept for each person, for use as a continuous variable.

7) Social Competence. As a general measure of the dependency level of each client the McConkey Scales (McConkey and Walsh, 1982, Appendices p. 303) were completed by the person's caregiver in the presence of myself.

8) Degree of Behaviour Disturbance (challenging behaviour). The Wilkinson Scales (Appendices p. 307) were selected as the instrument for obtaining a measure of behaviour disturbance, and were completed by the caregiver in the presence of myself.

Phase 2. Specific Information about Family Contacts, Distance between Residential Unit and Home, and presence of additional Psychiatric Problems.

The overall sequence during this phase of data collection was (1) establishing permissions and conditions for the use of all the research information/data, (2) obtaining family contact data from the caregivers and working out distances between residential unit and family, and (3) obtaining categorical information about the presence of additional psychiatric problems from the psychiatrist.

(1) Establishing Permissions and Conditions.

Ethical approval for this study was gained from the Advisory Committee on Ethics of Surrey University, and from the Director of Public Health of the local Health Board. Then the group home supervisors and the managers of the large residential unit were approached, informally by talking with them and explaining my area of research interest, and formally by asking them to read the Information Sheet which was left with them, a copy of which appears on page 295 of the Appendices. Any questions or comments were
dealt with by answers or explanations.

At this stage considerable interest was expressed in the project because there was felt to be a relevant issue involved. On the one hand there was a background policy of promoting family contacts, and on the other hand there was often resistance by family members to such approaches from the residential services. Residential unit managers and supervisors were interested in knowing what level of involvement there really was between people in residential care and their families. The managers and supervisors gave consent for the research to go ahead - a copy of the formal consent letter appears on page 297 of the Appendices.

Next the direct caregivers, who were the group home houseparents or care workers or qualified nurses, were approached formally by advance letter, a copy of which appears on page 298 of the Appendices, announcing my intention to contact them about this study,. A copy of the same information sheet which was shown above (p.295) and a copy of a consent form which is shown on p. 299 was enclosed with this advance letter.

The caregiver for any given person was defined and selected as the houseparent or careworker who had the greatest care role with the client. For group homes there are always two houseparents who work opposite shifts, and the one who had spent longest with the client in the group home was selected from these two.

Within the large residential unit, the nurse or careworker who had the longest and most recent care role with the client was selected. Rosterings were in any case arranged to ensure continuity of care for the clients in care. Because of staff changes and some nurses being on extended leave, it was sometimes necessary for a more senior nurse to be selected because the actual current caregiver was only recently appointed. In these cases, the senior nurse would have had at least two years of being a caregiver for the client.

About a week after the advance letter, information sheet and consent form had been delivered, the researcher followed up by telephone contact to arrange to meet with the
caregiver at a time most suitable to themselves and when there would be privacy. The
venue was invariably the group home or residential unit, that is, the psychologist went to
the caregivers rather than vice versa.

The researcher ascertained whether the caregiver had read the information sheet, and if
there was any doubt, he asked the caregiver to read a copy there and then. At this stage
the consent form was presented and the caregiver was asked to read this carefully before
deciding and signing. If anyone asked for clarification on a point this was given.

In fact, all caregivers were willing to give consent and provide the information requested.
A protocol questions sheet, which appears in Appendices, page 300, was then presented
to the caregiver, and before commencing she was asked to make available the clients
residential file in case it was needed for reference purposes. This questions sheet was not
filled in by anyone, and was only used for reference purposes to enable the caregiver to
see clearly the questions. The caregivers verbal answers were entered in coded form onto
a separate sheet retained by the researcher.

This protocol question sheet remained with the caregiver for her to look at whilst the
researcher also verbally asked the same questions, and the researcher filled in the coded
answer on a record form, a copy of which appears on page 302 of the Appendices.

The data were entered by the author into a computerised statistical package (S.P.S.S. for
Windows) for data analysis, keeping to the letter and code system so that neither the
identity of the client nor the meaning of the data could be known by anyone other than the
author.

**Presence of Additional Psychiatric Problems.**

The psychiatrist covering the learning disability service, like the author, had worked within
this service for over eight years. Therefore she knew most of the people in residential care on an ongoing basis which made it easier to say whether a person had psychiatric problems.

It was explained to the psychiatrist that what was required was a basic three-way categorisation of the sample, the categories being 1) people who have no significant psychiatric problems, 2) people who have mild psychiatric problems, and 3) people who have serious psychiatric problems.

It was explained that this categorisation was for current research purposes only, and could not be entered into any person's file; the procedures for ensuring confidentiality and security of data were emphasised.

The clients' files were made available to the psychiatrist during this step of the procedure in case she needed to refresh her memory of the client or consult the file for clarification purposes. The cases were considered by the psychiatrist in random order.

It was explained that each classification was to be made on the basis of her overall clinical psychiatric judgement. No attempt was made to apply rigid criteria for classification on the basis of behaviour disturbance, history of psychiatric hospital care, previous diagnoses, symptoms, medication or other such criteria, because any one of these by itself could be misleading. But the psychiatrist understood that all such relevant criteria could be useful in making her judgement.

No significant difficulties were expressed by the psychiatrist in carrying out this classification, and the task was completed within a three hour period. A few times the psychiatrist turned to the author for his own opinion or agreement but no opinion was offered back. On reaching the last case the psychiatrist wondered whether she had been too reserved in her judgement during the first few cases she had considered. She wanted to review her classification of the first twenty cases that had been presented, which was allowed, and this review resulted in her re-allocating one case into the "mild psychiatric
problems" category where the person had been in the "no significant psychiatric problems" category.

Overall the psychiatrist expressed satisfaction and confidence in making the categorisations.

THE PILOT STUDY.

A pilot study was carried out with three of the caregivers who gave information about 18 of the people in their care, and as a result some minor modifications in design and procedure were made, and these are detailed below. None of these changes necessitated data being abandoned from the subjects in the pilot study itself.

For Question 2 it ought to be possible logically to distinguish between the situations of having one or both parents alive and one or more siblings alive as well, as against having one or both parents alive but having no siblings alive. In practice though, it was extremely difficult for the caregivers to make this distinction. If a parent was alive then caregivers knew this as a certainty, but they would not necessarily know if there were other siblings or not. In contrast, if parents were deceased, caregivers knew as a certainty if there was one or more siblings, and if there was any contact. The concept of next of kin is important for a person's care and this information is on the first page of their residential file and this partly explains how the caregivers become more certain about the presence or not of siblings only after the death of parents.

It was decided to simplify and reduce the number of all possible logical combinations to those below.

1) Parents deceased- no siblings.
2) Parents deceased- sibling(s) live abroad.
3) Parents deceased- one or more siblings live in Ireland.
4) One parent alive.
5) Both parents alive.

This effectively removes sub-categories of conditions 4) and 5) where there may be some with or without siblings who live within or outside Ireland, but this was not felt to be an important loss of information, given the main condition of having a parent alive.

For Question 4 the gradations of frequency categories for overnight stays with family were found to be too finely discriminated for the caregivers to cope with. For example, one caregiver said, "I'm not sure if he went home for 5 to 9 overnight stays in the last year or for 1 to 4 overnights- I think it was 4 or 5 nights." It was decided to collapse the frequency categories to some extent in order to eliminate uncertainty, and the final reduced categories are shown below.

1) Stayed 50 or more overnights with family in the last year.

2) Stayed 20 to 49 overnights with family in the last year.

3) Stayed 1 to 19 overnights with family in the last year.

4) Had no overnight stays with any family member in the last year.

These category reductions meant that time was not wasted in the pursuit of fine detail and the time taken for carrying out the interview questionnaire became about 25 to 35 minutes long for the usual case where one caregiver was providing information about 6 people in her care.

No serious difficulties were found in subsequent data collection and no further design modifications were needed.
CHAPTER 4.

RESULTS.

DESCRIPTION OF POPULATION.

Total Number and Sex.

In May 1997, some months after completion of data collection, basic demographic statistics from the National Database for Learning Disability (1997) became available on request by the author, and these enabled comparisons to be made between the sample in this study and the national population within residential care. The parameters for comparison were the proportions for sex, type of residential unit, age and level of disability.

There were 179 individuals examined in this study and of these 101 (56.4%) were male, and 78 (43.6%) were female. The proportions from the National Database (1997) indicated that within the whole national population of people with learning disability who are in residential care, 51.4% were male and 48.6% were female. A chi square test indicated no significant difference between the proportions observed in the present study and those expected from the National Database figures (chi square = 1.81, df = 1, not significant at $p = or <.05$). The null hypothesis of no significant difference between the sex proportions in this study and the proportions within the national residential population was accepted.

Geographical Area.

The overwhelming majority (96.1%) of people came from the three counties which make up the area covered by the Health Board which provided the residential services, and
which constituted the geographical area under consideration in this study.

**Type of Residential Unit.**

In the present study, 64.25% were living in a large-scale residential unit and 35.75% were living in community group homes. In the national residential population 68.40% were living in large-scale residential units and 31.60% were living in community group homes (National Database, 1997). A chi square test indicated that there was no significant difference between the proportions for this study and those expected nationally (chi square = 1.39, df =1, p=0.22, not significant). The null hypothesis was accepted and it was concluded that the sample in the present study was representative for the proportions of type of residential setting.

**Number of Placements, and Years Spent in Residential Care.**

The mean number of residential placements, including the client's present placement was 2.66 placements, and the range was from 1 to 7 placements.

The mean number of years that a client had spent in residential care of one form or another was 21.89 years, (S.D. = 13.86, Range = from 1 to 69 years).

**Age.**

The mean age of the population of people in residential care in this study was 42.94 years (S.D. = 15.06, Range = 4 years to 77 years). The mean age of the national population in residential care was 39.6 years (S.D. = 15.8). The mean difference of 3.34 years was statistically significant, (t = 2.27, p=0.005). The respective numbers and percentages within four age bands are for the present study sample and the national residential population are shown in Table 1 below.
Table 1. Age range of present population and national population.

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Present Study.</th>
<th>National Database.</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 to 19 years.</td>
<td>14</td>
<td>7.82%</td>
</tr>
<tr>
<td>20 to 39 years.</td>
<td>57</td>
<td>31.84%</td>
</tr>
<tr>
<td>40 to 59 years.</td>
<td>80</td>
<td>44.69%</td>
</tr>
<tr>
<td>60 years &amp; over.</td>
<td>28</td>
<td>15.64%</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td>179</td>
<td>100.00%</td>
</tr>
</tbody>
</table>

A chi square test was carried out testing the observed frequencies within age band found in the present study sample with those expected from the national population proportions, and chi square was 14.9, df=3, p=0.002. Observation of the data in Table 1 would seem to indicate that in the present sample the age group of 40 to 59 year olds was over represented and the age group of 20 to 39 year olds was under represented.

**Family Left.** Table 2 below shows the pattern of distribution of who is left in the family.

Table 2. Who is left in the family.

<table>
<thead>
<tr>
<th>Family members left.</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents deceased. No traceable siblings.</td>
<td>17</td>
<td>9.5%</td>
</tr>
<tr>
<td>Parents deceased. Any siblings live abroad.</td>
<td>15</td>
<td>8.4%</td>
</tr>
<tr>
<td>Parents deceased, but one or more sibs in S. Ireland.</td>
<td>71</td>
<td>39.7%</td>
</tr>
<tr>
<td>Has one parent alive.</td>
<td>41</td>
<td>22.9%</td>
</tr>
<tr>
<td>Has both parents alive.</td>
<td>35</td>
<td>19.6%</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td>179</td>
<td>100.0%</td>
</tr>
</tbody>
</table>
This distribution of who was left in the family was likely to be partly a function of the mean age of the sample. Younger people would be more likely to have both parents alive. Older people would be more likely to have parents deceased and possibly siblings who have emigrated. This relationship is shown in Table 3 below, which indicates the cross tabulation between age level and category of family who are left.

Table 3. Age range by family left.

<table>
<thead>
<tr>
<th>Age range</th>
<th>1 to 34 yrs</th>
<th>Age range</th>
<th>35 to 54 yrs</th>
<th>Age range</th>
<th>55 &amp; over</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>One or both parents alive.</td>
<td>38</td>
<td>37</td>
<td>1</td>
<td>76</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents deceased. One or more sibs in S. Ireland.</td>
<td>6</td>
<td>42</td>
<td>23</td>
<td>71</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents deceased. No siblings or siblings abroad</td>
<td>2</td>
<td>13</td>
<td>17</td>
<td>32</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Totals</td>
<td>46</td>
<td>92</td>
<td>41</td>
<td>179</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Chi square = 63.07  df = 4  p = <0.001
Contingency Coefficient = .5104  p = <0.001

Level of Disability. The frequencies and percentages of disability level of the people in residential care are shown below.

Table 4. Level of disability in present population and national population.

<table>
<thead>
<tr>
<th>Disability Level</th>
<th>Present Study.</th>
<th>National Database.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Borderline</td>
<td>8</td>
<td>4.5%</td>
</tr>
<tr>
<td>Mild</td>
<td>47</td>
<td>26.3%</td>
</tr>
<tr>
<td>Moderate</td>
<td>23</td>
<td>12.8%</td>
</tr>
<tr>
<td>Severe</td>
<td>67</td>
<td>37.4%</td>
</tr>
<tr>
<td>Profound</td>
<td>34</td>
<td>19.0%</td>
</tr>
<tr>
<td>Totals</td>
<td>179</td>
<td>100.0%</td>
</tr>
</tbody>
</table>
A chi square test indicated that there was a significant difference between the observed proportions of disability level in this study and those expected from the National Database (chi square = 60.94, df = 3, p < .001). The figures in Table 4 would seem to indicate that in the present study, people with a moderate learning disability were under-represented and people with a severe and profound disability were over-represented.

**Mental Age and Level of Social Competence.**

A person's degree of disability is based on their Mental Age or Intelligence Quotient (I.Q.). It transpired that there was a very high correlation of 0.91 between Mental Age and degree of social competence as measured on the McConkey Scales in this study. (On the Pearson's Rho Test $r = 0.91$, $p = <0.0001$.) These two measures were obtained by very different methods. For mental age the clients themselves had been assessed by the writer psychologist using standard I.Q. tests which measure mental abilities. For social competence the caregivers completed the McConkey scales which cover social and general independence abilities. The close association found between mental age and degree of social competence meant that particular care had to be taken for effects of collinearity in any subsequent analyses which included these two variables.

For most subsequent statistical analyses, the variable of disability level was collapsed into three category levels as shown below.

**Table 5. Three category levels of disability.**

<table>
<thead>
<tr>
<th>Disability Level</th>
<th>Freq</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Borderline and Mild</td>
<td>55</td>
<td>30.7%</td>
</tr>
<tr>
<td>Moderate and Severe</td>
<td>90</td>
<td>50.3%</td>
</tr>
<tr>
<td>Profound</td>
<td>34</td>
<td>19.0%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>179</strong></td>
<td><strong>100.0%</strong></td>
</tr>
</tbody>
</table>
Similarly, the variable of degree of social competence as measured on the McConkey Scales was also reduced to three categories for most subsequent analyses, and these are shown below.

High level of Social Competence - Raw scores 15 to 33 - n = 55
Medium level of Social Competence - Raw scores 34 to 49 - n = 63
Low level of Social Competence - Raw Scores 50 to 64 - n = 61

Degree of Behaviour Disturbance.

The Wilkinson Scales proved to be an effective instrument in measuring degree of behaviour disturbance because a broad range of scores on this scale was produced, which made for a meaningful categorisation into three levels of behaviour disturbance in subsequent analyses.

Mean score on the Wilkinson Scales - 25.55 Standard Deviation - 20.01

Three levels of behaviour disturbance, Low, Medium and High, were constructed from the raw scores, and these are shown below.

Low level of Behaviour Disturbance - Raw Scores 1 to 19 - n = 98
Medium level of Behaviour Disturbance - Raw Scores 20 to 39- n = 44
High level of Behaviour Disturbance - Raw Score 40 to 60 - n = 37

In most subsequent analyses these three category levels of behaviour disturbance were used, because the raw scores could not be used in tests which required interval measures and/or an assumption of normal distribution.
Presence of additional psychiatric difficulties.

The psychiatrist classified people as having either no significant psychiatric difficulties, or mild psychiatric difficulties, or very significant psychiatric difficulties, and the results of this tripartite categorisation are shown below.

No Significant Psychiatric Difficulties - \( n = 96 \) 53.6%
Mild Psychiatric Difficulties - \( n = 49 \) 27.4%
Very Significant Psychiatric Difficulties - \( n = 34 \) 19.0%

Distance in Miles between Residential Unit and Family.

The distance measure had a wide range and large variation, and this meant that it was legitimate and meaningful to collapse the data into three categories of distance: Near Distance, Medium Distance and Long Distance.

Near Distance - 1 to 15 miles between home and unit \( n = 58 \)
Medium Distance - 16 to 129 miles between home and unit \( n = 85 \)
Long Distance - 130 miles and over between home and unit \( n = 36 \)

Within the total sample there were 6 cases where the next of kin family member lived in the U.S.A., and to avoid statistical artifacts in parametric analyses these 6 outliers were assigned the next 6 numbers greater than the highest distance in the remaining dataset. The mean distance, range and standard deviation are shown below for the dataset excluding these 6 outliers in the U.S.A.

Mean Distance = 75.792 miles. \( N = 173 \). Range - 1 mile to 589 miles.
(Median = 27 miles and Mode = 11 miles, this latter being the distance between the large residential unit and the nearest large town.)
THE FAMILY CONTACT VARIABLES.

Measures of Family Contact. - Overnight Stays with Family.

Table 6 below shows the frequency distribution of different categories of overnight stays with a family member.

Table 6. Frequency of overnight stays.

<table>
<thead>
<tr>
<th>Overnight Stays</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had no overnight stays with any family member in the last year.</td>
<td>107</td>
<td>59.8%</td>
</tr>
<tr>
<td>Stayed 1 to 19 overnights with family in the last year.</td>
<td>23</td>
<td>12.8%</td>
</tr>
<tr>
<td>Stayed 20 to 49 overnights with family in the last year.</td>
<td>18</td>
<td>10.1%</td>
</tr>
<tr>
<td>Stayed 50 or more overnights with family in the last year.</td>
<td>31</td>
<td>17.3%</td>
</tr>
<tr>
<td>Totals.</td>
<td>179</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Measures of Family Contact. - Visits Received by the People in Residential Units.

Table 7 below shows the distribution pattern for categories of visitation rates received by the people in residential care from family members.
Table 7. Frequency of family visits received.

<table>
<thead>
<tr>
<th>Family visits received</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received no visits from family members in the last year.</td>
<td>59</td>
<td>33.0%</td>
</tr>
<tr>
<td>Received one visit from a family member during the last year.</td>
<td>26</td>
<td>14.5%</td>
</tr>
<tr>
<td>Received 2 to 5 visits from a family member during last year.</td>
<td>54</td>
<td>30.2%</td>
</tr>
<tr>
<td>Received 6 to 20 visits from a family member during last year.</td>
<td>21</td>
<td>11.7%</td>
</tr>
<tr>
<td>Received more than 20 visits during the last year.</td>
<td>19</td>
<td>10.6%</td>
</tr>
<tr>
<td><strong>Totals.</strong></td>
<td>179</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

The relationship between the two forms of visitation contact is shown below in Table 10.

Table 10. Overnight stays by visits received.

<table>
<thead>
<tr>
<th></th>
<th>No visits p.a.</th>
<th>One visit p.a.</th>
<th>2 to 5 visits p.a.</th>
<th>6 to 20 visits p.a.</th>
<th>Over 20 visits</th>
<th>Row totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>No over nights p.a.</td>
<td>43 (A1)</td>
<td>18 (A2)</td>
<td>30 (A3)</td>
<td>7 (A4)</td>
<td>9 (A5)</td>
<td>107</td>
</tr>
<tr>
<td>1 to 19 over nights</td>
<td>6 (B1)</td>
<td>3 (B2)</td>
<td>8 (B3)</td>
<td>4 (B4)</td>
<td>2 (B5)</td>
<td>23</td>
</tr>
<tr>
<td>20 to 49 over nights</td>
<td>2 (C1)</td>
<td>1 (C2)</td>
<td>6 (C3)</td>
<td>5 (C4)</td>
<td>4 (C5)</td>
<td>18</td>
</tr>
<tr>
<td>50 or + over nights</td>
<td>8 (D1)</td>
<td>4 (D2)</td>
<td>10 (D3)</td>
<td>5 (D4)</td>
<td>4 (D5)</td>
<td>31</td>
</tr>
<tr>
<td>Column totals</td>
<td>59</td>
<td>26</td>
<td>54</td>
<td>21</td>
<td>19</td>
<td>179</td>
</tr>
</tbody>
</table>

The real focus of interest is the difference between those people who have zero or minimal
contact with family and those people who have some significant amount of contact. The people who have zero or minimal contact can be neatly defined as those in cells \( A1, A2 \) and \( A3 \) in Table 10 above. Those in cell \( A1 \) had no overnights and no visits during the last year. Those in cell \( A2 \) had no overnights and only one visit. Those in cell \( A3 \) had no overnights and 2 to 5 visits. Therefore the group comprising cells \( A1, A2 \) and \( A3 \) can be designated the **Minimal Family Contact** group, and all the other cells can comprise the **Significant Family Contact** group.

There were 91 people in the **Minimal Family Contact** group, which was 50.8% of the total sample, and there were 88 people in the **Significant Family Contact** group, which was 49.2% of the total sample.

In words, the **Minimal Contact** group was defined as those people who had no overnight stays with family and less than six visits from family in the last year. In words, the **Significant Contact** group was defined as those people who had one or more overnight stays with family and/or six or more visits from family in the last year. This dichotomisation made statistical sense. Family contact had not proved to be a continuous variable, nor even an ordinal variable because of the large percentage of people who had zero rates of family contact.

**Measures of Family Contact. Contacts by Phone, Letters or Cards.**

This variable was not as useful in contributing to the overall picture of family contact as the variables of overnight stays and visits by family. Because of the inherent drawbacks of the dichotomous variable of contact by phone, letters or cards, no attempt was made to amalgamate this statistic with the main combination variable described above which distinguished between the Minimal Contact group and the Significant Contact group. But the relationship between that kind of "meeting in person" contact and "distant" contact by phone or mail is illustrated in Table 11 below.
Table 11. Contacts by phone, cards or letters.

<table>
<thead>
<tr>
<th></th>
<th>People who had no contact by phone, cards or letters last year.</th>
<th>People who had some contact by phone, cards or letters last year.</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Family Contact</td>
<td>41</td>
<td>50</td>
<td>91</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>50.8%</td>
</tr>
<tr>
<td>Significant Family Contact</td>
<td>13</td>
<td>75</td>
<td>88</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>49.2%</td>
</tr>
<tr>
<td>Totals</td>
<td>54</td>
<td>125</td>
<td>179</td>
</tr>
<tr>
<td></td>
<td>30.2%</td>
<td>69.8%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Chi square = 19.47  df = 1  p = <.001

Contingency coefficient = 0.313 (positive association)  p = <.001

There were 41 people who were in the Minimal Contact group (no overnight stays and less than six visits) who also received no contact by phone, cards or letters during the previous year, this being 22.9% of the total sample.

The figure for absolute zero contact (no overnights, no visits, no phone calls, cards or letters) was 28 which was 15.6% of the total sample.
CHAPTER 5.

RESULTS

FACTORS ASSOCIATED WITH FAMILY CONTACT.

For the purposes of most statistical analyses which are presented below, each of the factors associated with family contact was collapsed into a three-category variable, with the exception of the factors of sex and type of residential unit which were two-category variables. The dataset as a whole did not lend itself to statistical analyses which relied on assumptions of interval measurements, normality of distribution, homogeneity of variance and absence of homoscedasticity. Some of the variables (age, years in residential care, distance from family and mental age) were at least ordinal measurements and an analysis of means was appropriate and legitimate for these variables. Other variables (scores for behaviour disturbance and for social competence) were not completely ordinal, and any comparison of means would have been open to question.

The remaining variables, which were family left, level of learning disability, dual disability, sex and type of residential unit, were category variables and it would be illegitimate to make any assumptions about the shape of the population of scores or about any underlying continuity in these variables. For these reasons most of the analyses in this section are chi square tests with the contingency coefficient as a measure of association.

As shown in the last chapter, the one important variable of family contact was the dichotomy between the Significant Contact group who had one or more overnight stays with family and/or six or more visits from family in the last year, and the Minimum Contact group who had no overnight stays with family and less than six visits from family in the last year.
The factors associated with family contact are considered in terms of groups of variables which are logically or in practice related to each other. The first variable is family (members who are) left, and this is related to the second variable, age (of person in residential care) because it is reasonable to assume that older clients will have less family members left. Age is in its turn related to years in residential care because it is reasonable to assume that older people have had more years during which they might have been in residential care.

As noted in Chapter 4, there was a strong correlation of 0.91 (Pearson's Rho) between mental age and social competence, so these two factors needed to be considered together in examining their association with family contact.

Presence of dual diagnosis i.e. psychiatric disorder in addition to learning disability could be expected to be related to degree of behaviour disturbance insofar as the latter is often seen as a major symptom or indication of psychiatric illness.

Distance, sex and type of residential unit were considered next. These factors were not expected to be related to each other in any simple way.

A multivariate analysis was the appropriate technique for testing the relative importance of two or more independent variables which are themselves inter-related (such as family left, age, and years in residential care), and the results of logistic regression tests appear in the next Chapter 6. Below are the results for each factor considered separately for its association with family contact.
Family Members Left.

The ‘family members left’ variable was the factor of who exactly was left in the family of origin for the person in residential care to have any contact with.

Table 12 below shows the cross tabulation of the distinction between Minimal and Significant Contact, and three categories of who is left in the family, which will hereafter be referred to as the family left variable.

Table 12. Crosstabulation of family contact by family left.

<table>
<thead>
<tr>
<th>One or both parents alive.</th>
<th>Parents deceased. One or more sibs in S. Ireland</th>
<th>Parents deceased. No sibs or sibs live abroad.</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Family Contact</td>
<td>20</td>
<td>42</td>
<td>91</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>50.8%</td>
</tr>
<tr>
<td>Significant Family Contact</td>
<td>56</td>
<td>29</td>
<td>88</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>49.2%</td>
</tr>
<tr>
<td>Totals</td>
<td>76</td>
<td>71</td>
<td>32</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>179</td>
</tr>
<tr>
<td></td>
<td>42.5%</td>
<td>39.7%</td>
<td>17.9%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Chi square = 40.52   df=2   p = <.0001

Contingency coefficient = 0.43   (Negative association)   p = <.0001

It was concluded that the family left variable was strongly associated with whether a person had minimal contact as against significant contact with family.

The variable of family left was also associated with age (c = .51, p = <.0001) and with years in residential care (c = .46, p = <.0001). Less predictably, family left was also
associated with distance from family ($c = .60$, $p < .0001$), and with degree of behaviour disturbance ($c = .28$, $p < .01$).

Age of the person in residential care.

Table 13 below shows three age categories of the sample in a cross tabulation with the dichotomised family contact variable.

<table>
<thead>
<tr>
<th>Table 13. Crosstabulation of family contact with age categories.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age range</strong></td>
</tr>
<tr>
<td>1 to 34 yrs.</td>
</tr>
<tr>
<td>Minimal Family Contact</td>
</tr>
<tr>
<td>Significant Family Contact</td>
</tr>
<tr>
<td>Totals</td>
</tr>
</tbody>
</table>

Chi square = 25.72  $df = 2$  $p = <.0001$

Contingency coefficient = 0.354 (Negative association)  $p = <0.0001$

Age was also associated with years in residential care ($c = .34$, $p = <.001$), and the association of age with family left has been analysed in more detail in Table 2, Chapter 4.

Since age is an interval measurement, it was possible to express the difference between the group with minimal family contact and the group with significant family contact in terms of their respective mean ages, and these data are presented in Table 14 below. A Bartlett's Test indicated there was homogeneity of variance, so a Student's T Test was used to compare means.
Table 14. Showing the Means of Age for each group of Family Contact.

<table>
<thead>
<tr>
<th></th>
<th>Obs.</th>
<th>Total</th>
<th>Mean</th>
<th>Variance</th>
<th>Std. Dev.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Family Contact</td>
<td>91</td>
<td>4431</td>
<td>48.69</td>
<td>193.57</td>
<td>13.91</td>
</tr>
<tr>
<td>Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Significant Family</td>
<td>88</td>
<td>3255</td>
<td>36.99</td>
<td>193.07</td>
<td>13.89</td>
</tr>
<tr>
<td>Contact Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Variation SS df MS F statistic p-value
Between 6127.95 1 6127.95 31.69 .000007
Within 34218.37 177 193.32
Total 40346.32 178

Those with minimal family contact tend to be older than those with significant family contact. There was an 11.7 year age difference between the two groups.

Years in Residential Care.

Table 15 below shows the association between three categories of years spent in residential care in a cross tabulation with the family contact variable.

Table 15. Crosstabulation of family contact with years in residential care.

<table>
<thead>
<tr>
<th></th>
<th>1 - 9 yrs in Residential Care</th>
<th>10- 34 yrs in Residential Care</th>
<th>&gt; 34 yrs in Residential Care</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Family Contact</td>
<td>12</td>
<td>53</td>
<td>26</td>
<td>91</td>
</tr>
<tr>
<td></td>
<td>50.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Significant Family Contact</td>
<td>35</td>
<td>45</td>
<td>8</td>
<td>88</td>
</tr>
<tr>
<td></td>
<td>49.2%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Totals</td>
<td>47</td>
<td>98</td>
<td>34</td>
<td>179</td>
</tr>
<tr>
<td></td>
<td>26.3%</td>
<td>54.7%</td>
<td>19.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Chi square 21.39 df = 2 p = <.0001
Contingency coefficient = 0.327 (Negative association) p = <.0001
It was concluded that years spent in residential care was strongly negatively associated with family contacts.

Since years in residential care could be expected to be an interval measurement, it was meaningful and appropriate to compare the mean period in residential care between the two groups, those with minimal family contact and those with significant family contact. A Bartlett's Test indicated that the variances were homogeneous with 95% confidence, so a Student's T Test was used. Table 16 below shows the result of this analysis.

Table 16. Showing the Means of Years in Residential Care for each group of Family Contact.

<table>
<thead>
<tr>
<th></th>
<th>Obs.</th>
<th>Total</th>
<th>Mean</th>
<th>Variance</th>
<th>Std. Dev.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Family Contact Group</td>
<td>91</td>
<td>2436</td>
<td>26.77</td>
<td>198.27</td>
<td>14.08</td>
</tr>
<tr>
<td>Significant Family Contact Group</td>
<td>88</td>
<td>1482</td>
<td>16.84</td>
<td>137.12</td>
<td>11.71</td>
</tr>
</tbody>
</table>

Variation SS df MS F statistic p-value
Between 4409.84 1 4409.84 26.22 .000020
Within 29773.93 177 168.21
Total 34183.77 178

Level of Social Competence.

Table 17 below shows the cross tabulation of the distinction between Minimal and Significant Contact, and three levels of social competence as measured on the McConkey Scales.
Table 17. Crosstabulation of family contact with level of social competence.

<table>
<thead>
<tr>
<th></th>
<th>High *a Social Competence</th>
<th>Medium *b Social Competence</th>
<th>Low *c Social Competence</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Family Contact</td>
<td>26</td>
<td>27</td>
<td>38</td>
<td>91</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>50.8%</td>
</tr>
<tr>
<td>Significant Family Contact</td>
<td>29</td>
<td>36</td>
<td>23</td>
<td>88</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>49.2%</td>
</tr>
<tr>
<td>Totals</td>
<td>55</td>
<td>63</td>
<td>61</td>
<td>179</td>
</tr>
<tr>
<td></td>
<td>30.7%</td>
<td>35.2%</td>
<td>34.1%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

*a = scores from 15 to 33 on the McConkey Scales.
*b = scores from 34 to 49 on the McConkey Scales.
*c = scores from 50 to 64 on the McConkey Scales.

Chi square = 5.09  df = 2  p = 0.08 Not significant.
Contingency coefficient = 0.166  p = 0.08 Not significant.

It was concluded that there was no significant direct association between level of social competence and family contact.

Social competence was found to be associated with level of disability (c = .70, p = <.0001), sex (c = .34, p = <.0001), type of residential unit (c = .48, p = <.0001), and with presence of additional psychiatric disorder (c = .47, p = <.0001).

Level of Learning Disability.

It had been hypothesised that people with more severe learning disabilities might have less family contact, because their disabilities might make family contact difficult or upsetting. In fact, as Table 18 below indicates, there was no direct association between level of disability and receiving significant family contact.
Table 18. Crosstabulation of family contact with level of learning disability.

<table>
<thead>
<tr>
<th></th>
<th>Borderline or Mild Learning Disability</th>
<th>Moderate or Severe Learning Disability</th>
<th>Profound Learning Disability</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Family Contact</td>
<td>27</td>
<td>46</td>
<td>18</td>
<td>91</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>50.8%</td>
</tr>
<tr>
<td>Significant Family Contact</td>
<td>28</td>
<td>44</td>
<td>16</td>
<td>88</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>49.2%</td>
</tr>
<tr>
<td>Totals</td>
<td>55</td>
<td>90</td>
<td>34</td>
<td>179</td>
</tr>
<tr>
<td></td>
<td>30.7%</td>
<td>50.3%</td>
<td>19.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Chi square = 0.130  df = 2  p = 0.937 Not significant.
Contingency coefficient = 0.027  p = 0.937 Not significant.

Level of disability was associated with exactly the same variables that level of social competence was associated with - not surprising given that the latter variables were highly correlated with each other (Spearman's Rho was .91  p = < .0001)

Level of disability was associated with sex (c = .29, p = < .001)
type of residential unit (c = .47, p = < .0001), degree of behaviour disturbance (c = .29, p = < .01) and with presence of additional psychiatric disorder (c = .46, p = < .0001).

Level of Behaviour Disturbance.

It had been hypothesized that people in residential units who had high levels of behaviour disturbance might have less family contact because their disturbed behaviour might be difficult for families to cope with or the contact could be upsetting. In fact the results below in Table 19 indicate that the correlation of behaviour disturbance with family contact did not reach statistical significance.
Table 19. Crosstabulation of family contact with level of behaviour disturbance.

<table>
<thead>
<tr>
<th></th>
<th>Zero or Low Level of Behaviour Disturbance</th>
<th>Moderate Level of Behaviour Disturbance</th>
<th>High Level of Behaviour Disturbance</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Family Contact</td>
<td>44</td>
<td>24</td>
<td>23</td>
<td>91</td>
</tr>
<tr>
<td></td>
<td>50.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Significant Family Contact</td>
<td>54</td>
<td>20</td>
<td>14</td>
<td>88</td>
</tr>
<tr>
<td></td>
<td>49.2%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Totals</td>
<td>98</td>
<td>44</td>
<td>37</td>
<td>179</td>
</tr>
<tr>
<td></td>
<td>54.7%</td>
<td>24.6%</td>
<td>20.7%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

*1 = Scores 0 to 19 on the Wilkinson Scales.

*2 = Scores 20 to 39 on the Wilkinson Scales.

*3 = Scores 40 to 60 on the Wilkinson Scales.

Chi square = 3.524  df = 2  p = 0.172 Not significant.

Contingency coefficient = 0.139 (Negative association)  p = 0.172 Not sig.

Degree of behaviour disturbance was however associated with sex (c = .23  p = <.01),
type of residential unit (c = .39, p = <.0001), family left (c = .28 p = <.01),
years in residential care (c = .26, p = <.01), social competence
(c = .39, p = <.0001), and with level of disability (c = .29, p = <.01).

Presence of additional psychiatric difficulties.

It had been hypothesised that the presence of a psychiatric disorder would militate against
frequent or significant family contact, because the additional difficulties of a psychiatric
condition might be expected to make contacts hard to maintain. In fact, the indication
from Table 20 below was that there was no direct association between having additional
psychiatric difficulties and family contact.
Table 20. Crosstabulation of family contact with psychiatric difficulties.

<table>
<thead>
<tr>
<th></th>
<th>No Significant Psychiatric Difficulties</th>
<th>Some Mild Psychiatric Difficulties</th>
<th>Has Significant Psychiatric Difficulties</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Family Contact</td>
<td>49</td>
<td>24</td>
<td>18</td>
<td>91</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>50.8%</td>
</tr>
<tr>
<td>Significant Family Contact</td>
<td>47</td>
<td>25</td>
<td>16</td>
<td>88</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>49.2%</td>
</tr>
<tr>
<td>Totals</td>
<td>96</td>
<td>49</td>
<td>34</td>
<td>179</td>
</tr>
<tr>
<td></td>
<td>53.6%</td>
<td>27.4%</td>
<td>19.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Chi square = 0.129   df = 2   p = 0.937 Not significant.

Contingency coefficient = 0.007   p = 0.937 Not significant.

Psychiatric difficulties were however associated with sex (c = .23, p = < .01), social competence (c = .47, p = < .0001) and with level of disability (c = .46, p = < .0001).

It was not found to be associated with degree of behaviour disturbance (c = .16, p = .29 N.S.), which was surprising since behaviour disturbance can be a strong symptom of psychiatric problems.

Distance between Residential Unit and Family.

The prediction was that the further away the family members lived from a person in residential care the smaller the amount of contact there would be. Table 21 below shows the cross tabulation between family contact and three categories of distance between person in residential unit and their remaining family.
Table 21. Crosstabulation of family contact with distance.

<table>
<thead>
<tr>
<th>Family Contact</th>
<th>1 to 15 miles.</th>
<th>16 to 129 miles.</th>
<th>130 miles and over.</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal</td>
<td>22</td>
<td>35</td>
<td>34</td>
<td>91</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>50.8%</td>
</tr>
<tr>
<td>Significant</td>
<td>36</td>
<td>50</td>
<td>2</td>
<td>88</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>49.2%</td>
</tr>
<tr>
<td>Totals</td>
<td>58</td>
<td>85</td>
<td>36</td>
<td>179</td>
</tr>
<tr>
<td></td>
<td>32.4%</td>
<td>47.5%</td>
<td>20.1%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Chi square = 34.43  df = 2  p = <.0001

Contingency coefficient = 0.402 (Negative association)  p = <0.0001

Distance was also associated with family left (c = .60, p = <.0001) and with years in residential care (c = .28, p = <.01).

It seemed meaningful and appropriate to compare the mean distance from family for the group which had minimal family contact as against the group which had significant family contact. It was thought inappropriate to use a Student's T Test because distance was really an ordinal measure rather than an interval measure. (In a westerly direction from the western seaboard of Ireland the distance measure would jump from 2 to 2,500 miles, and in an easterly direction the distance measure jumps from 130 miles to something over 200 miles after the Irish Sea is crossed.) As noted earlier, the 6 outliers whose family were in the U.S.A. had been converted to the next highest values for distance from the remaining dataset. For these reasons the non-parametric Kruskal-Wallis Test for two groups was the appropriate choice.
Table 22. Showing the Means of Distance from family for each group of Family Contact.

<table>
<thead>
<tr>
<th></th>
<th>Obs.</th>
<th>Total</th>
<th>Mean</th>
<th>Kruskal-Wallis H</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Family Contact Group</td>
<td>91</td>
<td>13880</td>
<td>152.53</td>
<td>18.676 (df = 1)</td>
<td>.000015</td>
</tr>
<tr>
<td>Significant Family Contact Group</td>
<td>88</td>
<td>2787</td>
<td>31.67</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

It is possible that this massive difference of 120.9 miles between the means of the two groups is exaggerated by Ireland's island status geographically.

Sex.

It had been hypothesised that there would be no direct association between the sex of the person in residential care and their family contacts, and indeed no such association was found, as Table 23 below shows.

Table 23. Crosstabulation of family contact with sex.

<table>
<thead>
<tr>
<th></th>
<th>Males.</th>
<th>Females.</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Family Contact</td>
<td>52</td>
<td>39</td>
<td>91</td>
</tr>
<tr>
<td></td>
<td>50.8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Significant Family Contact</td>
<td>49</td>
<td>39</td>
<td>88</td>
</tr>
<tr>
<td></td>
<td>49.2%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Totals</td>
<td>101</td>
<td>78</td>
<td>179</td>
</tr>
<tr>
<td></td>
<td>56.4%</td>
<td>43.6%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Chi square = .039 df = 1 p = .844 Not significant.
Contingency coefficient = .015 p = .844 Not significant.
Type of Residential Unit.

It had been hypothesised that there would be no direct association between type of residential unit and family contacts, and Table 24 below indicates that any association that there might be failed to reach an acceptable level of significance.

Table 24. Crosstabulation of family contact with type of residential unit.

<table>
<thead>
<tr>
<th></th>
<th>People resident in large size institution.</th>
<th>People resident in community group homes.</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Family Contact</td>
<td>64</td>
<td>27</td>
<td>91</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>50.8%</td>
</tr>
<tr>
<td>Significant Family Contact</td>
<td>51</td>
<td>37</td>
<td>88</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>49.2%</td>
</tr>
<tr>
<td>Totals</td>
<td>115</td>
<td>64</td>
<td>179</td>
</tr>
</tbody>
</table>

64.2% 35.8% 100.0%

Chi square = 2.983 df = 1 p = .084 Not significant.

Contingency coefficient = .128 p = .084 Not significant.
SUMMARY OF MAIN FINDINGS.

Four variables were found to be strongly associated with family contacts, as hypothesised, and these were the three age-related variables of family left, age of client and years spent in residential care, plus the factor of distance between residential unit and family.

Four other variables hypothesised as having some degree of association with family contacts were found to be not significantly related as individual correlates, and these were behaviour disturbance, presence of additional psychiatric problems, level of learning disability and level of social competence.

The two variables which were hypothesised to be unrelated to family contacts were indeed found to be not significantly associated.

The main findings above were the examination of the degree of association of the 10 hypothesised relevant factors with family contacts, dichotomised between significant versus minimal family contact. The tabulated summary of findings is in Table 25 below. A summary table of all the inter-correlations among all the variables appears in Table 36 (p.310) in the Appendices, together with an explanation of the use and limitations of contingency coefficients as measures of association (p. 309).
Table 25. Factors associated with significant family contact.

<table>
<thead>
<tr>
<th>Factor tested for association.</th>
<th>Degree of association (contingency coefficient)</th>
<th>Degree of significance.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family left.</td>
<td>.43</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Age of client.</td>
<td>.35</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Years in residential care.</td>
<td>.33</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Level of social competence.</td>
<td>.17</td>
<td>.079 N.S.</td>
</tr>
<tr>
<td>Level of learning disability.</td>
<td>.03</td>
<td>.937 N.S.</td>
</tr>
<tr>
<td>Level of behaviour disturbance.</td>
<td>.14</td>
<td>.172 N.S.</td>
</tr>
<tr>
<td>Additional psychiatric problems.</td>
<td>.03</td>
<td>.937 N.S.</td>
</tr>
<tr>
<td>Distance from resid. unit to home.</td>
<td>.40</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Sex.</td>
<td>.04</td>
<td>.844 N.S.</td>
</tr>
<tr>
<td>Type of residential unit.</td>
<td>.13</td>
<td>.084 N.S.</td>
</tr>
</tbody>
</table>
CHAPTER 6.

RESULTS.

BUILDING A DISCRIMINANT MODEL.

Many of the factors which were associated with family contact on a chi square test were associated with each other as well. A regression technique was necessary in order to take account of interactive variables and build up a discriminant model to establish the important factors influencing family contact.

The computerised statistics programme which was available to handle logistic regression was S.P.S.S. for Windows (Statistical Package for the Social Sciences). A sequential logistic regression was used for the main analysis.

The starting point for building a discriminant model is shown in Table 26 below, which represents the background likelihood of being in either the minimal contact group or the significant contact group.

Table 26.

<table>
<thead>
<tr>
<th>Observed</th>
<th>Predicted</th>
<th>Percent Correct</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>0= Min. Contact</td>
<td>91</td>
<td>0</td>
</tr>
<tr>
<td>1= Sig. Contact</td>
<td>88</td>
<td>0</td>
</tr>
</tbody>
</table>

Overall 50.84%
The method for entering variables into the equation was based on the initial hypotheses made at the outset of this study, modified by the findings from the chi square analyses in Chapter 5. It seemed pragmatic to avoid entering into the equation two variables which were either highly correlated with each other, such as level of learning disability and social competence, or two variables which logically were related very closely to each other, such as age and years spent in residential care. For the variables of sex and type of residential unit, no significant association with family contact had been shown in the chi square analyses reported in Chapter 5, and these variables had not been among the hypothesised correlates at the outset of the study. Therefore, these two factors were not entered at this stage in running the logistic regression analyses.

The first variable to be entered was family left, because this had been hypothesised as a strong correlate at the outset of the study, and because the strongest contingency coefficient had been produced by this variable in the chi square cross tabulations with family contact. In addition to this, there was a strong logical association:- you need to have some family members left in order to have any contact with them. The result of entering the family left variable into the logistic regression equation is shown in Table 27 on page 308 in the appendices. The percentage of correctly distinguished cases rises from 50.84% to 70.95% as a result of this one variable by itself.

Enter distance.

The next variable to be selected for entry was distance between residential unit and family, because by itself it had the second strongest association with family contact on a chi square analysis.

As Table 28 on page 309 indicates, entering distance into the logistic regression equation resulted in a 1.12% improvement in the percentage of cases correctly discriminated by the model.
Enter age level.
The next variable to be selected for entry into the equation was age level because age was a central hypothesised variable, though it had been found to be related to years in residential care and family left itself. This resulted in a further 1.11% improvement in the percentage of correctly discriminated cases, from 72.07% to 73.18% (Table 29 on page 310).

Degree of Behaviour Disturbance.
The factor of the degree of behaviour disturbance was entered next because this variable had been hypothesised as a correlate at the outset of the study, and it was not logically or necessarily associated with the other three variables entered already. Although, by itself, degree of behaviour disturbance had not proved to be significantly associated with family contact on a chi square analysis, when it was entered into the model at this stage there was a 5.03% improvement in the percentage of cases correctly discriminated. There was also a highly significant increase in the Improvement of the Model Chi square statistic - as indicated in Table 30 on page 311.

Finally, one of the two measures of dependency was needed to complete a coherent picture of the factors relating to family contact. Both level of learning disability and degree of social competence were measures of dependency, and had been found to be strongly associated with each other. Degree of social competence was selected because as an individual variable it had more nearly approached statistical significance in the chi square analysis (Table 18).

Table 31 below shows that addition of this factor into the equation results in a further 2.80% improvement in the percentage of cases correctly predicted by the model. There was also a highly significant increase in the Improvement of the Model Chi square statistic.
Table 31. Results of sequential logistic regression analysis.

Variables entered - Family left, distance, age, behaviour disturbance and degree of social competence.

-2 Log Likelihood 152.98  
Goodness of Fit 167.32 

<table>
<thead>
<tr>
<th>Chi square</th>
<th>df</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model chi square</td>
<td>95.12</td>
<td>10</td>
</tr>
<tr>
<td>Improvement</td>
<td>16.71</td>
<td>2</td>
</tr>
</tbody>
</table>

Classification Table for Minimal/Significant Contact.

<table>
<thead>
<tr>
<th>Observed</th>
<th>Predicted</th>
<th>Percent Correct</th>
</tr>
</thead>
<tbody>
<tr>
<td>0= Min. Contact</td>
<td>0</td>
<td>71</td>
</tr>
<tr>
<td>1= Sig. Contact</td>
<td>1</td>
<td>20</td>
</tr>
<tr>
<td>Overall</td>
<td>81.01%</td>
<td></td>
</tr>
</tbody>
</table>

Variables in the Equation

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>S.E.</th>
<th>Wald</th>
<th>df</th>
<th>Sig.</th>
<th>R</th>
<th>Exp (B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family left</td>
<td>6.406</td>
<td>2</td>
<td>.041</td>
<td>.098</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family left (1)</td>
<td>1.411</td>
<td>.991</td>
<td>2.027</td>
<td>1</td>
<td>.154</td>
<td>.010</td>
<td>4.099</td>
</tr>
<tr>
<td>Family left (2)</td>
<td>.077</td>
<td>.881</td>
<td>.008</td>
<td>1</td>
<td>.931</td>
<td>.000</td>
<td>1.080</td>
</tr>
<tr>
<td>Distance</td>
<td>12.758</td>
<td>2</td>
<td>.002</td>
<td>.188</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distance (1)</td>
<td>3.355</td>
<td>.994</td>
<td>11.403</td>
<td>1</td>
<td>&lt;.001</td>
<td>.195</td>
<td>28.654</td>
</tr>
<tr>
<td>Distance (2)</td>
<td>3.537</td>
<td>.997</td>
<td>12.594</td>
<td>1</td>
<td>&lt;.001</td>
<td>.207</td>
<td>34.352</td>
</tr>
<tr>
<td>Age</td>
<td>13.988</td>
<td>2</td>
<td>.001</td>
<td>.201</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (1)</td>
<td>2.980</td>
<td>.799</td>
<td>13.898</td>
<td>1</td>
<td>&lt;.001</td>
<td>.219</td>
<td>19.688</td>
</tr>
<tr>
<td>Age (2)</td>
<td>1.660</td>
<td>.580</td>
<td>8.197</td>
<td>1</td>
<td>.004</td>
<td>.158</td>
<td>5.258</td>
</tr>
<tr>
<td>Beh. disturb.</td>
<td>7.603</td>
<td>2</td>
<td>.022</td>
<td>.121</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beh. disturb. (1)</td>
<td>1.430</td>
<td>.566</td>
<td>6.385</td>
<td>1</td>
<td>.012</td>
<td>.134</td>
<td>4.177</td>
</tr>
<tr>
<td>Beh. disturb. (2)</td>
<td>1.716</td>
<td>.682</td>
<td>6.335</td>
<td>1</td>
<td>.012</td>
<td>.132</td>
<td>5.562</td>
</tr>
<tr>
<td>Social compet</td>
<td>14.388</td>
<td>2</td>
<td>&lt;.001</td>
<td>.205</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social compet(1)</td>
<td>1.898</td>
<td>.595</td>
<td>10.190</td>
<td>1</td>
<td>.002</td>
<td>.182</td>
<td>6.672</td>
</tr>
<tr>
<td>Social compet(2)</td>
<td>2.003</td>
<td>.566</td>
<td>12.521</td>
<td>1</td>
<td>&lt;.001</td>
<td>.206</td>
<td>7.411</td>
</tr>
<tr>
<td>Constant</td>
<td>-7.781</td>
<td>1.344</td>
<td>33.506</td>
<td>1</td>
<td>&lt;.001</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
This procedure constituted a sequential logistic regression analysis, and these results represent the main analysis and findings. Still using logistic regression, a further analysis was tried on the basis of heuristic interest and is reported on below.

**Parsimonious Models.**

There had been a total of ten variables which were capable of being entered into a logistic regression procedure, and five of these were entered into the main sequential analysis above. But what if the task was set to establish the most parsimonious model which could achieve good discrimination from only three variables? Which would be the three best discriminant variables?

All combinations of three variables were run on S.P.S.S.Windows logistic regression using the standard "enter" command and only a model which was able to correctly discriminate more than 75% of cases was accepted. This resulted in just two model equations, both of which, it transpired, included the variables family left and social competence. These two models are shown in the Tables 32 and 33 below.

**Table 32. Three factor regression model number 1.**

Variables entered - Family left, social competence, and distance.

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
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<tbody>
<tr>
<td>-2 Log Likelihood</td>
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<tr>
<td>Goodness of Fit</td>
<td>181.99</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Model chi square</td>
<td>73.11</td>
<td>6</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Improvement</td>
<td>73.11</td>
<td>6</td>
<td>&lt;.0001</td>
</tr>
</tbody>
</table>

Classification Table for Minimal/Significant Contact.

<table>
<thead>
<tr>
<th></th>
<th>Predicted</th>
<th>Percent Correct</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0= Min. Contact</td>
<td>55</td>
<td>36</td>
</tr>
<tr>
<td>1= Sig. Contact</td>
<td>5</td>
<td>83</td>
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</table>

Overall 77.09%
--- Variables in the Equation ---

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>S.E.</th>
<th>Wald</th>
<th>df</th>
<th>Sig</th>
<th>R</th>
<th>Exp(B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family left</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>.858</td>
<td>7.810</td>
<td>1</td>
<td>.0052</td>
<td>.153</td>
<td>11.004</td>
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<td>Family left(2)</td>
<td>.570</td>
<td>.816</td>
<td>.489</td>
<td>1</td>
<td>.4843</td>
<td>.000</td>
<td>1.769</td>
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<td>14.838</td>
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<td>.0006</td>
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<tr>
<td>Soc. comp.(1)</td>
<td>1.622</td>
<td>.504</td>
<td>10.331</td>
<td>1</td>
<td>.0013</td>
<td>.183</td>
<td>5.063</td>
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<tr>
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<td>.495</td>
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<tr>
<td>Distance</td>
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<td>Distance(1)</td>
<td>2.603</td>
<td>.887</td>
<td>8.609</td>
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<td>.0033</td>
<td>.163</td>
<td>13.500</td>
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<td>Distance(2)</td>
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<td>.0029</td>
<td>.166</td>
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<tr>
<td>Constant</td>
<td>-4.673</td>
<td>.955</td>
<td>23.930</td>
<td>1</td>
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</table>

Table 33. Three factor regression model number 2.

Variables entered - Family left, social competence, and age.

-2 Log Likelihood 179.26  
Goodness of Fit 176.73

<table>
<thead>
<tr>
<th>Chi square</th>
<th>df</th>
<th>Significance</th>
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<tr>
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<td>68.84</td>
<td>6</td>
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<tr>
<td>Improvement</td>
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<td>6</td>
</tr>
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</table>

Classification Table for Minimal/Significant Contact.

<table>
<thead>
<tr>
<th>Observed</th>
<th>Predicted</th>
<th>Percent Correct</th>
</tr>
</thead>
<tbody>
<tr>
<td>0= Min. Contact</td>
<td>67</td>
<td>24</td>
</tr>
<tr>
<td>1= Sig. Contact</td>
<td>17</td>
<td>71</td>
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</tbody>
</table>

Overall 77.09%
From these analyses indicated by Table 31, Table 32 and Table 33, it would seem reasonable to conclude that a model which includes family left, social competence and either distance or age will produce good discrimination, and even better discrimination can be achieved by including all these together, plus behaviour disturbance. This conclusion is indicated by the summary of the analyses in Table 34 below.

**Table 34. Summary of the logistic regression analyses.**

<table>
<thead>
<tr>
<th>Three factor model</th>
<th>Three factor model</th>
<th>Five factor model</th>
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<tr>
<td>Family left</td>
<td>Family left</td>
<td>Family left</td>
</tr>
<tr>
<td>Social competence</td>
<td>Social competence</td>
<td>Social competence</td>
</tr>
<tr>
<td>Age</td>
<td>Distance</td>
<td>Age</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Distance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Behav. disturbance</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>77.09% correctly discriminated.</td>
<td>77.09% correctly discriminated.</td>
<td>81.09% correctly discriminated.</td>
</tr>
</tbody>
</table>

---

**Variables in the Equation**

<table>
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<th>S.E.</th>
<th>Wald</th>
<th>df</th>
<th>Sig</th>
<th>R</th>
<th>Exp(B)</th>
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<tr>
<td>Family left</td>
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<tr>
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<td>3.298</td>
<td>.747</td>
<td>19.488</td>
<td>1</td>
<td>.0000</td>
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<td>Family left(2)</td>
<td>1.962</td>
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<td></td>
<td></td>
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<tr>
<td>Soc. comp.(1)</td>
<td>1.736</td>
<td>.512</td>
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<td>1</td>
<td>.0007</td>
<td>.195</td>
<td>5.677</td>
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<tr>
<td>Soc. comp(2)</td>
<td>1.895</td>
<td>.502</td>
<td>14.239</td>
<td>1</td>
<td>.0002</td>
<td>.222</td>
<td>6.655</td>
</tr>
<tr>
<td>Age(1)</td>
<td>1.887</td>
<td>.669</td>
<td>7.949</td>
<td>1</td>
<td>.0048</td>
<td>.154</td>
<td>6.000</td>
</tr>
<tr>
<td>Age(2)</td>
<td>1.074</td>
<td>.520</td>
<td>4.268</td>
<td>1</td>
<td>.0388</td>
<td>.095</td>
<td>2.927</td>
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<tr>
<td>Constant</td>
<td>-4.554</td>
<td>.876</td>
<td>26.988</td>
<td>1</td>
<td>.0000</td>
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<td></td>
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</tbody>
</table>
CHAPTER 7.

DISCUSSION AND CONCLUSIONS.

The single most forceful conclusion from this study is that it is age-related factors which are most strongly related to diminished family contacts. The chronological age of the person in residential care was negatively associated with family contact. Of those in the 1 to 34 years age group, 74% had significant contact with their family, whereas of the 55 years and over age group, only 20% had significant contact. The pattern of results was very similar for years spent in residential care. Of those who had been in residential care for less than 10 years, 75% had significant family contact, whereas of those who had been in residential care for 35 years or more, only 24% had significant family contact.

These findings accord with those studies which had taken great care to achieve representative population samples (Wille and Intagliata, 1982; Stoneman and Crapps, 1990; D'Onofrio et al., 1980; Hill et al. 1989; Mulcahy, 1976).

The age-related variable of who is left within the family was found to be the single factor most strongly associated with family contacts. Having one or both parents alive would seem to be in itself an important factor in maintaining family contact. Of those with one or both parents alive, 56 out of 76 (73.7%) received significant family contact. Of those with parents deceased, only 32 out of 103 (31.1%) received significant family contact. Having parents deceased and no siblings, or sibling(s) living abroad, leads to even less family contact. Only 3 out of 32 (9.4%) of this group received significant family contact.

A majority of 57.5% of clients in residential care are in the situation of having both parents deceased. In 19.9% of cases the situation was that parents were deceased and the remaining siblings, if any, lived abroad. The largest single category was where parents were deceased but there were one or more siblings who remained in S. Ireland (39.7%).
Typically, these would be adult siblings who might be partnered and with children of their own.

A minority of 42.5% had one or both parents alive. In the case where only one parent was alive (22.9%) this was more likely to be the mother because of the greater life expectancy of females of that generation in rural Ireland. Only 19.6% of the sample were in the situation of having both parents alive.

The factor of family left has been ignored or underestimated by a majority of other studies in this area, including Baker and Blacher (1996), Baker, Blacher and Pfeiffer (1993) and Stoneman and Crapps (1990). These two research groups chose to eliminate from their sample those cases where there were no family members left, on the grounds that those cases might 'compound age trends' (Blacher and Baker, 1992 p. 37), or else because such cases 'were treated as missing' (data), (Stoneman and Crapps, 1990, p. 423). Other studies have failed to include family left as a variable and failed to report on how cases with no contactable family were treated in their analyses (Anderson et al., 1975; D'Onofrio et al., 1980; Kelleher et al., 1988).

One of the few research studies to appreciate adequately the significance of family left was that of Anderson et al. (1992) who found that 24% of their sample had no family contacts because there were no living family members left, but her study covered elderly people only so she could not comment on the significance of this factor across the whole age range.

The results of the present study lend qualified support to an explanation based on lifespan factors: as people with learning disability grow older, they are more likely to enter residential care, and the longer they stay in residential care the less often that family visitation occurs. As time goes by there may be fewer family members left and this will contribute in itself to a decrease in family contact. In particular, as and when parents die, there can be a further diminution in sibling contacts because siblings and more extended family members may be unable or unwilling to maintain contacts. Nevertheless, in a
minority of cases family contacts remain high throughout the lifespan.

Within the able general population it is common for people in their twenties, thirties and forties to reduce their contacts with parents and siblings, even though these family members might be very much alive. So it can be expected that this phenomenon would also be observed within the disabled population who are in residential care. An additional factor is that many people from the able general population will start families of their own whereas this would be a rarity among the learning disabled population, and this would tend to make age a more important influence in reducing family contacts for the learning disabled population over the lifespan.

It had been hypothesised that persons in residential care whose family members lived long distances away would have less contact than persons whose family still lived fairly close to the residential units, and a highly significant association of 0.40 was found between family contacts and distance.

Of those living 1 to 15 miles from family, 36 out of 58 (62.1%) had significant contact. The percentage is very similar for those living somewhat further away. Of those living 16 to 129 miles away from family, 50 out of 85 (58.8%) had significant contact. But for those living 130 miles or more from family, only 2 out of 36 (5.5%) had significant contact. It should be noted that in most cases for this last category of 130 miles or more, the family were living out of the country and across a sea. Distance was also associated with family left (c = .60, p = <.0001) and with years in residential care (c = .28, p = <.01). This probably reflects lifespan developments of people who have been in care a long time being more likely to have deceased parents and siblings who live at some considerable distance from the residential unit.

The vast majority (96.1%) of people under study hailed from the three counties in the Health Board area, and most of the rest came from neighbouring counties. But this did not mean that the remaining family members still lived there now. Some did remain at the family home or within the same neighbourhood, but others had moved to large population
areas such as Dublin or Galway, and yet others had emigrated to Britain or the U.S.A., and this social mobility was reflected in the large variation in the distance factor.

This also accords with a lifespan explanation: as families of origin grow older, parents with a son or daughter in residential care may themselves change occupations and move house causing them to be further away from the long-term residential unit. The siblings of the person in care are more likely than the parents to move out and away, and as and when the parents die over time, these siblings may be the only family left and they may live at some considerable distance from the residential unit. Just how far these distances can be is illustrated by the enormous difference in mean distance between the group who had significant family contact, whose family lived on average 32 miles away, as against the group with minimal contact whose family lived on average 153 miles away.

An analysis of this minimal contact group indicated that 33.0% of them had family living outside the landmass of N. and S. Ireland whereas only one person (1.1%) of the significant contact group had family living outside Ireland. It is possible that emigration from Ireland and factors inhibiting families from bringing with them their learning disabled family member have contributed to the physical distancing over time of this minimal contact group. It is noteworthy that 6 people in the minimal contact group (6.6%) had their family members living in the U.S.A., a country whose immigration laws discourage people with learning disability from entry.

Taking account of the probable interactions of distance with the factors of age, family left, lifespan and social mobility, distance is associated very strongly with family contacts in its own right and this finding accords with that of other studies which have shown the significance of distance (Ballinger, 1970; Balla and Zigler, 1971; Baker, Blacher and Pfeiffer, 1993; Anderson et al., 1975; Anderson et al., 1992; Baker and Blacher, 1996).

Policy makers may have to choose between the rights of the person with learning disability to have continuity of care and to remain in their own (residential) home, as against the
right to remain within visiting distance of their family when a family moves away. In practice it might be very difficult to define when exactly a family has moved away, because different family members may depart from the family home at different stages of life.

The variables associated with family contact are influential within a context of very low overall visitation rates, and it might be more accurate to describe them as correlates of non-contact. Over half (50.8%) of the total sample were within the minimal contact group, defined as those people who had no overnight stays with family and less than six visits from family within the last year. Forty three people (24.0%) had no direct contact with family, that is, no visits and no overnight stays during the last year.

Overnight stays with a family member were felt to constitute the most important measure of family contact because usually a greater involvement and commitment is needed than is the case for when a family member visits the person in residential care. An overnight stay usually involves twenty four hours of contact whereas a visit by a family member to residential unit would typically last one or two hours.

An illustrative finding was that nearly 60% of people in residential care had not had any overnight stays with any family member during the last year. These people form a core majority who never go home. At the other end of the spectrum were 17.3% who had more than 50 overnight stays with family. The most usual pattern of such overnights was something like the following:- a week at Christmas, four or five days at Easter, two or three or four weeks during the Summer, and other weekends or Bank Holiday weekends during the rest of the year.

The picture for visits to the residential unit was very similar to that of overnight stays with family. One third of all residents never received a visit from any family member during the previous year, and a further 45% received one to five visits during the year. This meant that 77.8% of people in residential care received less than six visits from family members during the previous year. Only 10.6% of the residential population received more than 20 visits during the previous year.
These rates seem to be broadly comparable with those found in other studies which had larger sample sizes over the whole age range, but exact comparisons are difficult because of different methods of data collection and classification. Hill et al. (1984a) found that 20% had no direct contacts with family, and in 1989 the same team (Hill et al., 1989) found that 31% had no direct contacts. (Our figure was 24% for those who had no visits and no overnight stays during the last year.)

Two studies (Wilier and Intagliata, 1982; Hill et al., 1989) found that 50% of their residential population were never visited by a family member, and our figure for never being visited was 33%. Baker, Blacher and Pfeiffer (1993) found that 32% of their sample had no family contacts (our figure was 24%), but theirs was a study of children with dual diagnosis of learning disability and psychiatric disorder, so the results are not comparable. Other studies quote their figures in a manner which makes comparisons impossible.

The characteristics of the person in residential care, which in this study included level of disability, degree of social competence, degree of behaviour disturbance, presence of psychiatric disorder and sex, contributed relatively little in terms of their individual association with family contact. None of these factors reached a 5% level of significance in the chi square analyses in Chapter 5.

This is not to suggest that these factors would not have been important in determining whether or not a person came into residential care in the first place. There is a consistent body of research to suggest that levels of disability and social competence, and presence or degree of behaviour disturbance and psychiatric difficulties are indeed significant factors precipitating the decision to place a person into residential care (Tausig, 1985; Sherman, 1988; Bromley and Blacher, 1991). The evidence from the present study suggests that, once placed, the factors of the clients' characteristics are not strongly related to the continuance of family involvement.

But the results of the main logistic regression analysis (Table 31) detailed in Chapter 6 indicated that, after most of the variance had been explained by the factors of family left,
age and distance, then some of the remaining variance could be accounted for by the factors of behaviour disturbance and degree of social competence.

Most of the research where behaviour disturbance and social competence were found to be related to family involvement were studies of children (Baker et al., 1993; Sherman, 1988; Bromley and Blacher, 1991; Anderson et al., 1975). Because of the limited age range of the younger people in those studies, it would not have been possible for age itself to have been found the more critical variable, as in the present study.

The results of our study accord most closely with those of Stoneman and Crapps (1990) who also had a sample representative of the whole age range from 3 to 76 years and who found that age, distance, behaviour disturbance and social competence were significant correlates, and they also took a lifespan approach in accounting for their findings. As in the present study, Stoneman and Crapps (1990) found that the client characteristics were only moderate correlates of family involvement. The conclusion from our study is that age-related factors are primary, and factors of client characteristics, residence characteristics and other factors are secondary.

Being male or female, as hypothesised, did not seem to be related to family contacts for people in residential care.

It had been hypothesised that having an additional psychiatric disorder would be related to (a lack of) family contacts, but the results failed to support this hypothesis. At no stage in analysis was the factor of having an additional psychiatric disorder found to be associated with family contact, and it was even found not to be associated with behaviour disturbance—surprising since behaviour disturbance can often be a symptom of psychiatric disorder. But having a psychiatric disorder was positively associated with level of disability and degree of social competence, and it seems that only more intelligent and socially competent people were given a classification of psychiatric disorder, which may have weakened its overall influence as a factor. This result is in contrast with that of Baker, Blacher and Pfeiffer (1993) who found that, for children at least, having both a
learning disability and a psychiatric disorder did militate against family contacts. It is possible that a degree of diagnostic overshadowing (Moss et al., 1993) led to too few people in our sample being classified as having significant additional psychiatric problems, and that more stringent procedures would have identified more of the people with lower ability as having psychiatric problems.

In this study 19.0% were categorised as having very significant psychiatric difficulties, and a further 27.4% were categorised as having mild psychiatric difficulties, making a total of 46.4% categorised as having some degree of psychiatric difficulties in addition to their learning disability. Lyster and Kinsella (1988) reported a prevalence rate of 40% and Corbett (1979) a rate of 51% for people in large residential units in both studies.

Overall the present results lent scant support to the general hypothesis that characteristics of the client would be the principal correlates of family contacts, and are in accord with the conclusion of D'Onofrio (1980).

The type of residential unit - large 110-bed unit or small 6-bed group home- was not found to be significantly associated with family contacts. This finding was as hypothesised, and is in line with research findings over the last 15 years which have also failed to find the type of residential unit to be significantly related to family contacts when other factors such as distance, client characteristics and period spent in residential care are adequately controlled for (Latib et al., 1984; Grimes and Vitello, 1990). Within the client population under study, the type of residential unit might have been expected to be related to degree of behaviour disturbance and to level of learning disability because a previous study of the writer showed that policy changes within the last decade have resulted in a concentration of the more disabled and behaviourally disturbed people within the larger residential units (Clarke and Ferry, 1992). That finding was re-affirmed in the present study results which indicated that there was a significant association between residential type and behaviour disturbance, social competence and level of disability, in the direction of the more disabled and disturbed people being over-represented within the large scale residential unit.
But behaviour disturbance and disability level were not in themselves strong correlates with family contact, and type of residential unit, even with these compounding factors, was not significantly associated with family contacts. Most group homes in this study had been established 9 years ago - one had been in existence for 12 years and two were 5 years old. The present results failed to confirm the expectation that provision of group homes in the community would lead to increased family contacts. The writer's own impressions were that in both types of residential setting the caregivers made the same degree of effort to promote or maintain family contacts.

Efforts were made in this study to try to achieve a sample which would be representative of the whole residential population of people with learning disability within Southern Ireland. The main approach for achieving this aim was to obtain a highly representative sample from one defined geographical area. Some months following completion of data collection the preliminary report of the National Database became available, and this made possible the comparisons of the present sample with the national population on basic demographic variables.

Comparisons with the National Database indicated that the present sample population could be considered representative in terms of the proportions of males and females in the residential population, and in terms of the relative proportions in large scale residential care versus community group homes. But the sample in this study was not representative for age because it contained a somewhat greater proportion of older people in the 40 to 59 year band and the mean age was 3.3 years older than for the national residential population. Within the context of a broad representation of all the age bands (Table 1) and an age range of 4 to 77 years, this is thought to be a modest age difference from the national population and should not affect the overall validity of the present findings.

The present sample was also found to differ from the national population insofar as people with a moderate learning disability were under-represented and people with a severe to profound disability were somewhat over-represented: - 56% were in the severe/profound range in this study whereas 43% were in that range in the national residential population.
Within the context of a representation of all the disability levels (Table 4) and the fact that level of disability did not emerge as a significant variable for family contact, this discrepancy was not thought to have affected the overall validity of the findings in this study.

The present study results and the National Database findings were more or less contemporaneous, based on the year 1996. But the National Database revealed that the current population of people in residential care is very different from the populations which existed in previous decades, and the implications of this finding are considered below.

**Re-evaluation of the age factor in the light of demographic changes in the learning disabled residential population of S. Ireland.**

The present study reinforced findings from earlier studies showing that the age of the person in residential care was strongly associated with family contacts. But there are strong grounds for believing that the age distribution of the residential population has itself changed over the last 25 years. Hill *et al.* (1984b) carried out two national surveys in the U.S.A. for 1977 and 1982 covering the total learning disabled residential population which numbered a quarter of a million persons. Their findings showed that whilst the total residential population numbers remained relatively static during this five year period, there was a strong trend indicating decreasing numbers of residents aged 21 or younger in out-of-home residential care (from 36.8% to 24.8% of all residents).

Hill *et al.* (1984b) attributed the decrease in the number of children and youth to social policies and funding practices designed to encourage families to support their children at home for as long as possible and they strongly predicted that this trend would continue until the end of the century. Together with increased life expectancy of people with learning disability this trend would result in the residential population shifting towards the older end of the age spectrum.
Until May 1997 it was not possible to examine whether the same trend obtained for S. Ireland as a whole because the last census of the learning disabled population had been in 1981. But following the development of the computerised National Database (for Learning Disability) in 1996, it became possible to enquire about the age, sex, area, intelligence and residence distribution of the total population of people in residential care in S. Ireland. The following table shows the percentages of people within three age groups for the years 1974, 1981 and 1997 for the total residential population of learning disabled people in S. Ireland.

Table 35. Age groups in three different year periods.

<table>
<thead>
<tr>
<th>Age of Resident</th>
<th>1974</th>
<th>1981</th>
<th>1997</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 to 19 years.</td>
<td>41.6%</td>
<td>34.3%</td>
<td>10.2%</td>
</tr>
<tr>
<td>20 to 34 years.</td>
<td>24.8%</td>
<td>31.0%</td>
<td>32.3%</td>
</tr>
<tr>
<td>35 to 54 years.</td>
<td>20.8%</td>
<td>21.6%</td>
<td>40.4%</td>
</tr>
<tr>
<td>55 &amp; over</td>
<td>12.7%</td>
<td>12.0%</td>
<td>17.1%</td>
</tr>
<tr>
<td>Total number</td>
<td>8,138</td>
<td>8,088</td>
<td>7,572</td>
</tr>
</tbody>
</table>

It is apparent from this table that the population of people in 1997 is strikingly different in age distribution from that in 1974. Currently only 10% of people in residential care are under 20 years of age whereas in 1974, 42.0% were under 20 years. Currently there are twice as many people in the 35 to 54 years age bracket than was the case in 1974.

The mean age of the population of people in residential care in the present study was 42.9 years, and the mean age of the national population in residential care was 39.6 years. Older people were somewhat over-represented in the present study, especially in the age bracket 35 to 54 years, in line with the national trend towards an older population of people in residential care.

There is now an extended life expectancy for people with learning disability (Mulcahy,
1997; Anderson et al., 1992) and a tendency to only enter residential care at a later age than would have been the case two or three decades ago (Hill et al., 1984b). These two factors lead to a relatively older population of people in full-time residential care.

The implications of the finding of a national trend towards an older population of people in residential care are quite far-reaching for research findings on family contacts, and indeed for any other research on people in residential care where age could be a factor. The population in residential care today does not have the same age characteristics as the population from twenty years ago, and therefore research findings from some years ago are not directly comparable with research results from today unless this factor is taken into account.

The Irish population of people with learning disability seems to have followed the same lifespan development as predicted by Hill et al. (1984b) in terms of the drift into residential care. Social policies and an ideological Zeitgeist have contributed to fewer people under the age of 25 years coming into residential care. Since the total number of people in residential care has not changed very much- the total for 1997 is 93.6% of the total for 1981- it seems that the shortfall of younger people coming into care has been made up by greater numbers of older people coming into care than was the case 16 years ago.

It is speculated that this is because when parents become infirm or die, the siblings are no longer able or willing to continue with the responsibility of care at home for the learning disabled person. Indirect support for this speculation comes from our own findings that when parents are deceased there is a very low rate of contact from any other family members. Conliffe (1993) also found that the care commitment of siblings towards their disabled brother or sister was very much less than that of parents.

The changes in the age distribution of the residential population over the last two decades may not have finished yet, and it may not be until the end of the first decade in the new millennium that the pattern becomes stable.
A number of researchers into family contacts of people in residential care have concluded that where low visitation rates were found, they were to be deplored, and the services should make more efforts to facilitate family contacts (Evans et al., 1994; Baker and Blacher, 1993; Anderson et al., 1992), or that future services should be designed in ways which might encourage family contacts (Felce et al., 1980). One researcher noted that when specific efforts had been made by residential caregivers, there was a disappointing response from the family or next of kin (Stoneman and Crapps, 1990).

The findings of this study failed to confirm the findings of those studies which suggested that apparently improved rates of family contact following initial placements in community group homes would be maintained (Felce et al., 1980; Kelleher et al., 1988; Baker and Blacher, 1993). Instead, the present results support the findings of the studies which have failed to find significant or long-lasting improvements in family contacts following placement in community group homes (Lowe and de Paiva, 1991; Grimes and Vitello, 1990; Latib et al., 1984).

The results of the present study force a consideration of whether it is reasonable to deplore or be disappointed by low visitation contacts, for the following reasons:- a significant proportion (9.5%) have no traceable family to have contacts with. A larger proportion (48.1%) have parents deceased but they do have siblings, whether in Ireland or abroad. From the variation in the rates of such sibling family contacts it is apparent that some siblings maintain a great deal of contact and others have little or no contact. It may be disappointing to the people in residential care if they receive minimal family contact (Hill et al., 1989), but from the siblings' point of view, minimal contact may be exactly what they want. The findings from the present study force a questioning of the common underlying assumption that "...family involvement is generally worthwhile for all parties involved..." (Blacher and Baker, 1992, p. 38).

For the group with one or both parents alive, a majority had maintained significant contact with their family. Those who had failed to maintain contact with a parent present a challenge to current service assumptions and a service philosophy which stresses the
importance of family involvement. It may be that services simply need to come to terms with the fact that there will always be a minority of parents who over a period of time reach a stage of wanting minimal or zero contact with their son or daughter, no matter how conducive the facilities for visitation are made.

Evans et al., (1994) regretted the failure of any comprehensive partnership between service providers, service users and their families in providing care plans in their assessment of the All Wales Mental Handicap Strategy. The present results indicate that such a partnership might be a vain objective for the majority of cases where there are few close family members with whom to form such a partnership, and the very low level of family contacts in these cases indicates that no such involvement might be desired.

The present study suffers from the disadvantage of all cross-sectional correlational studies in that it is not possible to reach firm conclusions about causation and trends over time. Strong inferences from the data could be made to support a lifespan interpretation for the reduction in family contacts over time, but longitudinal studies over a period of at least a decade would be needed to confirm and describe more precisely what the lifespan pattern of contacts might be.

Another general drawback to this study was that it was a broad based quantitative piece of research. A qualitative approach, subject to ethical considerations, could examine more closely, with only a few subjects and their families, what family contact represents to the person in residential care, and to the family members. It might be possible to elicit both positive and negative feelings about contact which are only hinted at in a quantitative study.

A few particular difficulties were experienced in the design and data collection stages of this study, which relied to some extent on the current caregivers having impartial and accurate memories of the contacts of the people they are looking after. Because detailed accuracy could not be relied on, some variable categories had to be broadened and this resulted in loss of information. Whilst this would not have affected the broad picture, it
was regrettable that the variable of "family left" was reduced to consist of only five broad categories. It would have illustrated the picture more clearly to have discriminated between parents who have other children as against parents who have only the disabled child, for example.

A general difficulty with this study and nearly every other study in this area is that very little is revealed about the families who have virtually no contact with their learning disabled relative. These families are unlikely to want to participate in a research study, but until this group is examined in some systematic fashion, the picture of the determinants of family contacts, or the lack of them, will remain incomplete.
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Information Sheet for Caregivers and their Managers.

Re SURVEY ON FAMILY CONTACTS OF PEOPLE WITH LEARNING DISABILITIES WHO ARE IN RESIDENTIAL CARE.

Researcher :- Stephen Clarke, Senior Clinical Psychologist, Dept. of Psychology

I am registered to do a higher degree in psychology with Surrey University, and partly towards this I am carrying out a research project on the family contacts which clients in residential care have with their family of origin. I have the required permission from the Health Board to do this project as long as any carer like yourself understands that participation is completely voluntary and that there can be no negative comeback for anyone who does not want to take part in giving the information I am seeking.

I shall explain what the project is about. We know that there are big differences among clients in the amount of family contact which they receive with members of their own family: some have hardly any contact, whereas others receive lots of visits and go home for regular periods. Some get cards, letters or phone calls on a regular basis from their family, whereas others hardly ever get such contact.

I am interested in finding out what are the factors which influence the amount of family contact which people in residential care receive. Is it connected with their age, or how long a person has been in residential care? Do people with only mild disabilities get more family contact than people with severe disabilities? Does it also depend on how far away the family lives? Do the people who have a high level of challenging behaviour or an additional psychiatric disorder tend to get less family contact, or would that be not particularly relevant? Probably a combination of these factors affects the amount of family contact which people receive. Through this research project I hope to find out which are the most important factors underlying the degree of family contact which
people get.

To carry out this study I would need to use basic information about the client in your care which is on the client's file, which is age, sex, date of admission, type of residential unit and a measure of how far away the next-of-kin live. This information will be treated in strict confidentiality and to this end I shall be using an identification number rather than the client's name in any records I use for this study.

As you probably know or remember, with the help of caregivers like yourself, I have assessed nearly all the people in residential care over the last five years, and in the client's psychology file there is a record of a person's IQ, level of social competence and any degree of challenging behaviour as measured on the Wilkinson Scale. If you were to give your permission I would intend to also use this information, again whilst respecting the individual's confidentiality by only using an identification number rather than names. As with the other information, this information would only be used for the purpose of this study, to see if IQ, social competence or behaviour factors would be related to how much family contact a person receives. On the same basis of confidentiality, I shall also be asking Dr. (Name) to assign a number code for every client according to whether there is a significant additional psychiatric disorder, or some mild psychiatric difficulties, or no psychiatric disorder at all.

If you want to consent to participate in this study, I would like to ask you seven questions (a copy of the questions is provided) concerning the family contact received by the person(s) in your care. It would probably be helpful to consult with the client's file as well as your own memory to help answering these questions.

The interview questionnaire of seven questions would take about 20 minutes. Please understand that if for any reason you do not wish to participate in this study, that would be fine, and it would not be held against you in any way.
Consent Form for Supervisory and Management Staff.

Headed Paper of the Health Board - Community Care Section.

re: SURVEY ON FAMILY CONTACTS OF PEOPLE WITH LEARNING DISABILITIES WHO ARE IN RESIDENTIAL CARE.

Researcher :- Stephen Clarke, Dept. of Psychology, (Service and Address).

To whom it may concern,

I am the residential unit manager/care provider/group home supervisor of the client(s) under consideration, and I have read the research outline of Stephen Clarke about family contacts. I understand that any information provided will be treated with respect and confidentiality, and that individuals will not be identifiable in the results. I understand that I would have access to the broad findings of this research on its completion.

I understand that if I or the care staff or the client(s) in care do not wish to take part in this study, we can refuse, and that this could never be held against us in any way.

I consent / do not consent to completing the questionnaire about family contact and to making available only those file details detailed in the research outline.

signed ____________________________

Date ____________________________
Advance Letter.

Headed Paper of the Health Board - Community Care Section.

Date e.g. 14th July 1996

To: (Name of caregiver)

From: Stephen Clarke, Clinical Psychologist. Dept. of Psychology, (Health Board)
Address and Phone).

Please find enclosed information about a research study I am hoping to carry out and for which I would need your agreement to participate, if you wished to give such agreement. The enclosed sheets explain what the study would be about, so that you can decide whether or not you would want to participate. I would be planning to contact you in this regard in about two week's time, but if you had decided beforehand whether or not you wished to participate, you could complete and return the enclosed consent form to me. Please note the completely voluntary nature of any such participation and your right not to take part if you do not wish to.

Yours sincerely,

Stephen Clarke.

Enclosed with this letter were the Information Sheet shown above on page 295, together with the following consent form.
Consent form for Caregivers.

Headed Paper of the Health Board - Community Care Section.

re: SURVEY ON FAMILY CONTACTS OF PEOPLE WITH LEARNING DISABILITIES WHO ARE IN RESIDENTIAL CARE.

Researcher :- Stephen Clarke, Dept. of Psychology, (Service and Address).

To whom it may concern,

I am the houseparent/caregiver of the client(s) under consideration, and I have read the research outline of Stephen Clarke about family contacts. I understand that any information I provide will be treated with respect and confidentiality, and that individuals will not be identifiable in the results. I understand that I would have access to the broad findings of this research on its completion. I understand that if I or the client(s) I care for do not wish to take part in this study, we can refuse, and that this could never be held against us in any way.

I consent / do not consent to completing the questionnaire about family contact and to making available only those file details detailed in the research outline.

signed ______________________________

Date ________________
Family Contact Questions.

Questions Sheet.

Question 1.
Considering ____________________ (name of client) who hereafter will only be known by an identification number in this study, how far away in miles as the crow flies do his/her next of kin or family of origin live. (The carer would usually know but might need to double check from the client file that the next of kin lives in, for example, Dublin, and I would there and then measure on a map the distance between the group home and Dublin, and I would write in the relevant box on the coded paper record 128 (miles).

Question 2.
Again considering ______________ (name of client), which of the following are true?
1) Both his/her parents are alive.
2) Only one of his/her parents is alive.
3) He/She has a sibling/siblings who live in Ireland.
4) He/She has a sibling/siblings but living abroad.
5) None of the above i.e. he/she has no immediate family members left.
A code number was assigned there and then on the basis of the answers to the above and entered onto the record form.

Question 3.
Did the individual receive a visit from parents, relatives or family member.
   a) more than 20 times in the last year.
   b) 6 to 20 times in the last year.
   c) 2 to 5 times in the last year.
   d) once in the last year.
   e) never in the last year.
A code number was assigned according to which of the above was indicated by the carer,
and entered on to the record form.

Question 4.
Did the individual go home or go to relatives or family members, or holiday with them...

a) for 50 or more overnight stays in the last year.
b) for 30 to 49 overnight stays in the last year.
c) for 20 to 29 overnight stays in the last year.
d) for 10 to 19 overnight stays in the last year.
e) for 5 to 9 overnight stays in the last year.
f) for 1 to 4 overnight stays in the last year.
g) for 1 to 4 overnight stays in the last 5 years.
h) never since admission into care.

A code for which of the above was indicated was assigned there and then on the record form.

Question 5.
Within the last 12 month period, would ____________ (name of client) have received
a) any indirect contact from family members or relatives, such as phone calls or enquiries, letters or cards, or
b) no such indirect contact within the last 12 months.

A code for which of the above was indicated was assigned on the record form.

Question 6.
How many residential placements has ____________ (name of client) had?

Question 7.
How many years has ____________ (name of client) been in residential care?
Coded Record Form.

A   B   C   D   E   F   G   H   I   J   K   L   M   N   O   P   Q   R   S   T

Only the author knew that A was the client's identification number, B was the month and year of birth of the client, C was the age of the client, D was the gender of the client, E was the coded county where the client hailed from, F was the code for type of residential unit, G was the number of residential placements a client has had in his/her care history (the answer to Question 6, H was the number of years spent in residential care (the answer to Question 7, I was the Mental Age of the client, J was the level of learning disability, K was the score on the Index of Social Competence, L was the coded category of that score (low, medium or high), M was the score on the Wilkinson Scales for Behaviour Disturbance, N was the category of that score (low, medium or high), O was the distance in miles between the residential unit and the family (the answer to question 1), P was the coded variable for family members who are still alive (coded answer to Question 2), Q was the coded answer to Question 3 about family visitation received, R was the coded answer to Question 4 about overnight stays/holidays with family members, S was the coded answer to Question 5 about whether or not there was other indirect contact, and T was the code to indicate whether there was a mild or significant additional psychiatric disorder.
St. Michael’s House Research and Training
McConkey Scale. INDEX OF SOCIAL COMPETENCE

Insert in the box the item number that describes the person’s BEST level of functioning

Additional Handicaps
VISION
1. Normal Vision
2. Partial sight - problems in mobility
3. Blind for all practical purposes

HEARING
1. Hearing normal (includes deafness in one ear)
2. Partial hearing; hearing aid prescribed
3. Profoundly deaf - only residual hearing

EPILEPSY
1. No fits - no medication
2. Has or had fits; taking medication to control fits; not real problem at present
3. Has or had fits; taking medication to control fits; recurring problem at present

Communication Skills
INSTRUCTIONS
1. Can remember to carry out a sequence of instructions e.g. a shopping list or directions to a place
2. Can remember instructions and carry them out later, e.g. a message from work
3. Follows a simple instruction which can be carried out there and then - “switch on the light”
4. No response when talked to, except to own name

COMMUNICATION
1. Speaks well - intelligible to all; uses appropriate language; able to give accurate information
2. Some difficulty in speaking - lack of clarity or fluency (e.g. may tend to stammer), but language appropriate
3. Difficulty in speech - only intelligible to those who know
him/her well
4. No speech - relies on gestures if attempting to communicate

Self-Care Skills

EATING
1. Feeds self and can manage all activities at table with no problem
2. Feeds self and can manage most activities (e.g. cutting meat) but needs some guidance/help
3. Feeds self competently but needs help in seasoning foods, cutting meat etc.
4. Needs to be fed or if left alone is a messy feeder

PERSONAL NEEDS
1. Can look after his/her personal needs completely independently - cleanliness, toilet, dressing and chooses appropriate clothes
2. Generally looks after personal needs but requires checking and reminding
3. Has to be helped to wash, dressed, etc.
4. Dependent on other persons for all personal needs

MOBILITY
1. Able to walk, run and climb stairs with no difficulty
2. Able to walk fair distances (around 1 mile) but finds running and climbing stairs difficult
3. Can walk only short distances; tires easily
4. Unable to walk alone

USE OF HANDS
1. Fully competent use of hands and fingers - can hit nail with hammer, thread needle, use tin-opener
2. Manages most day-to-day activities involving hands, doing up buttons, using knife and fork, ties shoelaces
3. Slow and rather clumsy in using hands but manages some day-to-day activities
4. Only capable of very basic hand skills or not at all
AROUND THE HOUSE
1. Capable of doing most jobs around the house without supervision—makes beds, washes and dries dishes, cleans floor, etc.
2. Attempts most jobs but needs supervision and help to complete the job properly
3. Able to do simple repetitive jobs—setting the table, dries dishes
4. Attempts these simple jobs but cannot do them properly
5. Unable to do any household jobs

PREPARING FOOD
1. Can prepare an adequate variety of meals without supervision
2. Prepare simple hot food without supervision—makes eggs, warm soup
3. Makes up food which does not require cooking or with which he/she is familiar—cereals, teas, sandwiches
4. With supervision, can prepare simple foods
5. Needs all food prepared for him/her
Community Skills

READING
1. Can read and follow a series of written instructions, e.g. directions on a packet of food, recipes etc.
2. Can read and act appropriately to signs giving directions in shops or in the street
3. Recognize own name written down
4. Recognize and pick out around six different labels on tins and boxes of food, e.g. cereals, washing powder
5. Unable to recognize any writing

WRITING
1. Can write short notes, e.g. shopping lists
2. Can write own name and address without help
3. Writes full name without help
4. Writes name and address from copy
5. Unable to write

TIME
1. Regularly uses watch or clock timing of activities, e.g. when a friend might call
2. Tells time in hours and minutes, with clock or watch
3. Knows what hour it is by the clock
4. Shows by behaviour that he/she can anticipate some events of the day e.g. start of T.V. programme
5. Seems to have no idea of time

MONEY
1. Able to use money responsibly-no difficulty in coping with everyday money transactions; giving right amount and checking change
2. Can select the amount of money appropriate to stated price of article
3. Estimates roughly what different amounts might buy e.g. if given 50p has some idea of what he/she could get for that
4. Picks out coins by name e.g. 50p, 10p etc.
5. No understanding of money
WILKINSON CHALLINGING BEHAVIOUR SCALES.

<table>
<thead>
<tr>
<th>CODE</th>
<th>TYPE OF BEHAVIOUR</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>Bites/scratches/hits staff (that is, generally aggressive to staff)</td>
</tr>
<tr>
<td>02</td>
<td>Screams at staff</td>
</tr>
<tr>
<td>03</td>
<td>Bites/scratches/hits other residents (that is, generally aggressive to other residents)</td>
</tr>
<tr>
<td>04</td>
<td>Screams at other residents</td>
</tr>
<tr>
<td>05</td>
<td>Injures self when frustrated, angry, or in order to manipulate</td>
</tr>
<tr>
<td>06</td>
<td>Injures self in a way related to an obsession (such as skin-picking, face-flicking) or if prevented from fulfilling an obsessional desire</td>
</tr>
<tr>
<td>07</td>
<td>Injures self for no apparent reason</td>
</tr>
<tr>
<td>08</td>
<td>Makes loud and/or irritating noises when disturbed</td>
</tr>
<tr>
<td>09</td>
<td>Makes loud and/or irritating noises for no apparent reason</td>
</tr>
<tr>
<td>10</td>
<td>Is deliberately destructive with objects (for example, smashes cups, tears clothes, rips books, breaks windows, pulls down curtains)</td>
</tr>
<tr>
<td>11</td>
<td>Aloof/indifferent with other people; a loner</td>
</tr>
<tr>
<td>12</td>
<td>Obsessed with content and arrangement of the environment</td>
</tr>
<tr>
<td>13</td>
<td>Becomes disturbed when an obsession is not met (for example, bangs windowsdoors if they are left open, runs around “tidying”, addresses people aggressively)</td>
</tr>
<tr>
<td>14</td>
<td>Exhibits a bizarre habit/obsession (such as object waving, string twirling, material sucking)</td>
</tr>
<tr>
<td>15</td>
<td>Exhibits a socially unacceptable habit/obsession (such as spitting, swearing, manual evacuation, self-induced vomiting, rubbish eating, excessive masturbation)</td>
</tr>
<tr>
<td>16</td>
<td>Exhibits a habit/obsession that is a problem in terms of management (such as rubbish hoarding, absconding to collect rubbish, removal of clothes, masturbation in appropriate places)</td>
</tr>
<tr>
<td>17</td>
<td>Is disturbed/unsettled during the night (for example, wanders around, wakes others, noisy)</td>
</tr>
<tr>
<td>18</td>
<td>Overactive/wanders aimlessly; due to boredom/no stimulation</td>
</tr>
<tr>
<td>19</td>
<td>Overactive/wanders aimlessly; despite appropriate</td>
</tr>
</tbody>
</table>
activity being available
Can communicate verbally
Can communicate non-verbally
Changes mood suddenly for no apparent reason (for example, laughing when suddenly tearful, noisy then suddenly withdrawn)
Behaviour is unpredictable (for example, may hug/kiss and then suddenly hit/bite)
Throws objects around aimlessly
Throws objects when angry/frustrated/disturbed
Becomes disturbed if change occurs (for example, in people, routine, or environment)
Shows bizarre and purposeless movements (such as finger-weaving, arm-waving, face-pulling)
Bullies weaker residents
Manipulates and/or attention seeks by exhibiting problem behaviour (such as hitting, biting, scratching, furniture throwing, soiling, wetting, window-breaking)
Absconds if unsupervised
Soils/wets with awareness in places other than toilet
Becomes disturbed when prevented from having own way
Is obsessed with food and drink resulting in a management problem
Bizarre, one-sided attempts at interaction
Becomes withdrawn suddenly
Is difficult to manage when disturbed/having a temper tantrum (that is, affects the other residents due to most staff being occupied or the environment being altered, or a tense atmosphere developing)
Can understand communication
Is sexually delinquent with awareness
Asks questions (that is, meaningful questions rather than just repetitive speech)
Steals property of others
Takes no notice of what others do
Shows inappropriate emotional reaction (for example, laughs when reprimanded)
Masturbates in public
Contingency coefficients.

In Chapter 5 most of the results are presented as 3x2 chi square analyses as this test makes few assumptions other than that category variables are being used. For indication purposes the contingency coefficients based on these chi square analyses are also presented. As a measure of association the contingency coefficient requires only nominal measurement of variables. One limitation of the contingency coefficient is that two contingency coefficients are not comparable unless they are yielded by contingency tables of the same size (Siegel 1956).

Another drawback of contingency coefficients is that they cannot be as high as 1 even when there is perfect correlation. The upper limit is determined by the table size. In Table 35 below the contingency coefficients in the unshaded area are based on 3x3 chi square tables, for which the upper limit is .816. The contingency coefficients in the lighter shaded area in Table 35 are based on 3x2 chi square tables and are comparable with each other. The three contingency coefficients in the darker shaded area are based on 2x2 chi square tables and the upper limit for this size table is .707 (Siegal. 1956).

Another feature of contingency coefficients is that they are always positive. The actual direction of the associations for the main dependent variable of family contact is shown in the full chi square analyses reported section by section in Chapter 5 - in fact they were all negative associations where statistical significance was reached. For example, significant family contact was negatively associated with age, years in residential care and distance from family.
Table 36.

<table>
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<th>SEX</th>
<th>RES TYPE</th>
<th>FAM CON</th>
<th>AGE</th>
<th>YRS RESI</th>
<th>SOCC COMP</th>
<th>DISAB BEH</th>
<th>PSYC HIAT</th>
<th>DISTANCE</th>
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<td>N.S.</td>
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<td>.1821</td>
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<td>N.S.</td>
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</table>

Figures in this area based on 2x2 chi square tables.

Figures in this area based on 3x2 chi square tables.

Figures in this unshaded area based on 3x3 chi square tables.
Table 27.

Variable entered - Family left.

-2 Log Likelihood 203.55  
Goodness of Fit 179.00

<table>
<thead>
<tr>
<th></th>
<th>Chi square</th>
<th>df</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model chi square</td>
<td>44.55</td>
<td>2</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Improvement</td>
<td>44.55</td>
<td>2</td>
<td>&lt;.0001</td>
</tr>
</tbody>
</table>

Classification Table for Minimal/Significant Contact.

<table>
<thead>
<tr>
<th>Predicted</th>
<th>Observed</th>
<th>0</th>
<th>1</th>
<th>Percent Correct</th>
</tr>
</thead>
<tbody>
<tr>
<td>0= Min. Contact</td>
<td>71</td>
<td>20</td>
<td></td>
<td>78.02%</td>
</tr>
<tr>
<td>1= Sig. Contact</td>
<td>32</td>
<td>56</td>
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<td>63.64%</td>
</tr>
</tbody>
</table>

Overall 70.95%

Variables in the Equation

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>S.E.</th>
<th>Wald</th>
<th>df</th>
<th>Sig.</th>
<th>R</th>
<th>Exp (B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family left</td>
<td>31.766</td>
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<td>31.766</td>
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<tr>
<td>Family left (1)</td>
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<td>.0036</td>
<td>.161</td>
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<td>13.993</td>
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</tr>
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</table>
Table 28.

Variables entered - Family left and distance.

-2 Log Likelihood 192.32
Goodness of Fit 181.13

<table>
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<tr>
<th>Chi square</th>
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<th>Significance</th>
</tr>
</thead>
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<tr>
<td>Model chi square</td>
<td>55.78</td>
<td>4</td>
</tr>
<tr>
<td>Improvement</td>
<td>11.23</td>
<td>2</td>
</tr>
</tbody>
</table>

Classification Table for Minimal/Significant Contact.

<table>
<thead>
<tr>
<th>Observed</th>
<th>Predicted</th>
<th>Percent Correct</th>
</tr>
</thead>
<tbody>
<tr>
<td>0= Min. Contact</td>
<td>73</td>
<td>18</td>
</tr>
<tr>
<td>1= Sig. Contact</td>
<td>32</td>
<td>56</td>
</tr>
</tbody>
</table>

Overall 72.07%

Variables in the Equation

<table>
<thead>
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<th>B</th>
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<th>Wald</th>
<th>df</th>
<th>Sig.</th>
<th>R</th>
<th>Exp (B)</th>
</tr>
</thead>
<tbody>
<tr>
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<td>55.78</td>
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<td>.206</td>
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<td>.093</td>
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<td>&lt;.01</td>
<td>.093</td>
<td>13.464</td>
</tr>
<tr>
<td>Family left (2)</td>
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<td>.000</td>
<td>1.007</td>
<td>1</td>
<td>&lt;.005</td>
<td>.000</td>
<td>1.442</td>
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<tr>
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<td>&lt;.01</td>
<td>.130</td>
<td>11.181</td>
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<tr>
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<td>7.416</td>
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<td>.148</td>
<td>11.181</td>
</tr>
<tr>
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<td>14.901</td>
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<td>.001</td>
<td>14.901</td>
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Table 29.

Variables entered - Family left and distance and age.

-2 Log Likelihood 185.23
Goodness of Fit 176.97

<table>
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<tr>
<th>Chi square</th>
<th>df</th>
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</tr>
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<td>Model chi square</td>
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<tr>
<td>Improvement</td>
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</table>

Classification Table for Minimal/Significant Contact.

<table>
<thead>
<tr>
<th>Predicted</th>
<th>Observed</th>
</tr>
</thead>
<tbody>
<tr>
<td>0= Min. Contact</td>
<td>65</td>
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<tr>
<td>1= Sig. Contact</td>
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Overall 73.18%

Variables in the Equation

<table>
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<th>Wald</th>
<th>df</th>
<th>Sig.</th>
<th>R</th>
<th>Exp (B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family left</td>
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<td>.221</td>
<td>.000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family left (1)</td>
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<td>.518</td>
<td>1</td>
<td>.472</td>
<td>.000</td>
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<tr>
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<td>.862</td>
<td>.007</td>
<td>1</td>
<td>.934</td>
<td>.000</td>
<td>.931</td>
</tr>
<tr>
<td>Distance</td>
<td>9.809</td>
<td>2</td>
<td>.007</td>
<td>.153</td>
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<td>Distance (1)</td>
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<td>.176</td>
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</tr>
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<td>.003</td>
<td>.167</td>
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<td>18.598</td>
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</table>

313
Table 30.

Variables entered - Family left, distance, age and behaviour disturbance.

-2 Log Likelihood 169.68
Goodness of Fit 173.48

<table>
<thead>
<tr>
<th></th>
<th>Chi square</th>
<th>df</th>
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<td>Model chi square</td>
<td>78.41</td>
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<td>Improvement</td>
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</table>

Classification Table for Minimal/Significant Contact.

<table>
<thead>
<tr>
<th>Observed</th>
<th>Predicted</th>
<th></th>
<th>Percent Correct</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>0 = Min. Contact</td>
<td>66</td>
<td>25</td>
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<tr>
<td>1 = Sig. Contact</td>
<td>14</td>
<td>74</td>
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Overall 78.21%

Variables in the Equation

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<th>Wald</th>
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<th>Sig.</th>
<th>R</th>
<th>Exp (B)</th>
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<td>5.679</td>
</tr>
<tr>
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<td>.063</td>
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<td>.003</td>
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