Consumer perceptions of services for people with severe and profound intellectual disabilities

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CONSUMER PERCEPTIONS OF SERVICES
FOR PEOPLE WITH SEVERE AND PROFOUND
INTELLECTUAL DISABILITIES

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DECLARATION

This thesis is submitted to the Department of Nursing, University of Wollongong, in fulfilment of the requirements for the Honours Degree of Master of Science. It does not incorporate any material previously published or written by another person except where due reference is made in the text. The work described in this thesis is original work and has not been previously submitted for a degree or diploma in any university. Some findings have been presented at the Annual Conference of the Australian Society for the Study of Intellectual Disability, Newcastle, Australia, 1993.

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This study examined consumer perceptions of services for people with severe and profound intellectual disabilities in the Illawarra area. The nature and severity of the disability involved necessitated the use of family members, staff and advocates as sources of information. A total of 147 clients participated and a representative of each client (with one exception) was interviewed. They were asked to identify all services used by the client in the previous five years and to rate their level of satisfaction with these services on a 7-point Likert scale. They were then asked to identify factors important to them in rating these services (sources of satisfaction and dissatisfaction) and to nominate any services they needed but that were not available. A wide variety of types of services was identified as being used, with the most used services being various medical services and (for children) schools. Services were generally rated highly. Ratings given by family member respondents were compared with ratings given by staff respondents. Significant differences were identified between these groups of respondents for adults in relation to a number of service types, with family respondents rating services more highly than staff respondents. No significant differences were identified between these groups of respondents for children.

When respondents were asked to identify what was important to them in rating services, nine specific sources each of satisfaction and dissatisfaction emerged. The most frequently mentioned sources of satisfaction were the individual needs of the client being met and the caring attitude of staff. There was little difference between the responses of family member and staff respondents in relation to sources of satisfaction. The most frequently mentioned sources of dissatisfaction were inappropriateness of the service and poor quality of the service. However, there was much less consensus generally on sources of dissatisfaction than for sources of satisfaction and considerable differences between the responses of family member and staff respondents. Respondents indicated eight types of services that they believed they needed but were not available. The most commonly mentioned services were group homes, information and activity centres.
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INTRODUCTION

This study examines consumer perceptions of services for people with severe and profound intellectual disabilities in the Illawarra area.

Consumer evaluation as a legitimate and important form of program evaluation has been common practice in health and related fields for approximately 25 years. It is based on the assumptions that consumers of these services have both a right to evaluate the services they use and valuable information to contribute to the broader process of evaluation.

The areas of medical care, mental health, rehabilitation and many others now have extensive numbers of reported studies that evaluate services from the consumer perspective.

The disability field also has a substantial number of such studies, most of them evaluating services for, and from the perspective of, a small sub-group of the disabled population.

The term 'developmental disability' is used in NSW to describe that part of the disabled population where the disability commenced prior to the person reaching 18 years of age. The NSW Health Department definition of developmental disability is included as Appendix 1.

The largest sub-group within the developmentally disabled population is those people with an intellectual disability (also referred to as mental retardation) and this group is further divided into four categories, depending on the degree of intellectual impairment (Gething 1992). These categories are included as Appendix 2.

The population for this study, then, is the two categories with the greatest levels of intellectual impairment. In addition to a substantial intellectual disability, most of these people are non-verbal or have very limited verbal skills. The combination of these two factors makes these people generally unable to provide the type of information on services required for this study.
For this study then, a representative of each client (with one exception) was interviewed. This was either a family member, a care-giver or advocate. They were asked to identify all services used by the client in the previous five years and to rate their level of satisfaction with these services. They were then asked to identify factors important to them in rating these services and to nominate any services they needed but that were not available.

The Illawarra area is defined as covering the Wollongong, Shellharbour and Kiama Local Government Areas and stretches from Helensburgh to Gerringong (McDonald & Wilson, 1991).
CHAPTER 1

LITERATURE REVIEW

1.1 Program Evaluation

"Program evaluation consists of systematic efforts to determine the worth of services provided to a given population in pursuit of social ends. Worth may be defined as the achievement of specified goals (either as final outcomes or as intermediate steps in implementation); as costs of the services; as satisfaction with the service; or as combinations of one or more of these" (Levine & Rosenberg 1979, p 110).

Contemporary approaches to program evaluation in the health and related fields can be traced back to the mid to late 1960s. A questioning of traditional approaches and seeking of more useful and innovative ways of evaluating programs can be seen in the literature of the 1960s and 1970s.

According to Attkisson and Broskowski (1978), "......as the 1970s began, a quest for more constructive and useful program evaluation emerged" (p 3). Demone, Schulberg and Broskowski (1978) claimed that ".....fresh administrative practices are.....emerging with significant implications for human services delivery. Among this trend's several key elements are accountability and evaluation techniques......" (p 34).

One of the seminal early works in contemporary program evaluation is that of Donabedian (1966). He argues that the traditional use of outcome only as the accepted measure of quality of medical care is limited and needs to be questioned. He suggests that evaluation of both program structure and program process should also occur in any comprehensive assessment of program quality.
In another influential early article, Suchman (1967) discusses evaluation criteria in terms of program effort, performance, adequacy, efficiency and process. He defines 'effort' as the quantity and quality of program inputs and 'performance' as program outputs. 'Adequacy' is concerned with the relationship of program effort and performance to the level of need for the program. 'Efficiency' is the relationship among effort, performance and adequacy and 'process' is the means by which effort is translated into outcomes.

While many later writers refer to Suchman's work, they appear to have simplified some of his concepts.

Harper and Babigan (1974) identify the need for program evaluation to change as the structure and nature of services change. They claim that ".......(a)s new and innovative social welfare programs are being attempted, there has been an increasing concern with evaluating the effectiveness of such programs" (p 271).

James, in 1969, suggested that evaluation studies are directed at assessing organisational effort, effectiveness, adequacy and efficiency. Attikisson and Bronkowski (1978) endorse James' work. Epstein and Tripodi (1977) assert that "(p)rogram evaluation is the process by which program effectiveness and efficiency are assessed" (p 111). Freeborn and Greenlick (1973) express a similar view.

Holland (1983) claims that evaluation involves assessment of effectiveness, efficiency and acceptability. Lee and Sampson (1990) define evaluation as the process that leads to judgements about the worth, effectiveness and efficiency of programs.

Effectiveness and efficiency are identified by virtually all writers as components of service provision that are assessed in program evaluation. Effectiveness is a measure of the technical outcome of services and technical outcomes of health and related services can be seen in medical, social and/or psychological terms (Long & Harrison 1985). "Effectiveness considers
questions like: "...how successful has a child abuse program been in reducing incidents of child abuse, etc...... " (Epstein & Tripodi 1977, p 111).

Efficiency is ".....concerned with the costs, in money, time, staff resources and so on..... " (Epstein & Tripodi 1977, p 111) of achieving program goals. It is "....the ratio of the product produced to resource input..... " (Long & Harrison 1985, p 2).

Acceptability, as a further component of service provision assessed in program evaluation according to some writers, is the ".........judgement of an intervention as professionally and/or socially satisfactory and adequate" (Long & Harrison 1985, p 2).

1.2 Consumer Evaluation of Services

Consumer evaluation of health and related services as a legitimate and valued means of program evaluation dates from the 1960s. It had its beginnings in both the specific movement to find broader and more innovative ways to evaluate health and welfare services (discussed in the previous section) and the general consumer movement.

The general consumer movement, which has its strongest manifestations in the United States, aims to make the users of all types of services aware of a need for a consumer orientation to service usage and the accompanying rights to appropriate standards of services and active participation in decision-making.

There has been for many years now general agreement that consumer evaluation of services is a necessary and important component of program evaluation with identifiable benefits. Despite this, there is also substantial agreement that methodology and interpretation of results of such studies is problematic.

It is interesting to note that surveys of consumer satisfaction in developmental disability services in the United States are required by law (Davidson & Adams 1989). The Developmental Disabilities Bill of Rights and Assistance Act Amendments (1987) - PL 100-146 makes it mandatory for such surveys to be conducted.

1.2.1 The Role of the Consumer Movement

The consumer movement is often identified (Heath, Hultberg, Ramey & Ries 1984, el-Guebaly et al. 1983, Schulberg & Baker 1979, Kessner 1978) as a major contributing factor to increasing pressure throughout the 1960s and 1970s to assess the quality of health care from the consumer's perspective.
Reeder, writing in 1972, identified the concept of consumer participation in health care as part of the general consumer movement in society: "...a feature of societal change to be noted is the development of consumerism" (p 408). He claims that as part of this movement all professionals need to be more responsible and accountable to consumers. In relation to health professionals, this entails a move from seeing the client's role in terms of patient behaviour to one of active participation.

Locker and Dunt (1978) comment that the late 60s and early 70s have seen the increasing involvement of the consumer in a range of areas of life. They comment that "...studies of consumer opinion......are an indirect form of consumer participation" (p 283).

1.2.2 Consumer Evaluation of Health and Related Services

Consistent with the influence of the general consumer movement from the 1960s, consumer satisfaction studies with health services started to appear in the late 1960s and early 1970s (McPhee, Zusman & Joss 1975).

Writing in 1969, Hochbaum identified consumer evaluation as an emerging focus of attention by health professionals. He says that "(w)e must recognise and accept the fact that it is the consumers of health services who are the final and proper judges of what kinds of services they want, how they want them delivered, what form they should take, and in what setting they should be provided. It is only on the medical and other technical details that the health professions have any exclusive right to make decisions" (p 1701).

Several years later, Lebow (1974) argued that measuring consumer perceptions of health services is an additional way of evaluating medical care, rather than merely a variation of a more 'accepted' method (such as process or end-result approaches), as claimed by some other writers. He hypothesised that the fact that consumer perceptions had been used in so few studies up to that time "...may be due to fears of possible inaccuracies of patient opinion
by researchers, to the low status of patient opinion among physicians, or to the newness of quality medical care research" (p 330).

According to Edwards et al. (1978) "(t)here is increasing interest across the country in assessing patient satisfaction as one index of the quality and acceptability of services" (p 188). Similarly, Justice and McBee (1978) claim that "(a)n investigation of client satisfaction is a necessary element in the evaluation of services" (p 248). Kessner (1978) comments that "(p)atients have been excluded from quality-assurance activities, but they should also participate" (p 385).

Larsen, Atkisson, Hargreaves and Nguyen (1979) suggest that service evaluation is incomplete if the client's perspective is not taken into account and that services may be inadequate or of poor quality as a result. Marin (1980) concludes that "(c)onsumer opinions can provide systematic and scientific information regarding the existence of problems in service delivery as well as the efficacy of interventions designed to alleviate those problems" (p 312).

Virtually all writers in the field from this time, comment on the increasing legitimacy of consumer evaluation studies. For example, Schulberg (1981) says that "(d)espite continuing qualms about the true meaning of consumer satisfaction and valid procedures for assessing it, the client's perspective is increasingly sanctioned - even required - in outcome studies" (p 137).

Hulka and Zyzanski (1982) observe that there has been increasing interest through the 1970s in the topic of consumer satisfaction with medical care. "Perhaps the most important result of this activity has been the acceptance by providers as well as researchers of patient satisfaction as an important outcome of health care services....." (p 649).

el-Guebaly et al. (1983) claim that "(t)here has been a shift from the idea that sole reliance on professional opinion is enough to create service consistent with the needs of those who are being served" (p 24). They point out that such as approach recognises the need for
accountability to the client of the provider of services and that "(t)he growing body of knowledge in the area of consumer surveys points to the usefulness of monitoring this variable formally."(p 24) Schulberg and Baker (1979) describe the patient as "......a meaningful judge of the care he or she receives" (p17).

Lebow (1983a) concludes that "........client views remain important, and consumer evaluation remains essential for evaluating services" (p 743). He qualifies this, however, by pointing our that it must not be the only means of evaluating services. Pascoe (1983) says that "a consumer perspective ........ can contribute to a complete balanced evaluation of the structure, process and outcome of services" (p 203). Budde, Petty and Nelson (1989) describe consumer satisfaction evaluation as a "......popular, economical evaluation concept......" (p 62).

Holburn (1992) is critical of the accepted forms of evaluation (based on identifying deficiencies) of various types of mental retardation facilities in the US. He comments that "(o)ther forms of residential evaluation and monitoring could replace, or at least augment, deficiency audits. Citizens, consumers and parents could play a role in evaluating the quality of a residential program" (p 139).

According to Wilkin, Hallam and Doggett (1992), ".....the complexities of the relationship between needs, health care provision and outcomes" (p 16) has led to the strategy of evaluating care through the ".....intermediate outcome of patient satisfaction" (p 16). They also specify though that consumer satisfaction is a ".....legitimate objective" of health care providers in its own right.

Thus, there is considerable consensus that consumer evaluation of health and related services is a valuable means of ensuring consumer participation in the delivery and assessment of such services. Most writers agree that it is a legitimate and useful form of program evaluation, whilst cautioning that it must not be used as the only type of evaluation of any service.
1.2.3 Issues of Methodology and Terminology

There are several issues and problems related to the methodology of measuring consumer perceptions of services that are frequently raised.

1.2.3.1 Measuring Instruments and Psychometric Properties

Locker and Dunt comment in 1978 on the lack of a standard method for measuring satisfaction. They comment that such a scale should ".............take account of differential satisfaction with individual aspects of services, employ a multi-dimensional scale for rating the consumers' responses and.......base these responses on actual experiences of care" (p 287). Similarly, Kelman in 1976 claims that measurement methods and criteria are a problem.

The issue of a lack of a standardised scale for measuring satisfaction is discussed in detail by Larsen et al. (1979). They then describe the development of their scale, the Client Satisfaction Questionnaire (CSQ) and summarise by claiming that "the CSQ appears to be a useful measure of general satisfaction with services. It possesses a high degree of internal consistency and correlates with therapists' estimates of client satisfaction. .......... the CSQ can easily be supplemented by open-ended questions or items of special interest to a particular service program...." (p 204-5).

Heath et al. (1984) describe the CSQ (Larsen et al 1979) as ".....among the most sophisticated and psychometrically sound consumer evaluation instruments available" (p 126). Greenfield and Attkisson (1989) believe that the CSQ ".....goes a long way toward satisfying the need for a serviceable, standardised measure of consumer satisfaction" (p 272). However, they emphasise that there is a need for further development of multifactorial tools to provide more detailed information.
Pascoe (1983) and Wilkin, Hallam and Doggett (1992) also comment on the lack of standardisation of instruments for measuring satisfaction. Hulka and Zyzanski (1982) however, defend a more flexible approach to the design and validation of instruments for measuring consumer perceptions of services. They believe that the purpose the instrument is designed for must be considered and that ".........the character of the subject matter about which attitudes are being evoked must be understood" (p 653).

Marin (1980) argues that the type of questionnaire used is often too simple to be of any use and that there is thus often no link between research results and changes in service delivery.

Efforts to design an effective instrument for measuring client perceptions of health and related services continue to the present. Carey and Siebert (1993), for example, describe a four year American study to design a tool for use in hospitals. Over 50 000 patients, from more than 300 hospitals were surveyed in this process and the authors claim that the resulting tool demonstrates validity and internal consistency.


1.2.3.2 The Concept of 'Satisfaction'

There is a range of views in the literature relating to what satisfaction, in the context of consumer evaluation studies, actually means. Many writers and researchers do not specify a definition or explain their understanding of the term. With many studies then, the meaning of the concept of satisfaction is implicit and, as a result, frequently unclear.
Locker and Dunt (1978) raise the issue of defining what the term 'satisfaction' means and question why many researchers do not even attempt to define it. They also suggest that it probably means different things to researchers and consumers. They further claim that "(r)esearch is also needed to clarify the process whereby consumers arrive at assessments of the services they receive. While expressions of satisfaction and dissatisfaction are the end product of such a process, we know little as yet of the procedures, criteria and standards consumers employ" (p 291).

The problem of lack of precision in defining terms, particularly 'satisfaction', is also raised by Budde, Petty and Nelson (1989). Similarly, Pascoe (1983) comments that "(p)atient satisfaction research has not been explicitly guided by a well-supported definition or psychological model of satisfaction" (p 185). Wilkin, Hallam and Doggett (1992) also comment on the lack of a "......clear theoretical and conceptual framework" (231) of patient satisfaction. According to Winter and Keith (1988), "(i)n spite of considerable empirical research......an integrated conception of satisfaction has still been lacking" (p132).

Stimson and Webb (1975) suggest that satisfaction is related to the perception of the outcome of care and the extent to which it meets patient expectations. They believe that "........expressions of satisfaction should always be interpreted in the context of some understanding of the rationale that underlies those expressions rather than being taken at face value" (p 289). Further, they claim that some results say more about consumers' expectations than about the quality of the services actually received.

Lebow (1983a), writing in relation to mental health services, defines satisfaction as "........the extent to which a service gratifies the wants, wishes, or desires for treatment. Included here are inquiries into the felt adequacy of the........treatment itself and of the surrounding milieu: cost, continuity, availability, accessibility of care and the reaction to supporting services. Also included are satisfaction with process and with outcome" (p 730). He comments that
"satisfaction studies clearly measure more than an accurate assessment of the quality of care and the success in achieving a positive outcome" (p 739).

Zastowny, Roghmann and Hengst (1983) also consider in detail what satisfaction with health services actually is and comment on the multiple conceptualisations used by writers and researchers. They conclude that "satisfaction is a multifaceted concept, partly based on short-term and partly based on long-term processes. As a stable long-term phenomenon, it is probably independent of utilisation and probably has its roots in the provider-patient relationship. It probably is related to utilisation, but as a short-term control process, especially where satisfaction has already become an issue" (p 316).

Pascoe (1983) hypothesises that satisfaction results from a comparison between the person's actual experiences and a subjective standard. This standard may be an ideal, a sense of what one deserves, an average of past experiences in similar situations or some minimally acceptable level. Evaluation of actual experience involves both cognitive and affective components and overall satisfaction has multiple dimensions.

Elbeik (1985) points out that consumer satisfaction studies are attempting to measure a "perceptive phenomenon" (p 185). Wilkin, Hallam and Doggett (1992) believe that satisfaction represents a "complex mixture of perceived need, expectations of care and the experience of care. It is a wholly subjective assessment ......" (p 230).

MacKeigan and Larson (1989) believe that satisfaction "......represents the patient's evaluation of the structure, process and outcome of their care......" (p 522).

Other writers and researchers comment on the broader issues of the components of health care that are important to consumers, the relative weighting of these components, their correlation with 'success' of treatment and the meaning of quality in health care to these consumers.
Kelman, writing in 1976, claimed that the issue of what dimensions of health care are important to consumers is unresolved and that knowledge was very limited in terms of consumer definitions of health care quality. He believed that "a broader, multifactoral view of health care quality embodying variables believed more important to consumer interests has emerged and appears to be gaining increasing acceptance" (p 437).

el-Guebaly et al. (1983) point to the lack of a frame of reference for most clients as a factor in their reported levels of satisfaction and that the appropriate weighting to give each dimension of satisfaction is still an unresolved question. They also state that "satisfaction is an important outcome measure, but not one that completely defines success. Satisfaction cannot, therefore, replace other outcome indicators in the assessment of quality of care" (p 28). Davidson and Fifield (1992) concur with this view.

Edwards et al (1978) claim that "there is at best a moderate relationship between patients' ratings of satisfaction and success. It is concluded that patient satisfaction ratings cannot be used in lieu of success or other treatment outcome ratings. Satisfaction assesses a dimension other than success" (p 190).

Justice and McBee (1978) seem uncertain of both what is being measured and the value of its measurement: "although investigations of client satisfaction are necessary, it should not be expected that they will provide critical information for evaluation of services" (p 252). However, they do state that "expressions of client satisfaction do not necessarily reflect efficiency or effectiveness of agency programs" (p 252).

1.2.3.3 Lack of Variability of Results

Linn (1975, cited in Larsen et al. 1979) concludes that "...from study to study, levels of satisfaction are very high, regardless of the method used, the population sampled or the object of the rating" (p 198). Scheirer (1978) reports that services are evaluated positively even in the absence of any evidence of progress towards program goals.

Edwards et al (1978) point out that these high satisfaction rates lead to difficulty in interpreting the data as they do not necessarily mean that treatment is having a beneficial effect.

el-Guebaly et al. (1983) and Justice and McBee (1978) suggest that these high ratings may be due to fear on the part of consumers that criticism of services may result in their withdrawal. Justice and McBee (1978) add that a methodology needs to be developed that will help overcome the problem of unwillingness to criticise.

Locker & Dunt (1978) point out that, when questioned further, consumers will express different levels of satisfaction with different aspects of services or care. Similarly, Winter and Keith (1988) identified different levels of satisfaction with different components of care. Larsen et al (1979) discuss the lack of information on how the different components of satisfaction contribute to overall ratings.

Cohen (1971) comments that some consumers see services as a favour rather than a right and others are reluctant to criticise a service provided by someone who is liked. It has also been noted by some writers (el-Guebaly et al. 1983, Pascoe 1983) that more satisfied clients are more likely to participate in consumer evaluation studies, thus contributing to the production of overly positive results.

Lebow (1983a) comments on the lack of norms, which he says are necessary if the "...data are to have meaningful utility" (p 737). He believes that the use of norms would give some perspective to the consistently high ratings reported in consumer satisfaction research.
Ware and Davies (1983) challenge what they describe as ".......one of the more persistent misconceptions in the health care field......." (p 295), i.e. that most consumers are very satisfied with the health care they receive. These authors identify a clear need to discriminate degrees of satisfaction and see ".......the achievement of score variability on an attitudinal scale (as) a straightforward problem of scale construction that responds very well to standard scaling techniques" (p 295). They believe, for example, that differences between people at the 60th and 90th percentiles of satisfaction, would translate into substantial behavioural differences.

1.2.3.4 Other Issues

A range of other issues or problems related to the methodology of consumer evaluation research or interpretation of results is raised by many writers.

Ware (1978) demonstrated that there is a tendency, particularly amongst less well educated people to agree with all items, both positive and negative and that this is so great as to account for 25% of variation in inter-item correlation matrices. Budde, Petty and Nelson (1989) also point out that responses are often acquiescent to the question, whether positive or negative.

The issue of biased responses is similarly addressed by Lebow (1983a) who lists "(a)quiescence to the direction of response alternatives, social desirability, Hawthorne effects, experimenter bias and reactivity........" (p 739) as likely causes. He concludes that "(r)eported satisfaction actually equals satisfaction plus an error factor........likely to inflate satisfaction reports" (p 739). Reactivity, i.e. the degree to which the fact that feelings are being recorded alters the report, is also discussed by Locker and Dunt (1978).

The commonly identified poor response rate, particularly for mail and phone surveys is cited as a further problem (Lebow 1983a, Pascoe 1983).
1.2.4 Benefits of Consumer Evaluation

Locker and Dunt (1978) describe three ways of using consumer perspective data. They believe that it can be seen as an evaluation of the quality of care, as an outcome variable and as an indicator of which aspects of a service need to be changed to improve patient response.

According to Locker and Dunt (1978), satisfaction with care is an important influence on whether a person seeks medical advice, complies with treatment and maintains a continuing relationship with a practitioner. Similarly, Hulka and Zyzanski (1982) describe patient satisfaction "......as a potential determinant of utilisation and compliance behaviour" (p 649).

Marin (1980) describes several uses of consumer feedback on services. These include helping to create a good image for the organisation, as a reward to staff for good performances and as part of the process of planned change for services. Davis and Hobbs (1989) believe that seeking patient views on services reassures patients that their concerns matter to service providers.

Three reasons for measuring consumer satisfaction with medical treatment are identified by Ware, Davies-Avery and Stewart (1978). They are that satisfaction is an ultimate outcome of the delivery of health services, because satisfaction ratings contain useful information about the structure, process and outcomes of care and because there are behavioural consequences of dissatisfaction. They claim that this last reason means that results of consumer surveys may be useful in predicting how consumers will behave in the future.

Ware and Davies (1983) believe that the role of satisfaction in determining behaviour probably varies from decision to decision. They conclude that differences in satisfaction are significant predictors of both changes in doctor and disenrollments from pre-paid health plans and that relatively small differences in satisfaction have noteworthy consequences for behaviour.
Overall, these authors conclude that "(i)n addition to delays in care seeking, in the face of serious symptoms, dissatisfaction seems to have other negative effects .....These negative effects of consumer dissatisfaction are clinically and socially relevant" (Ware & Davies, 1983, p 296).

Zastowny, Roghmann and Hengst (1983) agree with the position of Ware and Davies (1983) and claim that ".........the prominence of concern with satisfaction has its roots in the premise that it is meaningfully and functionally related to specific health behaviours and other health attributes" (p 296).

This view is further reinforced by Pascoe (1983). Consumer satisfaction, according to Pascoe (1983), is "......predictive of such health-related behaviours as compliance and switching providers, and is related to self-reported improvement in health" (p 203). Similarly, MacKeigan and Larson (1989) claim that patient evaluation "......is a predictor of patient behaviours such as utilisation of care, continuity with provider and compliance” (p 522).

Wilkin, Hallam and Doggett (1992) identify that dissatisfaction with services is associated with non-compliance, delay in seeking care and inadequate understanding of information conveyed.

Budde, Petty and Nelson (1989) summarise a number of benefits of consumer evaluation identified by earlier writers. They claim that it can be used for quality control or to ensure that service provision meets established standards. It is inexpensive and ensures some degree of provider accountability. It can act as a predictor of consumer behaviour, as there is evidence that satisfied and dissatisfied consumers behave differently. Finally, it has public relations benefits in terms of demonstrating that consumer input is sought and valued.

Davidson and Fifield (1992) suggest that consumers should play a part in program planning and monitoring as part of a deliberate strategy to assure program relevance.
1.3 Evaluation of Services by Consumers in Areas other than Developmental Disability.

Consumer evaluation of services has been a part of program evaluation in many areas of health and welfare services for approximately 25 years.

Consumer evaluation is reported predominantly in three broad areas of service delivery. These areas are medical care, mental health services and rehabilitation services. In the first of these, the emphasis tends to be on the doctor-patient relationship, for the second and third areas the emphasis is more towards evaluation of specific provided services, e.g. an outpatient rehabilitation service attached to a hospital. Most of these latter studies also include a component of assessment of staff competence and/or attitudes.

In addition to these three, there are many other areas where consumer evaluation has been employed. Examples include social work services, pharmacy, paediatrics and dentistry.

1.3.1 Consumer Evaluation of Mental Health Services

Lebow, writing in 1982, comments that assessment of consumer satisfaction with mental health services is standard practice. He contends that such practice was unusual 15 years earlier and that its rapid growth can be attributed to an overall increase in mental health program evaluation, a more consumer oriented society and the ease of administration of measures of consumer satisfaction.

Published studies of consumer evaluation of mental health services have appeared in the literature from approximately 1970 to the present. There are not, however, great numbers of them. This appears to somewhat contradict Lebow's claim that by 1982 such studies were commonplace. Lebow himself though, makes the point that many studies are only disseminated locally and not therefore available in the broader literature.
Corrigan (1990) was able to identify only 20 published studies from 1970 that evaluated either institutional or community based mental health care, from a consumer perspective. The majority of published studies were undertaken in the United States, with small numbers each in Canada and the United Kingdom. There are few reported Australian studies.

Results of consumer satisfaction studies of mental health services have tended to show the high levels of satisfaction that are a common finding of consumer evaluation research. There are, however, some exceptions with lack of satisfaction focusing mostly on unacceptable staff attitudes and inadequate provision of information.

An early study by Frank, Salzman and Fergus (1977) reports satisfaction rates of between 66% and 90% to five questions sent on postcards to clients who had terminated services at a comprehensive community mental health centre.

Lebow (1982), in reviewing the literature prior to 1982 reports "....impressive but not unanimous levels of reported satisfaction" (p 250). He describes high levels of satisfaction as being particularly reported by clients of public facilities who often have little choice of service or practitioner.

More recently, Holloway (1989) describes satisfaction rates of 72% for medical and nursing care and 75% for current day care setting for users of psychiatric day care. Approximately 25% of clients had some criticism of medical and nursing care and 21% had some criticism of the day unit. The author claims that the results of this study are consistent with those of other studies and indicate that clients appreciate the practical activities available but are less enthusiastic about the therapies offered.

Satisfaction with a relaxed atmosphere, social activities offered and interpersonal interactions with others with similar problems were identified by Kaufmann, Ward-Colasante and Farmer (1993) as sources of satisfaction of users of mental health consumer operated drop-in centres.
An early study indicating high levels of dissatisfaction with some aspects of mental health services was that of Hatfield (1978). This study indicated a high level of contact with professionals but low level of satisfaction. Nearly half the participants reported that services had no value for them.

Holden and Lewine (1982) evaluated services from the perspective of relatives of people with mental illnesses. They report general dissatisfaction with both the nature and level of their involvement. "Many families reported that their involvement with professionals left them feeling guilty and defensive. More typically families were confused, felt left out of treatment and felt ignored by professionals" (p 627). These family members were also generally unhappy with a lack of support, a lack of practical information and coping strategies and inadequate emotional support.

Shields, Morrison and Hart (1988) sought information on specific sources of satisfaction (or lack of) and also report areas of client dissatisfaction. Patients in a psychiatric unit of a general hospital were asked to identify major areas of concern and reported dissatisfaction based on problems and comforts of everyday living, boredom and provision of information.

The approach of Shields, Morrison and Hart (1988) is consistent with the view of Corrigan (1990) who claims that arguments relating to whether a particular type of service setting, e.g. institutional or community based, is better for specific clients are fairly pointless. He suggests that what is important to consumers is how satisfactory a particular service is and what factors contribute to that satisfaction. Thus, he is suggesting a re-focusing of professional interest from supposed intrinsic advantages and disadvantages of different service settings to those components of services which "enhance and/or detract from the total satisfaction" (p 162).

Goering, Sylph, Foster, Boyles and Babiak (1992) also concur with the view of Corrigan (1990) and explore components of satisfaction and dissatisfaction of clients of a supportive housing project in Toronto. Seventeen former residents of the facility, all with severe and
disabling psychiatric illnesses, participated in the study. Overall ratings of satisfaction indicated that the program was "......generally well received......" (p 114).

Particular sources of satisfaction for the participants were the acquisition of new skills and knowledge, increases in insight and self-confidence and the development of new relationships. Congregate living, mandatory program requirements and transition to and from the program were identified as sources of dissatisfaction. Many respondents though, also recognised that the first two of these factors were primary contributors to their progress.

The issue of the importance of identifying components of satisfaction and dissatisfaction is also discussed by Lebow (1983b). He claims that "(t)he failure to probe sufficiently for sources of dissatisfaction possibly underlying global statements of satisfaction" (p 239) is one of the shortcomings of consumer evaluation research.

1.3.2 Consumer Evaluation of Rehabilitation Services

Consumer evaluation studies of rehabilitation services can also be found in the literature from approximately 1970 onwards. Again, there is a strong tendency to high ratings of satisfaction in most studies, but unlike the research on consumers of mental health services, there are few areas of strong dissatisfaction. Again, most studies originate overseas and there is little local literature.

Most of the studies in this area use relatively simple rating scale assessment tools. For example, studies by Davis and Hobbs (1989) and Spreitzer (1975) used this method; the former in a centre providing vocational, medical and psychological services and the latter in a hospital based outpatient service. Both studies report positive evaluations of services by clients.

Daly and Flynn (1985) report their attempt to devise such an assessment tool, using a 4-point rating scale and based on the Client Satisfaction Questionnaire (Larsen et al. 1979). Courts
(1988) describes a similar process of designing a tool for a rehabilitation unit in a teaching hospital. Unlike that of Daly and Flynn (1985), this instrument was not based on a previously used tool.

Winter and Keith (1988) assessed client satisfaction with outpatient rehabilitation services using a tool based on that of Ware, Davies-Avery and Stewart (1978). This tool used a 4-point rating scale with the addition of open-ended questions and found a high degree of overall satisfaction with services. There was little variation in ratings for different facets of service and an overall dissatisfaction rate of 10%.

Unlike many other studies, Winter and Keith (1988) also asked more detailed questions about specific areas of satisfaction. They claim that ".....when patients were asked about specific areas of satisfaction such as therapy and progress, a greater depth of information was acquired" (p 136-7). Many people were not happy with the amount of progress that they had made and felt that they needed more therapy. The authors question whether these clients had realistic expectations.

1.3.3 Consumer Evaluation of Medical Care

Traditionally, the predominant theme of research in this area was that of the doctor-patient relationship and level of patient satisfaction with various aspects of that relationship. Most studies considered such components as technical skill of the doctor, interpersonal aspects of the relationship and issues of accessibility and availability.

More recent literature continues this theme but has also expanded to include investigations of satisfaction with other health professionals (e.g. Sparr, Ruud, Hickam & Cooney 1994), institutions such as hospitals (e.g. Groupy, Ruhlmann, Paris & Thelot 1991), and of particular client groups (e.g. Seguin, Therrien, Champagne & Larouche 1989). There is also a contemporary emphasis on identifying components of satisfaction rather than global measures
as a way of deriving more meaning from the commonly reported high global ratings of satisfaction (Williams & Calnan 1991, Lebow 1983b).

An Australian study undertaken by Feletti, Firman and Sanson-Fisher (1986) involved 503 patients and 22 General Practitioners in the Newcastle area. The authors identified qualities that are important in a General Practitioner from both the literature and by asking community representatives. Patient participants in the study were asked to rate how important each of these qualities was to them and then to rate their own General Practitioner on each quality. Results indicted both that patients had high expectations of their General Practitioner and that overall, they were quite satisfied with the service provided.

In a very comprehensive British study Williams and Calnan (1991) used a questionnaire to identify the criteria important to consumers of health care. They also investigated the degree of convergence or divergence of these criteria across general practice, dental care and hospital settings. Results from the 454 returned questionnaires indicated a generally high level of satisfaction with all three care settings. More specific questions, though, revealed particular sources of dissatisfaction and some differences between settings.

Williams and Calnan (1991) conclude that ".......issues concerning professional competence, together with the nature and quality of the patient-professional relationship, are consistently the most important predictors of overall consumer satisfaction......." (pp 714-5). This applied irrespective of setting, although some organisational issues also appeared to be important for consumers evaluating hospital care. The giving of information and communication were consistently identified as sources of dissatisfaction in the general practice and hospital settings.

Soh (1991) identified perceptions concerning medical care and the influence of these perceptions on satisfaction with visits to the doctor. This study followed 1210 participants for a period of one year and results indicated that continuity of care and ease of access correlated with satisfaction.
The results of Soh's (1991) study contrast with those of Sparr et al. (1994) who found that satisfaction remained constant despite imposed changes of hospital doctor. This study also identified high general rates of satisfaction with doctors, nurses and the hospital.

An Australian study by Lloyd, Lupton and Donaldson (1991) investigated the level of 'consumerism' present in health service consumers. Consumerist behaviour was defined in terms of seeking information, exercising independent judgment, having appropriate knowledge and demonstrating critical attitudes. A total of 333 patients from four Sydney general practices participated in the study.

The authors concluded that most respondents did not display a consumerist orientation to general practice services, but ".........were attracted to the traditional model of medicine characterised by trust and dependence by the patient" (p 199). Most respondents ".........displayed a high degree of loyalty towards a particular doctor......." (p 199) and indicated that a caring manner was the most important consideration in their determination of degree of satisfaction with the doctor.

A caring service was also identified by Bursch, Beezy and Shaw (1993) as one of the most important components of satisfaction with an emergency department service in the US. Promptness and provision of information were the other most important components.

Kurata, Nogawa, Phillips, Hoffman and Werblun (1992) assessed consumer satisfaction with care in outpatient family medicine clinics. Consumers were asked for their opinions on the technical quality of care, waiting time, courtesy of staff and general satisfaction with medical care. A total of 156 patients was interviewed and results indicated that most people were very satisfied with the service. For example, 95% of respondents were satisfied with the technical aspects of care and 73% to 87% were satisfied with various aspects of access and waiting times.
A French hospital-based study involving both in-patients and out-patients (Groupy et al. 1991) identified high rates of satisfaction with care provided by physicians and nurses. Cleanliness, comfort, quietness, the time schedule and quality of meals were all ranked, in sequence, below quality of care.

Murphy, Kinmonth and Marteau (1992) assessed patient satisfaction with general practice based diabetes care after patients had experienced this model for one year. A total of 43 patients was interviewed and 77% indicated their preference to continue with this model. This preference was based on "...ease of communication with the doctor in this setting, and the convenience and accessability of care" (p 283).

Factors that determine women's satisfaction with maternity care were examined by Seguin et al. (1989). Women in the Montreal area were contacted four to seven months after the birth of their babies and 938 participated in the study. Satisfaction with services provided was generally high and was related to quality of care by health professionals, characteristics of relationships with health professionals, participation in the decision-making process and the provision of information and explanations by staff.

Harper and Wisian (1994) investigated satisfaction of parents, with services provided by physicians, following their child's death. Questionnaires were completed by 37 parents. The provision of information was the factor most influencing satisfaction, with emotional support, grief counselling and availability of physician also being important.

In recent years consumer evaluation studies relating to people with AIDS have begun to be reported.

Cleary et al. (1992) report on a US study to identify AIDS patients' perceptions of various aspects (e.g. education, communication, family involvement) of their medical care. Interviews with 50 patients indicated that they were generally very satisfied with the care they received.
There were, however, some differences between patients treated in a specialist AIDS unit and those treated in the general medical wards, with those in the specialist unit being more satisfied.

In a British study, McCann (1991) investigated patient satisfaction with a home support team for HIV positive homosexual men. A total of 86% of the 261 participants rated the overall care as excellent or very good and 78% found the team 'kind and understanding'. The role of the team was largely perceived as "......offering advice, social support and contacting other agencies......" (p 835).

Smith, Knickman and Oppenheimer (1992) report a similar majority of clients who were very satisfied with a day care program for people with AIDS in the US.

There is a substantial amount of American literature that deals with satisfaction with health plans, e.g. Bashshur, Metzer & Worden (1967). This is not particularly relevant to the Australian context, except that again, high reported rates of satisfaction are evident and the comment of Donabedian (1965) seems pertinent: "......the great majority of subscribers are satisfied with whatever plan they belong to" (p 7).

1.3.4 Consumer Evaluation in Other Areas

There are many examples in the literature of the use of consumer evaluation research in other areas of health and related services. There is much less consistency of theme in these studies than in the areas described above and there is an emphasis on the development of scales suitable for use in the particular areas involved.

Examples of studies that fall into this category include that of Garber, Brenner and Litwin (1986) who report on a consumer survey of patient and family satisfaction with social work services in a large medical centre. Similarly, MacKeigan and Larson report their attempts to develop a scale for assessing sources of satisfaction and dissatisfaction with pharmacy services,
based on the Client Satisfaction Questionnaire of Ware, Davies-Avery and Stewart (1978).

1.3.5 Issues of Methodology, Terminology and Application

Almost all authors who have written on consumer evaluation studies in the areas discussed above have made some comment on at least one of a number of issues and problems (discussed in general terms in the previous section) related to methodology, terminology and the application of information gained from these studies.

The first of these problems relates to the defining of the concept of satisfaction itself, i.e. what it is that is actually being measured. Winter and Keith (1988) comment: "In spite of considerable empirical research, however, an integrated conception of satisfaction has still been lacking" (p 132).

Davis and Hobbs (1989) in their study of outpatient satisfaction with rehabilitation services specified that they were defining satisfaction as the degree to which client expectations were fulfilled.

Many authors though, do not attempt to define in any way the entity that they are measuring nor often to identify component elements of that entity. Corrigan (1990) claims that ".......research findings..........fail to discriminate the elements within a setting that may be pleasing or aversive" (p 152).

When component elements of satisfaction are identified, there is often little consensus on what they are. Corrigan (1990), for example, describes four component elements of satisfaction with mental health services; concerns about the quality of staff, the physical environment, treatment services and activities that foster patient autonomy.

Shields, Morrison and Hart (1988) similarly describe four component elements of satisfaction
with mental health services. Their list consists of hotel facilities, communication and information, contact with staff and other aspects of life in hospital.

The lack of a standard scale for measuring satisfaction is another common cause for comment (Davis & Hobbs 1989, Lebow 1982). The scales devised by Ware, Davies-Avery and Stewart (1978) and Larsen et al. (1979) are widely, but by no means universally, used as starting points for the development of measures of satisfaction. It is much more usual for researchers to devise their own scale, based on what they perceive to be local needs.

Problems of obtaining a satisfactory sample of participants for studies such as these abound. Clients who are dissatisfied are considered less likely to participate in consumer evaluation research. Frank, Salzman and Fergus (1977) point out that they are less likely to return postcards and Lebow (1982) corroborates this view by claiming that there is evidence that responders are more likely to be satisfied than non-responders. Thus, there is a problem with the self-selection of those who are more satisfied with services and are then willing to report on that satisfaction.

A related problem is that of poor response rates. Lebow (1982), in his review of the literature, identifies an average response rate of 41% for phone surveys and 46% for mail surveys for mental health evaluation. This, combined with the bias in the sample outlined previously, is a cause of major concern. Of further concern is the practice of many researchers not to include the response rates of their studies in their publications.

The common high reported rates of satisfaction are also frequently commented on (Corrigan 1990, Davis & Hobbs 1989, Holloway 1989, Lebow 1982), along with suggestions for making this data more meaningful. Holloway (1989) believes that interviews, with verbatim comments, are more useful than just producing statistical summaries of ratings. Corrigan (1990) notes that a greater effort needs to be made to identify component elements of satisfaction and rate these individually.
Possible reasons for these high reported rates of satisfaction are discussed by Davis and Hobbs (1989). They suggest that the non-participation of dissatisfied clients in such studies is part of the equation, but that other factors such as a fear of repercussions and a tendency to give socially desirable responses are also operating.

Perhaps the most pertinent issue relating to high reported satisfaction rates is raised by Lebow (1982). He asks what the relationship between reported levels of satisfaction and actual satisfaction is: "(t)he correspondence between these reported levels of satisfaction and actual satisfaction in the population is a thorny issue" (p 251).

Holloway (1989) raises an interesting question, in relation to consumer evaluation of services in the mental health field. Who precisely are the consumers? Are they the patients/clients? Are they the families? Are they both of these groups? Many would argue that both groups are the consumers. Yet, as Holloway (1989) points out, often the views of these two groups conflict. Despite this difficulty though, Holloway (1989) believes that in a field like mental health where measuring outcomes is so difficult, consumer evaluation is a valuable tool.

Shields, Morrison and Hart (1988) raise the issue of application of results of consumer evaluation studies. They claim that similar results to those produced in their study have been produced for 15 years prior to it, yet practices in mental health services have not altered in response to this information. Professional resistance and a reluctance on the part of professionals to take such information seriously are suggested as possible reasons.
1.4 Evaluation of Services by Consumers in Developmental Disability

Almost all consumer evaluation studies in the developmental disability field obtain information from family members, care-givers or advocates, rather than the client. There are a small number of studies that collect information directly from disabled clients, but, predominantly, developmentally disabled clients are unable to provide useful information because of low intellectual levels, poor communication skills or a broader inability to reliably understand and answer questions.

It has also been argued that others, particularly parents, as well as their sons and daughters, can very legitimately be seen as clients of developmental disability services. These issues are discussed in detail in Chapter 2.5.2. Many studies in this area evaluate services for children and as would be expected, mainly use parents as the informants.

Problems of differing methodologies of studies and different populations being studied limit the comparative value of many of the studies in this area. Many writers also fail to adequately define terms used or to include relevant information on the characteristics of their sample or the services being evaluated. However, they do all contribute to an overall picture of how services for people with developmental disabilities are perceived by those using them or their representatives.

Relevant studies in this area fall into a number of different groupings. First, there are those that can be seen strictly as some form of assessment of client satisfaction with services (e.g. Grbich & Sykes 1990, McKay & Hensey 1990, Brown & Ringma 1989). These studies mostly use a large sample size and obtain ratings of level of satisfaction and/or dissatisfaction with various disability services. Many of these studies also obtain qualitative comments from informants, which are analysed for more detailed or personal information than can be provided by the quantitative data.
Second, there are 'needs' based studies (e.g. Caserta, Connelly, Lund & Poulton 1987, Tarron 1981) which attempt to identify what parents or others feel that they 'need' from services or what qualities they 'want' or 'expect' in professionals working in those services. These studies are not strictly consumer evaluation research, but do contain a lot of information related to possible sources of satisfaction or dissatisfaction with services. They will, therefore, be included in this discussion.

Finally, there are studies which use a very small sample size and produce large amounts of qualitative data from each person in the study (e.g. Paul & Beckman-Bell 1981, Hubert 1981). These articles often include detailed first-person comments from respondents. Thus, they provide a lot of detail about the perceptions of a small number of people and are not amenable to quantitative analysis. Included in this group are articles written by parents themselves.

Australian and overseas studies will be presented separately in the following discussion. While there will obviously be elements of relevance from overseas studies, the Australian studies, conducted as they are in the same service delivery system as the present study, are clearly the most pertinent.

1.4.1 Australian Consumer Evaluation Studies

A potentially interesting Australian study was conducted in the Western suburbs of Sydney by Rees (1983). Unfortunately, the published article does not contain many items of necessary information and this diminishes its possible value. Terms are not defined and there is no information on how the data were analysed.

Nevertheless, results showed that many parents were dissatisfied with their treatment by professionals. Parents indicated that "(h)ealth and welfare services did not make any difference to families' ability to cope, except where such services concentrated on extending the families' network of useful personal contacts" (p 475). The author concludes that the parents in this
study clearly related satisfaction or lack of same to the manner in which they were dealt with by professionals.

Steinberg (1983) reports on a Queensland conference, which dealt with the problems and needs of families with a disabled member. It was attended by 132 parents or other family members and a number of common problem areas identified. "The most crucial issue appeared to be the lack of information, communication and co-ordination at all levels of service provision...." (p 78).

Parents at this conference identified the need for ".....relief from the continuous burden of caring for a disabled family member. This need permeated all discussions...." (p 78). Steinberg concludes that "(m)any families appeared to be disillusioned with the attitudes and practices of many health professionals...." (p 79).

A very valuable Australian study is that conducted in Queensland by Brown and Ringma (1989). They interviewed 42 consumers of disability services for their views on accessibility of information on services, the exercise of consumer choice in service provision, access issues, quality of service provision, inadequacies in the service delivery system and consumer participation in decision making.

The participants in this study were physically disabled adults, intellectually disabled adults and the parents of disabled children. No attempt was made to separate the responses of the different groups, with the authors indicating that their deliberate intention was to obtain the views of a cross-section of disability services consumers.

Consumers indicated that ".....gaining adequate and relevant information regarding disability services was problematical" (p 43) and that this information had been gained in ".....rather haphazard ways" (p 43).
Choices and decisions tended to be made for clients, rather than by them and many expressed a lack of confidence in their capacity to make their own decisions. "Consumers are generally not consulted. They do not participate in making decisions regarding the agency. At the same time, consumers express a personal reluctance and a sense of inadequacy regarding the possibility of this type of participation" (p 46).

Brown and Ringma (1989) claim that when clients viewed services as appropriate, further investigation revealed that they were often judging on a limited set of criteria, e.g. that it allowed them to get out of the house.

The same process of further investigating responses was applied to consumer evaluations of access and revealed a similar problem. Consumers who claimed that access was acceptable were actually including in this evaluation travelling times of up to two and a half hours to get to services.

Overall, the participants in the Brown and Ringma (1989) study rated services positively, yet most suggested ways in which services could be improved and identified gaps in service provision. The gaps identified were predominantly in transport, accommodation and recreation services. Very significantly, only two consumers indicated that the service they were evaluating had helped them to grow towards greater self-reliance and independence; goals that all disability services should (and would generally claim to) aspire to.

Grbich and Sykes (1990), in contrast to Brown and Ringma (1989), found that parents rated many services for their disabled children as very unsatisfactory. In this Melbourne study, 40 parents of school aged severely intellectually disabled children and a further 40 parents of severely intellectually disabled young adults were interviewed. Approximately 25% of the children and young adults were also interviewed and both qualitative and quantitative data were collected.
Results indicated that 98% of parents rated advice and support from medical personnel as extremely unsatisfactory on a 5 point Likert scale. The major contributors to this lack of satisfaction were lack of information regarding diagnosis and support services, underestimation of the child's life expectancy and future capabilities, and management of the condition.

Further major sources of dissatisfaction identified in this study were lack of adequately trained professionals, inadequate provision of post-school options and lack of respite and permanent accommodation placements. The authors summarise: "(i)nformation and access to services from the time of diagnosis were claimed by parents to have been totally unsatisfactory" (p 269).

Grbich and Sykes (1990) concluded that more support services are required if the strains on families such as those in this study are to be lessened.

Baxter, Cummins, da Costa and Volard (1991) evaluated the accessibility of shared family care in a scheme using foster care-givers in Victoria. The small sample (12 care-givers and 7 service users) and bias towards those who were least stressed are acknowledged by the authors as shortcomings of the study. All participants were happy with the program and parents saw it as a positive experience for themselves and their children.

Foreman and Neilands (1991) conducted a survey of parents of children aged from 5 to 18 years, with moderate to severe levels of intellectual disability in the Hunter region of NSW. Questionnaires were sent to 256 families and 123 were returned, for a response rate of 48%. Parents were asked which services most understood their needs and early intervention services and schools rated most highly. Services rated most often as 'very useful' were special school, paediatrician, early intervention program, regular pre-school and other parents.

Foreman and Neilands (1991), in the same study, also looked at parental perceptions of the process of being informed of their child's disability. Whilst 75% of parents indicated that they had received factual information at this time, 10% were given out-dated terminology, 9%
'vague' information, 6% 'negative' information and 7% were advised to institutionalise their child. There were no changes over time in these results.

The most recent reported Australian study is that of Phan (1994). This study, in Sydney, used a questionnaire to assess parental perceptions of accessability, usefulness and efficacy of services for disabled children in the first five years of the child’s life. Both generic and specialist services were included in this study. A total of 80 completed questionnaires was received from parents of pre-school aged children with, it appears, intellectual disabilities. The precise nature of the disabilities of the children is unclear because of the author's incorrect usage of terminology.

Results of this study indicated that a majority (69%) of parents felt that the provision of information at the time of diagnosis was inadequate. The most commonly used service was the local doctor, with 95% of respondents reporting that they used this service. Maternal and Infant Care Centres were used by 72% of parents and 90% utilised various (unspecified) specialist developmental disability services. However, parents indicated that less than half the services they needed were actually available and a much smaller number (unspecified) indicated that the services met their needs.

A minority (21%) of parents reported their doctors as demonstrating positive attitudes towards developmental disability, with 10% reporting perceived negative attitudes and 69% unable to determine any attitude, either positive or negative.

When asked to identify needed changes to current services, respondents in Phan's study listed greater accessability of information, more effective communication between parents and professionals, more effective early intervention and ".........the development of professional competency in developing strategies that can be used by those caring for these children" (p 151).
1.4.2 Overseas Consumer Evaluation Studies

One of the earliest consumer evaluation studies in the developmental disability field is that of Barclay, Goulet, Holtgrewe and Sharp (1962-3). A questionnaire was sent to 89 parents of children attending a diagnostic out-patient clinic for children with suspected mental retardation. Questions related to three main areas: perceptions of the clinic prior to evaluation of the child, perceptions of the process of assessment of the child, including interpretation of results to parents, and perceptions of the implementation of the clinic's recommendations.

Eighty-four percent of questionnaires were returned and indicated a high level of satisfaction. However, there were some exceptions and these generally related to lack of information in a range of areas.

In a 1978 study, Waskowitz, interviewed 40 parents about their communication with professionals. She found that ".....only 25% of the parents indicated that their contact with professional people was satisfactory" (p 24). These parents requested more information in a form that they could understand, practical help with everyday problems and sensitive counselling.

In a US study that evaluated both mental health and mental retardation services, Justice and McBee (1978) surveyed current and past service users. Parents of the clients of mental retardation services represented the views of these clients and results indicated high levels of satisfaction. The authors hypothesise that this is at least partly because of a reluctance to criticise needed services, with the perceived attendant risk that services may be withdrawn or refused.

Breslau & Mortimer (1981) examined the satisfaction of mothers of children with various physical disabilities, with the care they received in four specialty clinics of teaching hospitals in the US. The results indicated systematic and marked differences across clinics, which were
explained by differences in continuity of physician and waiting time on arrival at the clinic. This study found no significant relationship between satisfaction and demographic variables.

Adults with cystic fibrosis attending a specialised clinic for management of their condition were more satisfied with professional aspects of their care than those attending general clinics, in a British study (Walters, Britton & Hodson, 1994). Clients attending the specialised clinics also had better symptom control.

In another US study, Suelzle and Keenan (1981) found that few parents of disabled children and young adults, from a total of 330, rated any of a list of 19 services (e.g. education, accommodation, support) as adequate.

A New Zealand study by Dittmer and Romans-Clarkson (1986) evaluated health care services for handicapped pre-school children. The authors comment that they ".....were surprised by the intense and frequently adverse comments from these parents about the care their children had received" (p 674). The 102 parents who participated in this study were specifically asked to identify helpful and unhelpful elements in the care of their child. "Parents appreciated people who gave them practical and emotional support" (p 673). Often, this was reported to be family members rather than professionals. Doctors were mentioned as helpful by only six parents and other professionals who were viewed as helpful were those who were prepared to become involved in the everyday problems of caring for a disabled child.

The pre-school centres attended by their children were identified by 70% of parents as the most helpful single factor. In terms of unhelpful factors, one third of families "......complained about their medical care, often angrily" (p 674). Specific complaints included problems with doctors' knowledge, attitudes, lack of emotional support and conflicting advice, lack of co-ordination of services and practical issues such as appointment times. Parents also described their "......desperate efforts to extract necessary information from doctors" (p 674).
Lynch and Staloch (1988) investigated parental evaluations of the process of being informed of their child's disability. They utilised a sample of 50 parents whose children were four years of age or younger. A 5-point Likert scale was used to measure degrees of opinion regarding statements representative of professional methods during the informing process.

Results indicated that most parents viewed the handling of this process in a positive way, with some reservations. Approximately half of the parents interviewed indicated that the informing person had left them with an unclear picture of the child's condition. A similar percentage claimed not to have been given enough information. The authors comment: "(t)hese findings reveal that a large number of these parents received a limited amount of information and desired much more" (p 80).

Many parents (64%) recalled that they were sent home with "......no knowledge of what to expect from the child and no information regarding strategies for facilitating growth and development" (p 80). Further, they reported that they received most assistance in this area from mental health agencies or early intervention programs and this only after prolonged personal efforts to find these services.

A similar study to that of Lynch and Staloch (1988) was undertaken by McKay and Hensey (1990) and produced similar results. McKay and Hensey (1990) obtained the views of parents of young children with cerebral palsy about their early contact with health professionals. The study was conducted in Ireland with 84 children.

Overall 70% of parents were dissatisfied with services and their sources of dissatisfaction were categorised as lack of explanation about the child's condition, having their initial worries dismissed, the way in which they were told of the diagnosis or a lack of understanding of their problems in handling a disabled child.

McKay and Hensey (1990) comment that "(l)ack of explanation, either about their child's
complaint or why they were being asked to attend for follow-up, was the commonest complaint" (p 376). This study found no relationship of dissatisfaction to severity of the disability.

Krahn, Eisert and Fifield (1990) set out to develop an assessment method that would ".....measure parental perceptions of service delivery outcomes" (p 763). This tool would need to be ".....useful to professionals across different settings, and....recognise the multidimensionality of satisfaction" (p 763). They also wanted to identify whether evaluation tools developed in other settings could be adapted for use in paediatric settings for children with special needs.

The Client Satisfaction Questionnaire (CSQ) developed by Larsen et al (1979) was used by Krahn, Eisert and Fifield as the starting point for their tool. They added additional items and ratings were given by parents on a 4 point Likert scale, with two narrative questions on positive and negative aspects of services at the end. The questionnaire was mailed to 475 parents and 295 were returned for a 62% response rate.

Four factors of significance were extracted from the results. The first, general satisfaction, accounted for 34% of the variance and covered all eight items from the CSQ plus staff helpfulness, usefulness of information and availability of recommended services. The other 3 factors were clarity of communication (8% of variance), pre-appointment wait and information (6% of variance) and efficiency (5% of variance).

Almost all of the positive comments about services were able to be categorised into these 4 groups. For the negative comments, it was necessary to add a fifth category labelled 'Convenience'. Krahn, Eisert and Fifield (1990) concluded that whilst the CSQ was as useful with this group of consumers as it was with the group it was designed for, it alone was not adequate. The single dimension of satisfaction measured by the CSQ did not reflect the ".....additional dimensions of satisfaction with services for children with special health needs (that)
Whitehead, Deiner and Toccafondi (1990) found that mothers of disabled infants and toddlers identified early intervention programs as the most helpful form of support followed closely by school or day care setting and professional helpers.

Sands, Kozleski and Goodwin (1991) surveyed consumers, and/or their families, of disability services in one state in the US (Colorado) regarding satisfaction with services and needs for additional services. From a possible population of 1198 consumers, only 346 (28.9%) agreed to be interviewed and only 240 of these actually completed the survey. The tool used for this study was the Consumer Satisfaction Survey (Temple University 1988), with some minor alterations and additions. Only 8% of consumers completed the survey without the assistance of a family or staff member.

Results of this study were very varied with levels of satisfaction ranging from quite high (e.g. general medical 90%, dental 72%) to very low (e.g. case management 15%, transport 11%). Most (79%) consumers were happy to remain in their current living situation and 80% of those working were at least somewhat satisfied with their work environment. These authors also note that "(m)any respondents expressed dissatisfaction with information and referral services........." (p 312).

1.4.3 'Needs' Based Studies

Tarron (1981) interviewed 67 parents of children with cerebral palsy in Scotland and found that practical assistance with everyday problems was frequently identified as needed. These parents noted the provision of information on an ongoing basis, flexibility and contact with other parents as similarly needed by them.

Coffman (1983) conducted a similar study to that of Tarron (1981) with parents of children
with cerebral palsy in the US. She found that 33% of parents had unanswered questions relating to the disorder, 28% did not understand how it would affect the child's development and a further 28% had difficulty getting their questions answered between regular clinic appointments. Thus, the main needs of these parents related to the provision of information.

Redman-Bentley (1982) focused on defining parent needs and expectations of professionals, for parents of young (under 6 years) disabled children. Results indicated that these parents had specific needs and expectations of professionals and that these were prioritised. Personal traits were considered important and professionals who were honest, knowledgeable and listened to parents were preferred. The author concludes: "(t)he implications ........ were that parents desire a more active role in the rehabilitation of their handicapped children. Parents wanted to have a say in decisions made concerning their child's program as well as information .......... The six most important needs of parents dealt with their role in and information on the child's rehabilitation" (p 25).

In a comprehensive study of older caregivers of developmentally disabled people, Caserta et al. (1987) identified reported needs for services and whether needed services were actually provided. Interviews were conducted with 198 subjects, average age 64 years, and respondents were asked to determine which of 23 types of services they needed to carry out their caregiving responsibilities.

The services with the highest reported need were doctor (45%), lawyer (44%), personal counselling (31%), housekeeping (22%) and home repairs (21%). All 23 services were needed by at least three caregivers, indicating a wide diversity of needs. In terms of needed services actually being provided, results were quite negative. For example, 70% of people who reported needing a lawyer did not have this need fulfilled. The corresponding percentages for housekeeping, home repairs and personal counselling were 81%, 84% and 59%.

Caserta et al. (1987) conclude that "......a significant proportion of the older caregivers in this
study reported a need for key services. For the most part, with the exception of those services rendered by a physician, these needs have gone largely unmet" (p 46). They further comment that "...........it is relatively clear that a need exists for greater service access and more effective information dispersal" (p 49).

Parents of young adults requesting alternative community living arrangements were asked by Black, Molaison & Smull (1990) to identify other needed services. Approximately two-thirds requested day programs, independence training and recreation activities. A further 46% asked for social skills training, 39% for respite services, 37% for financial assistance, 31% for behaviour management and 27% for psychological services.

In a New Zealand study by Hand and Reid (1989), 185 older (over 50 years) intellectually disabled people were interviewed about their service needs. For the most disabled group, a family member or other representative was interviewed. The most urgent needs identified included access to generic leisure and recreation services, more choice in place of residence, learning of self care and social skills, access to regular and thorough health care and development of non-verbal means of communicating.

Respondents in a study by Whitehead, Deiner and Toccafondi (1990) identified obtaining information on teaching their child, receiving help in finding babysitters and finding more time for themselves as their strongest needs.

In a study involving 422 parents or other care-givers of children in early intervention programs, Bailey, Blasco and Simeonsson (1992) identified needs using the Family Needs Survey (Bailey & Simeonsson 1988). This tool has six sub-scales; need for information, need for support, explaining to others, community services, financial needs and family functioning.

Results showed that the factor relating to greatest expressed need was information, particularly information about the child’s condition, how to teach the child and information about present
and future services. Also high were selected areas of financial help and opportunities to meet other parents of disabled children.

Bailey, Blasco and Simeonsson (1992) also identified differences in expressed needs between mothers and fathers, with mothers identifying significantly more needs than fathers. With this exception, these authors found no significance differences related to demographic variables.

Schultz et al. (1992) reported on a pilot program offering support to parents of children with disabilities. Whilst the program is not directly relevant, the researchers observe that "(o)btaining information about community supports and networks was viewed as being of particular value for participants" (p 52).

Simpson (1988) comments that ".....little empirical evidence about those services most needed and sought by parents of handicapped children is available" (p 40). This study reports that the most widely requested services by such parents were those related to the provision of information.

1.4.4 Small Sample, Qualitative Data Studies

Akerley (1975) presents a critical account, from the perspective of parents, of contact with professionals and points to the need for parents to be perceived as the primary decision makers, to have access to information and to be seen as part of a family which also has rights.

The issue of contact with professionals is also explored by Paul and Beckman-Bell (1981). They point out that parents often report that the most important part of their dealings with professionals is the person's sensitivity to themselves and their child. One parent commented that "(o)ur experience with professionals has been mixed. It has run the gamut from supportive and helpful to frustrating and counterproductive" (p145).
Hubert (1991) conducted what she describes as an intensive anthropological study of 20 families with a young adult member with severe or profound intellectual disability, who was living at home. These families, in the UK, were visited over 2-3 years and during this time the parents detailed their "......long and bitter struggle....." (p 18) to get needed services.

Parents were particularly critical of both the availability and quality of respite services. Specific complaints regarding repite care were numerous and included poor physical care, lack of dignity and concern for self esteem, lack of concern for emotional care, lack of communication and inadequate protection from physical harm. Many aspects of staffing were also heavily criticised. Attitudes of staff, lack of appropriate training and staff shortages were amongst these.

1.4.5. Relevance to The Present Study

This study does not replicate any of the previous studies, but shares the common elements present in most of them. It employs an interview format, as do most previous studies, with representatives of the consumers, rather than the consumers themselves. The interview format is a combination of questions that require the respondent to provide numerical ratings of satisfaction with services, and questions that allow for individual comment on sources of satisfaction or dissatisfaction and perceived deficits in available services.

None of the above studies relate to exactly the same group of disabled consumers, i.e. those with severe and profound intellectual disabilities, as this study. However, as all studies tend to use different sub-groups of the disabled population, this is not seen as a source of difficulty. Several themes (e.g. difficulty in obtaining information, problems in relating to professionals, inadequate support services) are identifiable in the findings of the studies discussed above and the findings from the present study will be considered in the light of these.
1.5 Service Utilisation in Developmental Disability

There is very little literature relating to actual utilisation of services by people with developmental disabilities. The literature relevant to the topic tends to be inconsistent in focus and to take multiple different approaches to the issue.

This inconsistency starts with the basic question of what is actually being measured in studies that look at aspects of service utilisation for this group.

Some studies, for example, assess needs for services. The person determining what services are needed may be a professional, a client, a family member, an advocate or a care-giver and it is reasonable to assume that each of these perspectives may produce a different assessment of needs.

Alternatively, there are studies which look at expressed desires for services, again often from a range of different perspectives. Others identify services that are requested, but not available and still others measure actual rates of usage of available services.

There are studies that concentrate on specific components of the service delivery system, e.g. accommodation services or respite care options, or on service usage for certain sections of the developmentally disabled population, e.g. children or the aged. Some look just at specialised disability services, others at usage of generic services and some at both.

Further compounding the difficulty of identifying common themes in the findings of studies related to service utilisation by people with developmental disabilities is the fact that service delivery systems differ greatly even within a single country. All states of Australia have different systems of service delivery for people with developmental disabilities, as do most of the states in the United States of America. Problems, then, of comparing between countries are enormous.
Many researchers who write on this topic are not at all precise in describing the nature or severity of the disability or disabilities present in the population they are studying. Thus, it is often very unclear exactly what the nature of the population is. Even when the population being studied is accurately described, it is almost always a sub-group of the whole developmentally disabled population, which again presents problems for comparison across studies, as these sub-groups vary enormously.

Despite the considerable inconsistencies and difficulties outlined above, it is possible to identify a theme that runs very clearly through the literature on the utilisation of services by people with developmental disabilities.

This overwhelming theme is that there are always major gaps and deficits in service delivery identified. Utilisation, therefore, tends to be governed simply by what is available, rather than by any realistic definition of choice. It is reasonable to hypothesise that utilisation would be greater and demonstrate a different pattern if real choice was possible and all services identified as needed were available.

Within this theme, a sub-theme that emerges (often implicitly) from the literature related to service utilisation is that services are frequently unco-ordinated. This is irrespective of location, type of disability, type of services, identity of informants or specific information being sought in the study. Lack of co-ordination also, of course, must impact on utilisation of services.

Further complicating this issue is the fact that the relationship between many of the factors discussed above is not clear. Would people, for example, actually use services that they say they need? There is some evidence that this is not the case. Thus, the interactions between need, expressed desire and actual usage are poorly understood and probably complex, yet frequently assumed to be simple and predictable.
1.5.1 Aspects of Service Utilisation by Children with Developmental Disabilities

Baxter (1987) found that diagnostic services had been used by all parents of disabled children in her Australian study, but no other service had been used by more than 75% of participants. This study designated 22% of 70 households as having 'high' service utilisation and 38% each as having 'medium' utilisation and 'low' utilisation. The author here comments that parents who find out about services make long-term use of them, with the clear implication that parents have difficulty finding out about services.

Foreman and Neilands (1991), in a study of 123 parents of disabled children in the Hunter region of NSW, found that approximately one third of children were under the care of a paediatrician, 38% were being assisted by the developmental disability service and 23% were under the care of a neurologist. The services of speech therapists (25%), physiotherapists (20%) and occupational therapists (15%) were also commonly used.

There appear to be clear differences of service need and use at different times of childhood (Suelzle & Keenan 1981). Parents of younger children are more likely to have received services (Baxter 1987) and to be more supportive of educational integration (Suelzle & Keenan 1981) than parents of older children.

The area of respite care and the adequacy or otherwise of its provision is complex. Salisbury (1990) identified a 32% utilisation rate of respite care for parents of children with disabilities who were actually on a list of users of the service. She claims that this is a similar rate to that of other studies, which have also found that respite care is not used as much as is assumed. "The discrepancy between level of interest and actual utilisation is, perhaps, the most perplexing finding of this study. Given the level of demonstrated need, why was there not a greater demand for services" (p 295)?

Malin and Todd (1981) claim that this apparent discrepancy between demand and need (as
evidenced by low utilisation rates) is explained by the fact that many parents use respite services only when desperate. This view is supported by Salisbury (1990) who suggests that mothers prefer to use informal support structures, but remain on respite care lists so that they have the option if needed.

There appears to be little or no correlation between usage of services and demographic variables or level and nature of the disability (Salisbury 1990, Black, Molaison & Smull 1990, Suelzle & Keenan 1981). There is some evidence though of service usage and requests for services being related to number or intensity of stressors on the caregiver/s (Salisbury 1990, Black, Molaison & Smull 1990). Cavanagh and Ashman (1985) contend that the main source of stress for these caregivers is the constant care and training of the child, without the usual breaks that most families are able to have.

Inequality of distribution of services on an urban/rural basis may well also be an issue in service utilisation. The nature of support mechanisms for rural families with a disabled child was investigated by Minnes et al. (1989). They conclude that ".......the results of this study highlight the importance of social support as an external family support at least for rural families......." (p 114) and hypothesise that because of their relative isolation, these parents had less access to support from service agencies and hence had had to develop strong social networks to cope.

Paul and Beckman-Bell (1981) suggest that utilisation patterns of services for disabled children are determined by factors such as availability of services, referral practices from one service to another and parents' abilities to find their own ways through a complex maze of services.

1.5.2 Aspects of Service Utilisation by Adults with Developmental Disabilities

Diagnostic, recreation and training services were identified by Slater & Black (1986) as the services used by most subjects in their study, at some time. All other services, out of a total of
16 were used by less than 25% of subjects.

Parents of disabled school leavers saw vocational services as the most important service in the present and for 10 years into the future (McDonnell, Wilcox, Boles & Bellamy 1985). They wanted stable and meaningful work for their children and residential services where these young adults would receive training (McDonnell et al. 1985).

In a large sample of intellectually disabled people living in the community, Minihan and Dean (1990) found that 87% had a regular physician and 62% had medical conditions requiring ongoing care. This same study also judged the adequacy of health care (based on expert opinion) for these clients and found very wide variations, with those clients living at home faring very much worse than clients living in other settings.

Paradoxically, Beange (1986) found that clients living at home were receiving better health care than those living in other settings. However, this difference may be at least partly explained by the fact that this is an Australian study, whereas that of Minihan and Dean (1990) is American. Beange (1986) is essentially arguing that adequate health care services are simply not being provided to those clients living in community group homes in NSW and this is clearly a local issue. It can also be seen as an example of utilisation being governed by availability.

McDonald (1985) reports a high rate (not defined) of utilisation of specialty medical services by young people with severe intellectual disabilities living in the community.

Marcenko, Herman and Hazel (1992) found that 79% of families in their study used the family support subsidy, 65% used respite care, 63% used information services and 41% used case management. Over the life-time of the person with the disability, 55% of families had used fewer than five services.

As with children, there appear to be few predictors of service usage for this population.
Engelhardt, Brubaker and Lutzer (1988), in a study of older carers of adults with disabilities identified current caregiving ability and future projected caregiving ability as correlates of amount of service usage. These assessments of caregiving ability were the caregivers' own.

Those with mild and moderate levels of intellectual disability have been demonstrated to use services more than those with severe and profound levels of intellectual disability (Slater & Black 1986). These same authors also identified that urban clients received more services than rural clients in many areas.

1.5.3 Aspects of Service Utilisation by Aged People with Developmental Disabilities

Janicki and MacEachron (1984) examined the living situations of aged people with developmental disabilities and found that 50-60% lived in institutions, a small number lived with their families and the rest in a group care setting. These patterns differ substantially from those found by Seltzer (1988). He identified 36% of such people living in institutions, 20% in nursing homes, 33% in community residential settings and 11% in the family home or living independently. These are both American studies which utilised very large samples.

The primary focus of the work of Seltzer (1988) was to identify the patterns of service usage of elderly intellectually disabled people. The majority (62.3%) of services used were age-integrated disability services, 32.9% were generic aged services and 4.8% were age-specialised disability services. The first group contained the highest proportion of support services, the second the highest proportion of residential services and the third the highest proportion of day programs.

With increasing age of people with developmental disabilities, there are fewer day and work placements available and a corresponding increase in medical and nursing services and recreation activities (Janicki & MacEachron 1984). This is not an unexpected finding, given that this population shows a similar decline, with increasing age, to the general population in terms
of mobility, sensory processes and competence in activities of daily living (Janicki & MacEachron 1984).

These same authors also identify though, that this decline differs for different sectors of the developmentally disabled population. Specifically, there is a greater loss of skills with increasing age for those who are less disabled. Seltzer (1988) points out that the aged population of people with developmental disabilities is increasing in number and level of frailty. They will, therefore, need more services in the future.

1.5.4 Identified Gaps, Deficits and Problems with Service Provision

Virtually every piece of literature relating to service provision and usage for people with developmental disabilities deals extensively with gaps, deficits and problems in services. It is very clear that inadequacies in the provision of services mediate usage and at least partly determine patterns of usage.

Cocks (1985) identifies 10 substantial Government commissioned reports in Australia from 1977 and states that: "(v)irtually all reports expressed concern about the quality, availability and accessibility of services for persons with an intellectual disability and their families" (p 77).

1.5.4.1 Inadequate health care provision

Adequate health care is identified by many authors as not being provided to people with developmental disabilities (Minihan & Dean 1990, Ziring et al. 1988, Parmenter 1988, Beange 1986, Slater & Black 1986). Adequate health care encompasses medical care, mental health care, dental services and health maintenance programs.

Beange (1986) points to a high number (2.6 per client) of unidentified health problems in a sample of intellectually disabled people. This is supported by the work of Slater and Black
(1986) who concluded: "(i)t appears from the file information and knowledge available from the primary care providers that although the majority of these clients have many severe medical and psychological difficulties, they have been provided a minimum of documented medical and psychological services" (pp 155-6).

Slater and Black (1986) also found that medical/dental services were one of only two types of services, from a total of 16, that were judged to be inadequate to meet the needs of over 20% of clients.

Many clients, according to the study by Ziring et al (1988), reported having tried unsuccessfully to obtain medical services in the community. This is despite the fact that many people with severe disabilities have complex health needs. They comment that "(t)he health care needs of this group are so extensive and pervasive that they provide many disincentives for community based practitioners to become involved" (p 1442). These same authors also report that many clients in their study had serious dental problems.

Parmenter (1988) describes mental health services for people with intellectual disabilities as "grossly inadequate" (pp 10-11) and claims that this "......is one of the most neglected areas of service delivery to people with mental retardation" (p 9). He also discusses the anecdotal evidence that ".....the deinstitutionalisation process has in some cases exacerbated mental health problems" (p 10) because of the stress of moving. This, in turn, means that already inadequate services are increasingly inadequate as more residents are moved from institution to community based residential services.

Minihan and Dean (1990) found that 61% of clients living at home were not receiving adequate health care and questioned whether generic services can provide adequate home based health care to the developmentally disabled population.
1.5.4.2 Other inadequate services

There are many other specific services that are identified in the literature as inadequate in some way. These include group home places, appropriate transport, leisure services, specialised therapy services and travel training (Janicki & MacEachron 1984).

Suelzle and Keenan (1981) point to the need for greater family support, crisis lines, respite care and counselling. They also identify that these services are provided inconsistently through the life-span of a disabled child, when they are needed continually. Castellani, Downey, Tausig and Bird (1986) describe a similar deficiency in the provision of adequate respite care and another inconsistency in service provision. They identified that clients in residential settings received far more services than those in day programs.

A lack of respite services was also identified by Sands, Kozleski and Goodwin (1991). Suelzle and Keenan (1981) identified unmet needs for diagnostic services and living alternatives amongst parents of young adults.

Slater and Black (1986) found that nine out of 16 types of services were inadequate to meet the needs of at least 10% of clients. Two of these (medical/dental and training) were inadequate to meet the needs of over 20% of clients.

Baxter (1987) identified several types of help more frequently not received than received by parents of disabled children; information, sympathetic understanding, the experience of talking to other people in a similar situation and practical help with everyday problems. This was despite these types of help being viewed as important by both parents and professionals.

The issue of inadequate information is raised by McDonnell et al (1985) who found that 65% of parents of disabled children finishing school received information about transition to work and adult disability services. This left "(a) significant number of parents (who) received no
Seltzer (1988) obtained information on waiting lists for services for aged people with disabilities. He found 356 people, out of 1911 currently using services, who were on lists for additional services and a further 50 people who were on a waiting list to access services for the first time. This author predicted an increase of 16% in the aged population in the next year, with corresponding increased pressure on already inadequate services.

Brown and Ringma (1989) indicated that "......consumers exercise limited choice in a narrow field of available service options" (p 43). Some consumers in this study specifically identified that they used the services they did because there was nothing else available.

This pattern of utilisation being determined by availability is further reinforced by Baxter et al (1991) who found that 27% of families with a disabled child requesting shared family care were unable to obtain this service.

1.5.4.3 Lack of co-ordination of services

Ziring et al. (1988) and Parmenter (1988) emphasise the need for co-ordination of services and comment that this is often lacking. Cocks (1985) comments that most of the 10 Government commissioned reports on intellectual disability in Australia between 1977 and 1985 have been very critical of the fragmentation and lack of co-ordination of services. Castellani et al. (1986) comment that "......for family support services, there is a lack of the linkages and relationships between and among agencies that characterise a true network or system of services" (p 78).

The need for more integrated services was identified by the parents in Waskowitz's study (1978). Similarly, parents interviewed in the study by Rees (1983) complained about a lack of co-ordination between services and a lack of co-operation between professionals. Steinberg
(1983) also reports parental complaints of lack of co-ordination at all levels of service provision. Parents in the study by Hubert (1991) indicated that lack of co-ordination of services was a problem that became more acute as their children reached adulthood.

The study by Foreman and Neilands (1991) identified 25% of parents who commented on deficiencies in the co-ordination of services.

1.5.5 Relevance to the Present Study

This study identifies all services used by the participants in the study during the previous five years and any perceived gaps or deficits in available services. The studies described above point to a generalised lack of co-ordination of services and to service utilisation being at least partly determined by availability. They identify multiple gaps in service provision and differing needs over the life-span of the person with the disability.

The findings from different age groups will be considered separately at appropriate times in the present study to determine age-related patterns to service utilisation and the broad issues of co-ordination of services and perceived deficits considered.
1.6 Staff versus Consumer Perceptions of Services

It seems reasonable to assume that consumers and staff members have different perspectives on services: they have different needs, different expectations and different experiences of services.

There is support for this assumption in the literature, with studies comparing client and staff perspectives on a range of services and issues generally finding differences between the groups.

Vuori (1982) comments on differences of perspective between consumers and providers of health services. He expresses the view that the main concern of the consumer of services is effectiveness; yet he believes that this is of limited interest to health professionals and of virtually no interest to service providers. Health professionals he perceives as most concerned with quality and providers with efficiency.

Budde, Petty and Nelson (1989) claim that staff perceptions of both process and outcomes often differ from those of the consumer. Mesibov and La Greca (1981) refer to the "......often differing perspectives of 'the patient' and 'the professional'......" (p 155).

Several studies where different groups involved in health care express different priorities are discussed by Lebow (1982). He comments "......that the evaluator must not assume that clients attach the same degree of importance to various aspects of service as do the professionals......." (p 253).

Kessner (1978) writes that "......the word 'quality' means degree of excellence, degree of confirmation to standards, and the question in medicine is: Whose standard should be observed - whose definition of excellence? Care accepted by the generalist may be rejected by the specialist and irrelevant to the administrator. The patient may legitimately disagree with all three" (p 382).
Studies comparing consumer and staff views show consistently that consumers or their representatives rate services more highly than staff and that they tend to perceive greater benefits of services.

There is also evidence to support the intuitively logical notion that staff and consumers judge services and benefits of services by different criteria. Specifically in relation to the disability field, there is evidence of a different philosophical focus for consumers (or their representatives) and staff.

1.6.1 Higher Consumer Ratings for Services

In an early study, Mayer and Rosenblatt (1974) compared patient and staff views of services offered in a psychiatric hospital. Patients rated a range of aspects of service delivery (e.g. physical amenities, program activities, safety) more positively than all categories of staff. The only aspect of care rated more highly by staff than patients was group therapy.

This pattern of consumers generally viewing services or outcomes of treatment more positively than staff has been consistently demonstrated in many studies, in a range of service areas, since that time.

Similar findings to Mayer and Rosenblatt (1974) were identified by Edwards et al. in 1978. Their study, in a mental health setting, found that therapists' mean ratings of success of treatment were much more conservative than the patients' ratings. el-Guebaly et al. (1983) also comment on this tendency for consumers to perceive greater success of treatment than staff.

Kurata et al. (1992) compared patient and provider perceptions of satisfaction with medical care in outpatient clinics. They found that providers were less satisfied than patients for all aspects of care, including technical quality of care, courtesy of personnel, access and waiting time.
Kadzin, French and Sherick (1981) looked at the acceptability of various forms of treatment for disturbed children. They found that the relative standings of treatment forms did not differ, but that parents rated treatments as more acceptable than staff. Perhaps not surprisingly, the children involved rated them as less acceptable than either their parents or the staff.

An exception to the above trend is seen in the study by Caradoc-Davies, Dixon and Campbell (1989). They examined differences between patient/carer and staff perceptions of the benefits of rehabilitation with elderly patients and there was a significant difference between the two perspectives with patients/carers perceiving less benefit than staff.

1.6.2. Different Criteria for Judging Services, Needs or Outcomes

Mayer and Rosenblatt (1975) compared factors perceived as contributing to their improvement by a group of psychiatric patients and the staff caring for them. Patients saw the five suggested factors (food, sleep, medication, keeping busy, talking about problems) as of approximately equal importance. Staff perceived talking about problems and medication as vastly more important than the other factors.

Spivak, St Clair, Siegel and Platt (1975) conducted workshops for professionals, advocates and funders of services in the mental health and mental retardation fields to determine what each group saw as important in evaluating services. Staff were predominantly interested in symptom changes and efficient administration, while advocates saw community involvement and quality of consultation and education as most important. The authors conclude that what is judged as important in services ".....depends on the vantage point or mission of the person....." (p 1299).

Marcenko, Herman and Hazel (1992) determined what criteria were important, to family members and staff, for judging family support programs for families with a disabled member.
Several significant differences were found with staff generally ranking attitudes of workers as most important, whereas family members were more concerned with qualifications of staff.

Caradoc-Davies, Dixon and Campbell (1989) identified little overlap between patients/carers and staff in terms of their reasons for judging the benefits of rehabilitation for elderly patients. The authors comment: "(i)t has been suggested that patients place more emphasis on social and psychological factors, whereas physicians place more emphasis on functional ability. The data presented here support such a notion" (p 27).

This theme is reinforced by Goering et al. (1992), who comment on the different criteria used by patients and staff to evaluate the success of a supportive housing program for patients with serious mental illnesses, with"......the staff orientation focusing more on instrumental skills development, while residents may attach more weight to the expressive, to emotional support and relationships" (p 117).

Simpson (1988) identified several significant differences between parents' use of or request for services and teachers' perceptions of needs of the same parents. These differences were in several areas, including advocacy training and counselling. Teachers also generally perceived parents' needs to exceed what the parents themselves requested or used.

Price, Forrester, Murphy and Monaghan (1991) discuss several studies that identify different need perceptions of family members and professionals in the critical care area. Staff consistently underestimated needs of family members and were frequently wrong in estimating the extent to which people felt their needs were being met.

1.6.3 Philosophical Differences Relating to Disability Services

A further aspect of different perspectives is illustrated in a study by Smith and Sykes (1981), where the parents of disabled school leavers were interviewed. Smith and Sykes found that
many parents represent disabling rather than enabling agents, as they restrict independence" (p 25). Thus, these parents are acting in opposition to disability services providers, all of whom would perceive fostering independence as one of their primary goals.

Klein, Gilman and Zigler (1993) report on a study comparing the views of parents (whose children had competed) and experts regarding the Special Olympics. Questions were asked about the program's perceived strengths, weaknesses and goals. Whilst both groups were generally positive in their views, there were clear differences between them. Parents focused on improvements in their own and their child's quality of life as a result of participation in the Special Olympics. The experts were more concerned with the program as a means of implementing theoretical constructs such as integration and normalisation.

Discrepancies between parent and staff/service provider views on the philosophical concept of normalisation are often reported. Normalisation can be defined as "making available to all persons with disabilities patterns of life and conditions of everyday living which are as close as possible or indeed the same as the regular circumstances and ways of life of society" (Nirje 1985, p 66). From the late 1960s to the early 1990s normalisation was the guiding philosophy underlying all developmental disability service provision throughout the Western world (Shaddock & Zilber 1991). There is substantial evidence though, that many parents maintain serious doubts about its applicability to their children.

Suezle and Keenan (1981) report that as children become older and their development more clearly deviates from the average, parents become "more resistant to the application of the normalisation concept" (p 273) and plan for more protected environments for their children.

Components of a normalised life-style were also considered by McDonnell et al. (1985) in a study identifying parents' perceptions of the post-school needs of their disabled children. "Factors that many professionals would consider critical outcomes of residential services -
autonomy and independence, participation in community leisure activities and contact with non-handicapped peers - were not ranked highly" (pp 64-5).

In 1989, Rowitz predicted that in the 1990s "(p)arents will continue to pursue residential placements for their offspring, while service providers and policymakers will continue to push for community placements" (p vi).

1.6.4. Relevance to The Present Study

This study employs both family members (predominantly parents) and staff as client representatives to express views on services that the consumers are themselves unable to formulate or express. Whilst data from both sources is dealt with collectively, it is also important in the light of the above evidence to, at times, separate information from each source and identify differences.
CHAPTER 2

METHODOLOGY

2.1 Research outline

This project identified all people in the Illawarra area who had previously been classified as having a severe or profound intellectual disability. These potential participants were contacted and asked to participate in the study. Ethics Approval was obtained from the University of Wollongong Human Experimentation Ethics Committee (Application HE 91/69).

A structured and semi-structured interview was conducted with each participant or a representative (family, care-giver or advocate) to obtain information on services used, level of satisfaction with these services, sources of satisfaction and dissatisfaction and perceived deficits in services. Qualitative and quantitative analysis were conducted on this data.

2.2 Participants in the study

The target group consisted of children and adults who had been previously classified as severely or profoundly intellectually disabled. These people were residing in the Illawarra area at the time of the study or were living outside the region but had their families residing in the area. A total of 254 possible participants was identified from the Developmental Disability Service data base, special education facilities and local media. Of these, 73 were children (5-16 years) and 181 were adults. Children under five years were excluded because of the difficulties of accurately assessing children of this age.

All possible participants were contacted, by letter, and invited to participate in the study. This correspondence was addressed to family members because of the nature and severity of the disability involved. Families who indicated that they were willing to participate were then
contacted by phone (or a second letter if they did not have a phone) and the details of their participation discussed. The voluntary nature of participation and the capacity to withdraw from the study at any time were emphasised to all family members.

During this initial phone contact it was determined whether a family member or staff representative would be interviewed for the client. Where possible, a family member was preferred. However, if family members were unwilling to undertake this role or had little contact with the client and were unable to provide the relevant information, a suitable staff member was sought. This staff member was the direct care-giver who knew the client best and was often the client's Case Manager. No staff member responded for more than one client.

A total of 147 (58%) agreed to participate and subsequently completed components of the project. Of the 147 participants, 41 were children and 106 were adults. The remaining 75 possible adult participants either declined to participate, were unable to be contacted, were deceased or had moved from the area. No information was available from the childrens' services regarding reasons for non-participation of 32 children.

A diagrammatical representation of those participating and the various non-participating groups for the adult population is shown in Figure 1.
Figure 1. Percentage participation for the adult population. (12.7% declined; 14.9% could not be contacted; 11.0% no longer lived in the area; 2.8% were deceased; and 58.7% of the initial population participated.)

Not all participants completed each section of the study and thus the number of participants varies slightly throughout the study.

All participants had the purpose of the study explained to them and signed the relevant Consent Form (see Appendix 3).

Data on children and adult participants were considered separately throughout this study, as specialist services for these populations, in the Illawarra, are separated.

2.2.1 Child Participants

Of the child participants, 54% were male and 46% female. A family member (mostly parents) was interviewed for 54% and a staff member for the remaining 46%.

Other relevant data on the 41 children who participated are represented in the Figures below:
Figure 2. Contact of parents with their children. (2.4% never; 31.7% seldom; 65.8% often; & 0% both deceased)

Figure 3. Children's accommodation. (65.8% from large residential; 34.1% from family home; 0% from group homes).
2.2.2 Adult Participants

Of the adult participants 51% were male and 49% female. Family members were interviewed for 67% and staff members for 31%. One client was interviewed and another represented by an advocate.

Other relevant data on the 106 adults who participated are represented in the diagrams below:

![Pie chart showing age ranges for adult population.](image)

Figure 4. Age ranges for adult population. (20.7% 16-20 years; 29.2% 21-25 years; 15.1% 26-30 years; 11.3% 31-35 years; 8.5% 36-40; and 15.1% over the age of 40 years).
Figure 5. Percentages of adults in different types of accommodation. (30.2% living in group homes; 39.6% large residential; and 30.2% family home).

Figure 6. Contact of relatives with adults. (6.6% never; 17.0% seldom; 74.5% often; and 1.9% had both parents deceased).
2.2.3 Representativeness of sample

The sample for this study was taken from the population of the Illawarra area. The Illawarra area has a population of 250,000, from multiple ethnic backgrounds, residing in both rural and urban settings and can be generally seen as representative of the broader Australian community.

2.3 Interview Format

A structured and semi-structured questionnaire was developed to obtain quantitative and qualitative information relating to specialist and generic services used by people with severe and profound intellectual disabilities and their families. Demographic information, service usage, ratings of services and perceived deficits in services were recorded. Participants were further requested to identify, in their own words, the aspects of services that were important to them in allocating ratings (sources of satisfaction and dissatisfaction). Finally, they were given the opportunity to make any additional comments relating to services. This questionnaire is included as Appendix 4.

2.4 Collection of data

The questionnaire was administered by a Research Assistant to each participant or representative (family member, staff member or advocate). The Research Assistant was experienced in working with people with disabilities and their families and was provided with training in interviewing techniques. Interviews were conducted in the participants' places of residence (family members) or work (staff members), were recorded and later transcribed.
2.5 Justification of Methodology

2.5.1 Questionnaire Design and Administration

This study employed a questionnaire designed to elicit both quantitative and qualitative information. Many writers emphasise that the use of both types of question will yield richer and more useful data (Schultz et al. 1992, Abel 1990, Krahn, Eisert & Fifield 1990, Holloway 1989, Larsen et al 1979, Cook 1977).

According to Larsen et al (1979) "(i)t is also useful to solicit qualitative comments to supplement scaled items. In this way it will be possible to achieve useful assessments of client satisfaction........" (p 199).

Narrative questions are described as important by Krahn, Eisert and Fifield (1990) because they allow the respondents to raise issues not covered by the prescribed questions.

Holloway (1989) claims that "(o)ne very real advantage of the interview is the possibility of generating verbatim comments from respondents: these provide much more powerful feedback to the evaluation than statistical summaries" (p 255).

Cook (1977) says that "......the response mode should be considered. Open-ended questions.......provide a rich source of data....... A more popular response format is to scale the degree of 'satisfaction' to any one question. Generally such a scale will consist of successive intervals, or points, along some continuum" (p110).

The need for both quantitative and qualitative measurement techniques specifically for studies in the disability area is emphasised by Schultz et al (1992) who claim that "(t)he merit of a dual approach to measurement becomes apparent, when the complexity of parenting a child with a disability is considered....... " (p 47).
Abel (1990) points out the limitations of quantitative analysis alone in measuring "......complex phenomena that cannot easily be scaled" (p 145).

The questionnaire used in this study did not provide suggestions for sources of satisfaction and dissatisfaction, but asked participants to identify these themselves. This is recommended by Corrigan (1990) who states: "(a)ssessment of consumer satisfaction is also limited by the finite domain of items included in the instrument. Investigators may not have the foresight to sample all components in the treatment milieu of interest to the patient. Several studies have overcome this limitation by asking consumers to generate a list of pleasing and unsatisfying aspects........" (p 154).

The provision of questions to delineate the meaning the client assigns to satisfaction is also suggested by Lebow (1983b).

To minimise reactivity and experimenter bias Lebow (1983b) suggests the following strategies: guaranteeing anonymity, separating data gathering from service delivery and never collecting data through the therapist. This study employed all of these strategies.

Cuthbert (1984) identifies the importance of conducting interviews in a pleasant and non-threatening environment. This point is further reinforced by Bilken and Moseley (1988) who state that "(e)ffective interviews need to occur in situations where the informant feels comfortable" (p 158).

This study interviewed participants either at home (family members) or work (staff), unless the participant indicated another preference. One mother, for example, did not wish to be interviewed at home because of her husband's opposition to talking about their disabled son. She was very clear that she wished to participate in the study and requested that the Research Assistant meet her at a local shopping centre. This request was agreed to.
2.5.2 Use of Families and Staff as Informants

This study, with one exception, interviewed a representative for each consumer of disability services. This is common practice, as identified by Heath et al (1984) who comment on the fact that few consumer evaluation studies utilise intellectually disabled clients themselves as sources of information. They discuss the general belief that ".....these clients are not competent to assess satisfaction with services" (p 124).

There is also a view that families of disabled consumers can legitimately be seen as consumers of disability services in their own right. Such family members typically seek information on services, select services, liaise with services and act as advocates for the disabled person.

2.5.2.1 Use of Representatives Because of Nature of Client Disability

Bilken and Moseley (1988) point out that it is sometimes necessary to use relatives or others as sources of information for intellectually disabled people, who they describe as inarticulate informants. "One strategy to handle language difficulties and communication problems is to use important people in the lives of informants" (p 159).

Sigelman, Budd, Spanhel and Schoenrock (1981) argue that the ability to respond to questions is related to intelligence and the mode of questioning. They claim that verbal interviewing techniques are applicable only to adults with moderate and mild degrees of intellectual disability. Flynn (1985) also discusses the problems related to interviewing this population, both from the literature and his own study and concurs with the views of Sigelman et al. (1981).

Hand and Reid (1989) attempted to interview intellectually disabled people with all levels of disability in their study. Only 8% of those with a severe level and none of those with a profound level of intellectual disability were able to be interviewed.
Heath et al (1984) excluded from their study "......retarded clients whose present functioning was moderate or below" (p 126).

Garber, Brenner and Litwin (1986) identify the presence of major organic impairment as one of the reasons for interviewing family members rather than clients themselves. Such major organic impairment would usually be present in those with severe and profound intellectual disabilities.

el-Guebaly et al (1983) claim that some researchers have argued for corroborative data from relatives or guardians, etc for some groups. They include here "......the mentally retarded, brain damaged patients and the severely mentally ill" (p 25).

For this study, then, it was assumed that people with severe and profound intellectual disabilities would be unable to provide the required information and representatives were used. The one client who was interviewed is a woman with a very severe physical disability who would appear to have been incorrectly classified previously, on the basis of her physical disability.

2.5.2.2 Families As Consumers of Disability Services

Parents are seen as the primary consumers of professional services for disabled children by Krahn, Eisert and Fifield (1990). Breslau and Mortimer (1981) refer to parents as 'proxy patients' and describe their levels of satisfaction with medical services for their disabled children as a measure of patient satisfaction.

Mesibov and La Greca (1981) comment that "(a)nother major issue which influences the professional's contact with the family involves the question of 'Who is the professional's client? Because parents of handicapped children almost always participate in the diagnostic and treatment process and are considerably more verbal than their children, professionals generally respond to the parents as their main clients" (p 159).
Several writers agree that families of mental health service consumers should also be seen as consumers of those services (Holloway 1989, Lebow 1983b, Schulberg 1981). It seems reasonable that these comments could also apply to consumers of disability services.

Schulberg (1981) comments that "(w)hile clients are the focal concern of most administrators and clinicians, it should be recognised that the families of clients....are also......directly or indirectly affected by mental health service delivery patterns" (p 135).

Lebow (1983a) argues that satisfaction with treatment of those intimately involved in the client's life is also worthy of attention. He claims that the client is not the only consumer of mental health treatment and families, even when uninvolved, are strongly affected by the results of treatment.

The argument that families are also consumers of disability services was accepted for this study and the results will be commented on in light of this assumption.
CHAPTER 3

RESULTS - SERVICE UTILISATION AND RATINGS OF SATISFACTION

Results presented in this chapter relate to Questions 10 and 11 of the questionnaire. These questions asked respondents to identify services used by the person with the disability or members of his or her family during the past five (5) years and rate their level of satisfaction with these services on a 7-point Likert scale.

3.1 Interview Procedure and Data Collation

Respondents were read a list of eight categories of services and asked to identify which of these the person with the disability or members of his or her family was currently using, or had used in the last five years. Both specialist disability services and generic services were included. If necessary, respondents were provided with examples from these categories to make clearer what services were covered by each category.

They were then asked to rate how satisfied they were with each service on a 7-point Likert scale, where a rating of 'seven' indicated complete satisfaction and a rating of 'one' indicated complete dissatisfaction. The eight listed categories of services provided to respondents were:

- accommodation
- home care services
- aids and equipment
- counselling and support services
- day placement centres
- information and resource organisations
- health services
- social, recreational and leisure services
These categories were further broken down as necessary into component services when collating the data. For example, the category of 'health services' was separated into hospitals, general practitioners and specialist medical services.

The number and percentage of respondents using each type of service and mean ratings for each type of service were calculated. Responses for children and adults were considered separately and comparisons made between staff responses and family member responses.

3.2 Respondents

All 106 adult participants and 41 child participants completed this part of the study. They have been described in detail in Chapter 2.

3.3 Service Utilisation and Ratings of Services

3.3.1 Children

A total of 13 services was identified by the respondents for children. The most frequently used services were schools, general practitioners and specialist medical services. Advocacy, support groups, information/resource services and home care services were the least used services.

Excluding advocacy where only one respondent indicated that they used the service, the most highly rated services were children's residential services and general practitioners. The lowest rating was given for respite accommodation services. All mean ratings were high and ranged from 5.5 to 7.0. This information is summarised in the following table.
Table 1: Mean rating scores in rank order from most to least satisfied for each service type for children, with % of usage (n = 41)

<table>
<thead>
<tr>
<th>SERVICES</th>
<th>RATING</th>
<th>n*</th>
<th>USAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advocacy Services</td>
<td>7.000</td>
<td>1</td>
<td>2.439%</td>
</tr>
<tr>
<td>Children's Residential Services</td>
<td>6.593</td>
<td>27</td>
<td>65.854%</td>
</tr>
<tr>
<td>General Practitioners</td>
<td>6.568</td>
<td>37</td>
<td>90.244%</td>
</tr>
<tr>
<td>Support Groups</td>
<td>6.500</td>
<td>2</td>
<td>4.878%</td>
</tr>
<tr>
<td>Specialist Medical Services</td>
<td>6.456</td>
<td>36</td>
<td>87.805%</td>
</tr>
<tr>
<td>Schools</td>
<td>6.303</td>
<td>38</td>
<td>92.683%</td>
</tr>
<tr>
<td>Community Support Services</td>
<td>6.203</td>
<td>25</td>
<td>60.976%</td>
</tr>
<tr>
<td>Social/Recreation Services</td>
<td>6.167</td>
<td>12</td>
<td>29.269%</td>
</tr>
<tr>
<td>Information/Resource Services</td>
<td>6.100</td>
<td>5</td>
<td>12.195%</td>
</tr>
<tr>
<td>Equipment Services</td>
<td>5.944</td>
<td>18</td>
<td>43.902%</td>
</tr>
<tr>
<td>Hospitals</td>
<td>5.917</td>
<td>18</td>
<td>43.902%</td>
</tr>
<tr>
<td>Home Care Services</td>
<td>5.667</td>
<td>6</td>
<td>14.634%</td>
</tr>
<tr>
<td>Respite Accommodation Services</td>
<td>5.545</td>
<td>11</td>
<td>26.829%</td>
</tr>
</tbody>
</table>

* n is the number of participants using and rating each service type.

3.3.2 Adults

Respondents for adults identified 16 types of services that they were using or had used in the previous five years. The most used services were general practitioners and specialist medical services and the least used were advocacy and support groups. Highest ratings were given for support groups (though this was only used by 9 respondents), general practitioners and non-government day placement centres. The lowest rating was given to information/resource services.
As with the responses for children, mean ratings were high and ranged from 4.5 to 6.3. Data for adults are summarised in the following table.

**Table 2:** Mean rating scores in rank order from most to least satisfied for each service type for adults, with % of usage (n = 106)

<table>
<thead>
<tr>
<th>SERVICES</th>
<th>RATING</th>
<th>n *</th>
<th>USAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support Groups</td>
<td>6.333</td>
<td>9</td>
<td>8.491%</td>
</tr>
<tr>
<td>General Practitioners</td>
<td>6.292</td>
<td>89</td>
<td>83.962%</td>
</tr>
<tr>
<td>Non-government Day Placement Centres</td>
<td>6.135</td>
<td>50</td>
<td>47.170%</td>
</tr>
<tr>
<td>Home Care Services</td>
<td>6.133</td>
<td>15</td>
<td>14.151%</td>
</tr>
<tr>
<td>Government Day Placement Centres</td>
<td>6.057</td>
<td>53</td>
<td>50.000%</td>
</tr>
<tr>
<td>Hospitals</td>
<td>6.044</td>
<td>34</td>
<td>32.075%</td>
</tr>
<tr>
<td>Schools</td>
<td>6.026</td>
<td>19</td>
<td>17.924%</td>
</tr>
<tr>
<td>Specialist Medical Services</td>
<td>6.015</td>
<td>89</td>
<td>83.962%</td>
</tr>
<tr>
<td>Adult Residential Services</td>
<td>6.004</td>
<td>43</td>
<td>40.566</td>
</tr>
<tr>
<td>Respite Accommodation Services</td>
<td>5.932</td>
<td>44</td>
<td>41.509%</td>
</tr>
<tr>
<td>Social/Recreation Services</td>
<td>5.875</td>
<td>42</td>
<td>39.623%</td>
</tr>
<tr>
<td>Community Support Services</td>
<td>5.750</td>
<td>50</td>
<td>47.170%</td>
</tr>
<tr>
<td>Children's Residential Services</td>
<td>5.625</td>
<td>32</td>
<td>30.189%</td>
</tr>
<tr>
<td>Equipment Services</td>
<td>5.175</td>
<td>25</td>
<td>23.585%</td>
</tr>
<tr>
<td>Advocacy Services</td>
<td>4.889</td>
<td>9</td>
<td>8.491%</td>
</tr>
<tr>
<td>Information/Resource Services</td>
<td>4.471</td>
<td>17</td>
<td>16.038%</td>
</tr>
</tbody>
</table>

* n is the number of participants using and rating each service type.
It is interesting to note that 32 respondents (30%) identified use of children's residential services. The clients here are all adults and yet continue to be accommodated in children's facilities because of a lack of alternative, more appropriate accommodation services.

3.4 Comparison between Ratings of Family Respondents and Staff Respondents

Mean ratings of services by family respondents and staff respondents were compared. It seems reasonable to expect that the differences in perspective of these groups of respondents may be reflected in identifiable differences in ratings.

3.4.1 Children

No significant differences were found in the ratings between family and staff respondents.

3.4.2 Adults

Significant differences between staff and family ratings of services were identified in six types of services. These categories were adult residential services, respite accommodation services, equipment services, non-government day placement centres, hospitals and social/recreation services. In all cases, family respondents rated these services more highly than staff respondents. The following table sets out mean ratings for these services for both respondent groups.
Table 3: Mean ratings of service categories with significant differences between staff respondents and family respondents for adults (n=106)

<table>
<thead>
<tr>
<th>SERVICE</th>
<th>STAFF</th>
<th>n*</th>
<th>RELATIVES</th>
<th>n*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Residential Services</td>
<td>5.478</td>
<td>15</td>
<td>6.308</td>
<td>26</td>
</tr>
<tr>
<td>Respite Accommodation Services</td>
<td>4.111</td>
<td>9</td>
<td>6.400</td>
<td>35</td>
</tr>
<tr>
<td>Equipment Services</td>
<td>4.261</td>
<td>11</td>
<td>5.808</td>
<td>13</td>
</tr>
<tr>
<td>Non-government Placement Centres</td>
<td>5.346</td>
<td>13</td>
<td>6.436</td>
<td>35</td>
</tr>
<tr>
<td>Hospitals</td>
<td>5.125</td>
<td>8</td>
<td>6.300</td>
<td>25</td>
</tr>
<tr>
<td>Social/Recreation Services</td>
<td>5.094</td>
<td>17</td>
<td>6.355</td>
<td>23</td>
</tr>
</tbody>
</table>

* n is the number of participants using and rating each service type.

Significant differences in ratings were determined by the use of unmatched, two-tailed t-tests. T-test results were:

- adult residential services [ t =2.647, df=39, p=0.0117],
- respite accommodation services, [ t =4.500, df=42, p=0.0001],
- equipment services, [ t =2.511, df=22, p=0.0199],
- non-government placement centres, [ t =2.519, df=46, p=0.0153],
- hospitals, [ t =2.281, df=31, p=0.0296],
- social/recreation services, [ t =2.973, df=38, p=0.0051].

There are several possible explanations for differences in ratings between the two groups of respondents. These include different degrees of relevance of specific services to family members and staff, different amounts of contact with services rated, different expectations of services and the different needs of family members as opposed to those of paid members of staff. It is worth noting, however, that these differences did not occur with the respondents for the children in the study and worth considering why these factors did not operate also for these respondents. These issues will be discussed in Chapter 5.
CHAPTER 4

RESULTS - SOURCES OF SATISFACTION/DISSATISFACTION AND PERCEIVED DEFICITS IN SERVICES

Results presented in this Chapter relate to Questions 12, 13 and 14 of the questionnaire. These questions asked respondents to identify what was important to them in rating services they used (sources of satisfaction and dissatisfaction) and whether there were services that they felt they needed but which were not available (perceived deficits).

4.1 Coding of Data

The data were coded using categories emerging from the data. Categories of responses were developed after surveying a sample of the responses obtained. This process was undertaken by two people and agreement reached on appropriate categories. Categories determined were mutually exclusive and as exhaustive as possible.

Coding of responses into specific categories was then undertaken by the same two people. This process was undertaken 'blind', i.e. the second person was not aware of the first person's coding. Where there was a disagreement or uncertainty about the coding of a particular response, a third opinion was sought. Information was also collected on a small number of responses that were of interest, but that did not fit into the determined categories.

4.2 Sources of Satisfaction and Dissatisfaction Identified

Nine specific sources each of satisfaction and dissatisfaction emerged from the data. Four of these, i.e. availability of service, staff expertise, availability of support to the family and the client liking/disliking the service, were sources of both satisfaction and dissatisfaction.
Further issues related to staff were also identified as sources of satisfaction or dissatisfaction, although the specific concerns were different. Lack of staff and negative staff attitudes caused dissatisfaction, whereas staff who were perceived as caring were a source of satisfaction.

Other sources of satisfaction were identified as the provision of information, the service understanding the client, the client's individual needs being met and the client improving after attending the service.

Final sources of dissatisfaction focused on poor quality of service, inappropriateness of service and inconvenient location of service.

Thus, where sources of satisfaction and dissatisfaction diverged, the former were focused on information and client needs and the latter on characteristics of the service.

4.3 Respondents

There were 95 adult participants who completed this part of the study. Of these, 73% were represented by a family member and 27% by a staff member. All those represented by a staff member were living away from the family home, in either a group home or slightly larger residential setting. Of those represented by a family member 44% were living in the family home and the remaining 56% were living in care, again in either a group home or slightly larger residential setting.

For the 40 child participants who completed this part of the study, 45% were represented by a staff member and 55% by a family member. As with the adult participants, all children who were represented by a staff member were living away from home. For children who were represented by a family member 54% were living at home with their families and 46% were in care. All children not living with their families resided in large residential (institutional) settings.
Response patterns for staff, family members where the client lives at home and family members where the client is placed in care (respondent categories) will, at times, be considered separately in the following discussion.

4.4 Overall Sources of Satisfaction and Dissatisfaction

4.4.1 Satisfaction

The most frequently mentioned sources of satisfaction were the individual needs of the client being met (60%) and the caring attitude of staff (53%). The fact that the client liked the service was identified as a source of satisfaction by 26% of respondents and the availability of the service by 24%. Family support, understanding of the client and staff expertise were identified as sources of satisfaction by 15%, 13% and 12% of respondents respectively. Approximately 1% each identified improvement in the client and provision of information as sources of satisfaction.

There was little difference between respondent categories but with an overall tendency for family members to indicate the above sources of satisfaction more frequently than staff. This is consistent with the finding that family members generally rated services more highly than staff and thus, may be more satisfied with services.

It is also open to the interpretation that not all services are as relevant to staff as they are to family members and that it is therefore illogical to expect staff to identify sources of satisfaction as frequently as family members. No staff member, for example, identified client improvement, family support or provision of information as a source of satisfaction. It is reasonable to suggest that the last two of these factors are not relevant to staff.
4.4.2 Dissatisfaction

The most frequently mentioned source of dissatisfaction was the inappropriateness of the service (27%) with poor quality of service being mentioned by 23% of respondents. Lack of expertise of staff, shortage of staff, negative staff attitudes, and lack of availability of service were identified respectively by 19%, 17%, 16% and 14% of respondents. Inconvenient location of service (12%), client disliking the service (8%) and lack of support for the family (6%) were the final sources of dissatisfaction mentioned.

Unlike sources of satisfaction, there were substantial differences between respondent categories for dissatisfaction. For example, 39% of staff identified inappropriateness of service as a source of dissatisfaction. However, only 18% of family respondents with the disabled family member living at home and 28% of those with the family member in care mentioned it. Negative staff attitudes were seen as a source of dissatisfaction by 24% (at home) and 18% (in care) of the family respondents, yet only 7% of staff mentioned this. Similarly, poor quality of service was mentioned by only 7% of staff but 35% (in care) and 26% (at home) of family members.

No consistent reason for the pattern of response based on respondent categories can be identified in relation to sources of dissatisfaction. The issue of relevance would seem to apply at times; as would the notion that staff may be reluctant to criticise an aspect of service delivery that they may perceive as reflecting on themselves.

4.5 Sources of Satisfaction and Dissatisfaction for Different Age Groups

The following discussion contains direct quotes from interviews with respondents. All names have been changed in these quotes to protect clients' and respondents' anonymity.
4.5.1 Children

Two sources of satisfaction were clearly identified as most important by this group of respondents. The individual needs of the client being met and caring staff were mentioned respectively by 61% and 53% of respondents. Staff expertise, parental support and service availability were the next most frequently identified sources of satisfaction at 28%, 21% and 19% respectively. All other sources of satisfaction were mentioned by 11% or less of respondents.

Whilst some different priorities were apparent for family and staff respondents, results were generally consistent across respondent categories. The same two factors (caring staff and child's individual needs being met) were mentioned most frequently as sources of satisfaction by both staff and family members. Between 50% and 71% of respondents in all categories mentioned each of these factors.

The comments of these mothers in relation to their children's needs are typical:

"That Louise is being educated or receiving good quality education and to meet her needs is the most important thing and at a level she is capable of. Part of the quality is the personal care that is given to her, not just as a number but as a person who exists as an individual."

"How they have filled the needs that I have had with Bob and the different situations that have arisen with his disability and how they have met these needs ......"

Comments relating to caring staff included:

"With the hospital and that, the way they treated Susan I think and that they were very good to her down there and nothing was too much of a bother. The same with the dentist......"

"We find them terrific with children with disabilities. The staff are terrific. They are extra helpful and really good as far as making sure our kids are comfortable and secure there."
"The girls (nurses) are really, really caring with him. Just the things you would normally look for from home. The things that you would expect from a parent........just the same as if they were at home with the mother."

No more than 15% of staff identified any other factor as a source of satisfaction. No staff member mentioned family support, client improvement or provision of information as sources of satisfaction. Few family members identified the last two of these factors either. However, 45% (at home) and 20% (in care) of family respondents identified family support as a source of satisfaction. Similarly, far more family respondents than staff identified staff expertise and availability of service. Only 5% of staff mentioned these factors, whereas they were identified by between 20% and 50% of family respondents.

Two mothers, referring to family support made the following comments:

"The support group made you feel as if you were not isolated although the problems were different with each child."

"Early Intervention was good. Some-one used to come around - even though Phillip wasn't doing much at that time. She picked me up a lot and helped me as well as trying to sort of get him to do things."

In terms of availability, one mother commented:

"Well, they are available when we need them. It is not all of the time that you need them, but when you do need them you know that you pick up the phone and ring them and they will be available."

There were also identifiable differences in responses for family members with the client living at home and those where the client was in care. The former group was more concerned with family support, availability of service and staff expertise.

Sources of dissatisfaction varied greatly between respondent groups; average figures will not be given as they are, therefore, somewhat misleading. Forty-two percent of family respondents
with the child living at home identified staff attitudes and poor quality of service as sources of dissatisfaction. They identified all other sources of dissatisfaction 16% or less of the time.

One mother described her interactions with health professionals in the following terms:

"Diane should have been diagnosed at four months and she wasn't diagnosed until 13 months and they didn't listen to me and nor was I all that impressed with the nine months screaming when I was told I was wasting the Sister's time. So that went down like a lead balloon and the paediatrician who we first saw told me I wasn't prepared to accept it. And I said that I came to you once before and you didn't want to know about it and from what I've heard, that is fairly normal."

Another said this:

"They don't tell you what is going on and tell you that you are a lunatic and there is nothing wrong with your child. I just think doctors should be more aware that parents know a bit more probably than what they do and to listen to the parent and not treat them like they are an idiot."

In terms of quality of service, one mother described her experiences of respite care:

"We have had him there sometimes and he has come home with almost the skin rubbed off his chin. It has just been blistered almost, because someone has put him on his tummy and left him there for several hours and he has been struggling and turning and trying to get away. Little things like that really annoy me. Sometimes he has had an infection in his penis and they have never done anything about it."

Forty percent of family respondents with the child in care identified lack of availability of service as a source of dissatisfaction. Similarly, 30% each named inappropriateness of service and inconvenient location of service. Lack of staff was mentioned by 20% of this group of respondents and all other sources of dissatisfaction by 10% or less.

A grandmother described her attempts to access a needed service:

".......she has booked me in to see a sexual assault counsellor but it will take about six weeks and then it would just be one meeting."
One mother commented on what she saw as the increasing inappropriateness of the residential facility where her daughter lived:

"Penny is sort of coming into adulthood and puberty and this type of thing and Cram House was virtually set up for younger children..........and that is probably where the system falls down because we don't have the type of place, even things like bathrooms equipped for older kids or adults."

Some parents also identified inappropriateness of service in relation to the school attended by their son or daughter. One mother said:

"The school is great but then, as I have said, Dennis should be in a normal school......."

Staff only identified four sources of dissatisfaction: lack of staff, expertise of staff, inappropriateness of service and lack of availability of service. All of these factors were named by between 10% and 21% of staff. Typical of staff respondent comments were:

"The only thing with Debbie is that she needs a lot of one-to-one work, which is not available here because we don't have the staff."

"He goes to high school because that is his age but his mental ability is really only four years old......There should be maybe something more specialised."

4.5.2 Adults 40 Years and Under

The same two factors that emerged as predominant from the responses for children, were also identified most frequently as sources of satisfaction with services for adults 40 years of age or less. The service meeting the needs of the client was mentioned by 61% and caring staff by 52% of respondents in this group. The client liking the service and availability of the service were each identified by 26% of this group. All other sources of satisfaction were mentioned by 17% or less of respondents. Availability of information was not mentioned by any respondent and improvement in the client by only 2%. 
One mother is very clear about what is important to her in terms of the services her son receives:

"Care. Not only physically because of him being a diabetic. You know, you only have to be in doubt and they give us a ring and we go over......it means people are caring enough to be concerned about what is happening to him.

Another mother relates her experience of taking her daughter to a medical specialist:

"Now there was always a waiting room full of people and he called out and said hello to Carol. I thought, you care and we went in to see him and he wanted to look at her throat and she would not show him. So he sat back and waited and then she waited and he waited and she opened her mouth then. He was willing to wait."

Responses across respondent categories were fairly consistent, with a small number of exceptions. Fifteen percent of family respondents nominated family support as a source of satisfaction. No staff member mentioned this. Family members with the client living at home identified the service understanding the client as a source of satisfaction far more often (31%) than did either staff (10%) or family members with the client in care (9%). Family members with the client in care mentioned the client liking the service far more frequently (46%) than either staff (30%) or family members with the client living at home (14%).

The mother of two disabled daughters living at home made the following comment in relation to her general practitioner and his level of understanding of her daughters:

"He is great. He understands the girls and that is really good and he treats Kim as an individual. He asks her what is wrong with her, not me and then if he cannot quite work out what she is saying or means, then he asks me. And that is great because she is not just sitting on the chair and ignored "

One father noted:

"The most important thing is that Jill likes it. She likes going there and it upsets her if she doesn't go."
As with the children, sources of dissatisfaction varied greatly across respondent categories. Fifty percent of staff respondents nominated inappropriateness of service as a source of dissatisfaction. All other sources of dissatisfaction were identified by between 5% and 20% of staff respondents, with the exceptions of inconvenient location and client disliking the service which were not mentioned at all.

One staff respondent saw inappropriateness of service in the following terms:

"I think that the service the client receives and how appropriate it is for the individual client as well. So for example, Kylie gets good service from having her accommodation here, but it's not real appropriate because of her mobility or the lack of her mobility. She doesn't have good access in and out of the home."

Another said:

"The reason that I didn't like the wheelchair or the boots was mainly because they were totally inappropriate for him. The boots - they sort of flash at you like, I'm disabled - look at me."

Family respondents with the client in care reported sources of dissatisfaction much more frequently than the other respondent categories. Forty-seven percent of this group nominated poor quality of service, 31% nominated inappropriateness of service, 28% nominated lack of staff and 22% each nominated staff attitudes and inconvenient location of service. All other sources of dissatisfaction were identified by between 12% and 16% of respondents.

One couple commented on what they perceived as the inappropriateness of services in the following way:

"She likes it at the moment but she is 38 years old. I don't think she is going to like this rushing around everywhere as she becomes older and that is the only system they have got."

A father talked about the difficulties involved in visiting his son and the capacity of himself and his wife to continue visiting in the future:
"The fact is that we go from here to Rydalmere and that is a difference of 200 odd kilometres return........by the time we get into Rydalmere, we pick him up at half past one and get him home by about four I guess......We are thinking of the future and say as we get older we may lose........we may not be able to drive due to health reasons or something like that."

Lack of staff was identified by a mother in the following way:

"I know they are short staffed and they could do with more staff but......The staff would like to take them on picnics and that but then when they do go on picnics there is only one staff and the two staff there on the weekend. Sometimes I've gone to the house and there is only one staff there. And if Troy took a fit and some-one else was throwing a tantrum......that is shocking."

When commenting on a particular specialist who had seen her son, one mother said:

"All he was interested in was getting his money and (you were) out the front door. He had no time for retarded.......We made the decision to change because he just had no time for them. I think somehow he felt they just didn't fit into his own social group and he looked down on them."

Family respondents with the client living at home were much more consistent in their responses than either of the above groups. All sources of dissatisfaction were nominated by between 5% and 30% of respondents. Staff expertise (30%), poor quality of service (23%), staff attitudes (19%), inappropriateness of service (19%) and lack of availability of service (19%) were the most frequently mentioned.

In relation to staff expertise, one mother commented:

".......but I do not think they know enough about people with disabilities and it is all trial and error with them."

4.5.3 Adults Over 40 Years

Respondents for this group of clients were very consistent in their views in terms of sources of satisfaction. Fifty-nine percent identified the service meeting the needs of the client as a source
of satisfaction. This was followed by caring staff (44%), the client liking the service (43%),
and availability of the service (32%). The only other factor identified by any respondents in this
group was family support and this was only nominated by family respondents (28%).

One mother discussed the availability of respite care for her daughter in the following terms:

".....it really wears you down. So by the time I get her there I am absolutely
exhausted and I need the break. But I am quite happy for her to go there so far. I think it
is one of the most marvellous things that has been invented - temporary care is just
absolutely marvellous."

In relation to caring staff, one staff respondent commented:

"I find that the neurologist that she attends is wonderful. He treats her like the lady that
she is.......The same with the psychiatrist. He actually addressed her and talked to
her which I found really gratifying."

In terms of differences between respondent categories, staff again identified sources of
satisfaction less frequently than family members. Family members with the client living at
home generally nominated sources of satisfaction more often than family members where the
client was in care. The exception to this was in relation to caring staff.

Consistency of response was not evident in relation to sources of dissatisfaction. All sources
except for lack of availability were mentioned by some respondents, but with great variation
between respondent categories. Because of this, overall percentages here are meaningless and
will not be given.

Staff respondents identified sources of dissatisfaction far more often than family members.
Fifty percent of staff respondents nominated inappropriateness of the service, 33% each
ominated negative staff attitudes and poor quality of the service and 17% each nominated lack
of staff expertise and inconvenient location.
One staff member made the following comment in relation to the attitudes displayed towards a client by her general practitioner:

"Well, a G.P. that examines a client from across the room I don't think is satisfactory. I really should have said definitely not satisfactory. He has actually asked Marion not to attend his surgery - I feel personally slighted......for Marion especially and when he does come and examine Marion, he, as I say, he examines her from across the room and asks the opinion of whoever is available at the time, what is wrong with Marion."

Family members with the client living at home only identified the client disliking the service and lack of family support as sources of dissatisfaction (25% each). Family members with the client in care nominated negative staff attitudes, lack of staff and staff expertise, inappropriateness of service, inconvenient location and poor quality of service in approximately equal numbers (between 10% and 15%). Thus, there was no overlap between the responses of these two respondent categories in terms of identified sources of dissatisfaction.

4.6 Identified Gaps in Services

Respondents identified eight types of services which they believed they needed, either for themselves or the disabled family member, but which were not available. The services they identified were; therapy, retirement accommodation, group homes, activity centres, day care centres, information, transport and family support. The term 'retirement accommodation' is used to describe the perceived need for suitable accommodation for adults with disabilities whose parents are aged or ageing. Thus, the clients themselves in this situation may only be middle-aged and not, strictly speaking, of retirement age as the term is commonly understood. Respondents also nominated greater affordability of existing services and more funding for services generally as being required.
4.6.1 Overall Responses

The most frequently identified additional needed service was group homes (34%). This was followed by information (24%), activity centres (22%), more funding for services (18%), and therapy, retirement accommodation and family support (all 15%). Greater affordability of existing services was nominated by 4% of respondents. Day care centres were identified by 17% of family respondents (no staff) and transport by 10% of family members with the client living at home.

There was considerable consistency of response between respondent categories, with a small number of exceptions. Approximately 20% of family respondents identified retirement accommodation as needed, whereas only 5% of staff respondents named this service.

Similarly, 30% of family respondents identified the need for more information and the corresponding figure for staff respondents was 16%. Family support was also nominated by more family than staff respondents (18% and 7% respectively). These discrepancies are all understandable from the perspective of relevance of these services to people in the different respondent categories.

4.6.2 Identified Gaps in Services for Children

There were great differences between respondent groups in identifying additional services needed for children. A clear majority (63%) of parents claimed that they needed more information; no staff nominated this factor. Similarly, no staff nominated day care centres, retirement accommodation or transport. Twelve percent, 10% and 5% respectively of family members identified each of these factors.

Many parents made very critical comments on the lack of information. Typical of these were:
"There was no communication about his disability and what was wrong with him. There was no information - I didn't know nothing. I just tried to buy books and things to read up on."

"Well the whole thing started off wrong, in so far as no-one explained what it was like to have a child with a disability. It was a total alienation........"

"When you first land home with a disabled child you have no idea, no concept of what is going to happen in the future, no concept of what services are available and virtually until you reach breaking point and go out and start screaming at some-one, you don't find out about them."

The presence of comments relating to accommodation needs for disabled adults with elderly parents was interesting to note in the responses of parents of young children. Some of these parents appear to be thinking about this issue perhaps 20 or 30 years before it may be personally relevant to them. The mother of one child commented:

"I feel for these people who are in their sixties and seventies, they can't cope with retarded kids. It is just not fair on them and we are going to be in the same position too I would say in another 20 years down the track."

Staff responses overall indicated that they perceived less deficits in services than family respondents. The main areas of deficit identified by staff were group homes (39%) and funding (28%). Less than 11% of staff respondents identified deficits in any other area.

In relation to group homes, the following comment is typical of staff responses:

"There does not seem to be anywhere to go once they reach the age of 18, and also even before they are 18. We definitely need a group home or homes....."

In terms of funding, another staff respondent said:

"We need more money, more help badly."

Responses from family members varied according to whether the disabled child was living at home or in care. Those with the child at home perceived greater deficits in therapy services
(25%) and family support (42%) than those with the child in care (10% and 28% respectively). They also saw a greater need for more funding for services (33% and 19%).

Family respondents with the child in care identified the need for more group homes (60%) almost twice as often as family respondents with the child living at home (33%). Whilst this may initially seem illogical, it could well be a function of the complete lack of any accommodation for children with disabilities in the Illawarra area, other than where these children are currently living, i.e. in institutions.

4.6.3 Identified Gaps in Services for Adults 40 Years and Under

Responses for these clients were fairly evenly distributed across areas of perceived deficit and with little variation between respondent categories. Areas of perceived deficit for all respondent categories were group homes (30%), activity centres (26%), information (22%), retirement accommodation (19%), therapy services (18%) and funding (15%).

A mother commented on the lack of activity centres:

"They definitely need more activity centres. They are badly needed because they just do not have the placings. I mean, Allison now, she is home one day a week but maybe she will have to be home two days a week and that is not good."

In relation to group homes, one father, whose son lives in such a facility said:

"I think there should be more group homes and that. Because there are a lot of people with their child at home and I would say that they would be getting on in years and that. I reckon if we did not have Jonathan in a group home we would never be able to control him. They should have more group homes."

Two mothers made the following comments on the lack of retirement accommodation:

"Well the way things are at the moment I think it is disgraceful that there are not more places like Mountview for the older ones. I mean I am one of the lucky ones. They are all ageing parents and some of them are coping with big adults."
"...there is nowhere for them to go when the parents have passed away. That aged accommodation perhaps would be my main concern. Like the respite care is there for now, but what happens when I am no longer around?"

Staff respondents made the following comments in relation to therapy services:

"It would be nice to have an occupational therapist in this service all of the time. There should be one here today......it has been difficult to get hold of them."

"As you know, physios are as rare as hens' teeth in this service. I wouldn't mind a physio having a look at Mark at the moment because he is leaning to one side a lot........It would be great but it is really hard to get a physio to look at him."

No staff respondents identified day care centres, affordability of services or transport as areas of deficit. Four percent of family respondents perceived affordability as an issue, 12% (all with the client living at home) identified transport deficits and 18% reported a need for day care centres. Family support services were nominated as an area of deficit by 17% of family respondents and 5% of staff respondents.

4.6.4 Identified Gaps in Services for Adults Over 40 Years

Staff respondents for this group of clients identified only three areas of deficit in services. Group homes and activity centres were each nominated by 67% of staff respondents and therapy services by 18%. Family respondents with the client living at home identified retirement accommodation (50%), group homes, day care centres and lack of funding (all 25%) as areas of deficit.

The following comment by the mother of a 50 year old man is typical of the views of these older parents on the need for retirement accommodation:

"The only thing that is at the back of our minds is when we are not here. And this is while we are thinking about going into a retirement village. But then again, I suppose that is at the back of all parents' minds, with handicapped children or adults."
One mother noted, in relation to a shortage of group homes:

"I think that we should just be grateful that we have someone to care for her. I know there is a lot of people that cannot get what........you know, cannot get them into the places. The group homes."

Family members with the client in care expressed concerns in more areas but, with the exception of greater affordability of current services (29%), no more than 14% of respondents named any single area. No respondents for these clients identified transport or family support as areas of deficit.

4.7 Additional Respondent Comments

There was a small number of responses that did not fit into the above categories, but are worth noting.

4.7.1 Need for Nurses

Approximately 6% of all respondents (family and staff) identified the need for more nursing staff. Two mothers commented on this in the following ways:

"One change I'm not too sure about is when they opened up they used trained nurses - sisters. They were excellent. Now I do not entirely think it is because they are cheap, but they now employ people who are not nurses........The nurses' training tells you that you are dealing with people who are responsible...."

"The Community Services took over instead of having the nurses and the sisters. That was a big mistake too, I feel, a big mistake. Because they need nursing care as well as the Community Services."

4.7.2 Need for Respite Care Services

A very small number of respondents indicated the need for increased respite care services. The small number of such comments is inconsistent with the common perception that more respite
services are wanted by parents. Family respondents in this study were far more concerned with permanent accommodation places for their disabled children than with more respite services.

Similarly, they were concerned that satisfactory arrangements be made for caring for their children when their own ageing process meant that they were no longer able to do so. Again, however, the emphasis was on permanent, safe places for their children to live.

Significantly, most of the comments related to the need for additional respite care services came from staff members and would seem to indicate that these staff may not understand the priorities of parents in terms of the accommodation needs of their children. This will be discussed further in Chapter 5.

4.7.3 Co-ordination of Services

There was a small number of comments made that related to some aspect of the need for greater co-ordination of services. These included the following:

"There should be a place where every-one can get together and with wheelchairs and things that they use. When you are finished you hand it back in and there is like a shop where you can say 'right I can do with that' or all the different ideas that people have tried to think up things like yourself - it drives you crazy."

"......what I consider would be the ideal situation is from the day dot you realise you have a disabled child, there should be a set co-ordinator of all of these services come to see you at home..."

"I think with the resources that they have, the service does a good job but it would benefit greatly from having a similar policy as say the Royal North Shore where they have people from different fields working together and bringing in a different knowledge to the problem. I haven't seen that same sort of teamwork in Wollongong.....where you have your psychologist not really working in with nurses.....they're not really working in with Sport and Rec. It is just something I noted before at Royal North Shore where there was very much more team work."
4.8 General Comments Relating to Respondents

4.8.1 Reluctance to Criticise Services

During the analysis of the interview data it was also noted that there was a reluctance by some respondents to criticise services. This occurred for 14% of family respondents with the client living at home and for 6% of those with the client placed in care.

These parents tended often to excuse clearly poor services with a range of reasons. One mother, for example, made the following comment about the care her son received whilst in respite care:

"A few times I haven’t been happy with the way he has come home. Like the skin off his toes and pressure sores on his feet and holes in his ears, different things, falling off wedges and having his teeth rammed into his gums, just general things that happen that are accidents - but I think they just probably need more staff."

Similarly, two other mothers were discussing the (different) facilities where their daughters were admitted for respite care:

"......they don’t feed her properly because she doesn’t like that food. But that is not their problem I think."

"......they take very good care of her. They do a lot....I mean she has a lot of those little accidents I suppose. Perhaps they are short staffed. I’m sure that’s not a problem."

Another, when discussing her daughter’s day centre, said:

"I do not know if they could be doing more or whether they are doing as much as possible and I do not like to be critical because I do not know enough about it."

A very small number of staff respondents also indicated an unwillingness to criticise. For example, when asked to explain an average rating given for the school attended by the child on whose behalf that she was responding, one respondent said:

"It is probably unfair, isn't it? I shouldn't, they are probably doing quite a lot for him......"
Another staff respondent started a comment on a service by saying: "I can't be nasty........". Despite the fact that this person clearly had reservations about the service she was evaluating, she then proceeded to make very positive comments on the basis that "he (the client) seems to be very happy".

4.8.2 Lack of Knowledge of Services

Some family respondents demonstrated a general lack of knowledge regarding what the services they used provided for the client. Approximately 10% of family respondents with the client living at home and 22% of those where the client was in care fell into this category. This issue will be discussed in greater detail in Chapter 5.
CHAPTER 5

DISCUSSION

Simpson, in 1988, claimed that "......the needs and concerns of parents of handicapped children......have for the most part been inferred through circuitous means" (p 40). This study has investigated aspects of the concerns of a group of such parents by asking them directly. A total of 147 representatives (mostly parents) of people with severe and profound intellectual disabilities was interviewed to determine:

- what services (both generic and specialist) had been used by the person with the disability and family members during the previous five years,
- how all services used were rated for satisfaction on a 7-point Likert scale,
- sources of satisfaction and dissatisfaction that influenced determination of ratings,
- perceived gaps and deficits in services provided.

The family members who participated in this study were accepted as consumers of services for people with disabilities, along with their children. The value of the input of family members into such services was also accepted, consistent with the view of Whitehead, Deiner and Toccafondi (1990) who conclude that "(i)t is important to listen to families and to value their input" (p 74).

The consumer movement, discussed previously, emphasises the concept of empowerment of consumers through participation and involvement in decision-making. According to Marcenko, Herman and Hazel (1992), "(m)eansful empowerment requires that families be involved at all program levels, from program development and implementation, to evaluation" (p 442). Thus, it is hoped that participation in a study such as this serves to further empower at least some of the family members who take part.
Simpson (1988) states that "...little empirical evidence about those services most needed and sought by parents of handicapped children is available" (p 40). Sands, Kozlewski and Goodwin (1991) claim that "(o)nly a small number of surveys has been conducted on consumer choice and/or satisfaction with service delivery systems for persons with developmental disabilities" (p 298). This study also therefore contributes to the available knowledge in this area.

Zastowny, Roghmann and Hengst (1983) point to the need to study satisfaction with services in special populations, such as low income families, disabled children and the elderly: "(t)he study of special populations allows specific and individual concerns to emerge and modifies the conceptualisation of how satisfaction operates in particular environments and its likely antecedent conditions" (p 297). Clearly, this study deals with a special population and the particular needs and concerns of this population in relation to the services used by its members.

The limitations of this study, comments on the results obtained and the significance and implications of the findings will now be discussed.

5.1 Limitations of the study

This study shares the weaknesses, as well as the strengths, of consumer evaluation research generally (discussed in Chapter 1.2.3). This study, like many others, employed a measuring tool specifically designed for it, rather than one previously devised and tested for adequate psychometric properties. The deficits of such an approach are accepted, but were considered unavoidable.

There is no single accepted tool for measuring consumer satisfaction with any type of health, welfare or community service. Even very large and wide-spread areas of service delivery such as hospital-based medical care have not been able to develop such a tool (Carey & Siebert
1993). A much smaller and less mainstream area of service delivery such as the one involved in this study is arguably a very long way from any such development.

The concept of 'satisfaction' was not explicitly defined in this study, but the notion of it being a "perceptive phenomenon" (Elbeik 1985) was accepted. Similarly, it was accepted that satisfaction with services is a complex concept that involves needs, expectations and actual experiences (Wilkin, Hallam & Doggett 1992).

In the developmental disability field it is also reasonable to hypothesise that satisfaction is partly a product of the availability of any services, irrespective of nature or quality, for parents with often desperate needs for relief from the constant demands and difficulties of caring for a child with a disability. Sands, Kozlewski and Goodwin (1991) refer to this possibility: ".....whatever a service recipient gets is satisfactory since it is better than not getting service" (p 312).

Lack of variability of results is another much cited criticism of consumer evaluation research and this study, like most others, produced high mean ratings of services. However, this study also identified factors that were important to people when rating services (sources of satisfaction and dissatisfaction) and gave respondents the opportunity to identify perceived gaps and deficits in services. Thus, there was not a reliance on a rating scale alone and substantially more meaning could be derived from the data.

Poor response rates are a feature of much consumer evaluation research, with the accompanying risks of biased samples. This study had a response rate of 58% from all identified possible participants. However, if adults who could not be contacted, those no longer living in the area and those who were deceased are excluded the overall response rate is 73.5%. This would almost certainly be higher again if information was available on the reasons for non-participation of 32 possible child participants. Lebow (1983a) identifies an average response rate of 67% for consumer evaluation studies involving at-home interviews. It is
reasonable then to conclude that the response rate for this study was quite good and thus, poor response rate should not be seen as a limitation.

Biased responses, in favour of positive ratings, are also frequently seen as a limitation of consumer evaluation research. It should be assumed that the respondents in this study may have had this tendency. Justice and McBee (1978) make the following comment on this issue: "(i)n any survey, there may be an inclination on the part of clients to express satisfaction because of a hidden fear that if they do not, services will be withdrawn - or in the case of former clients, fear that treatment will be withheld if needed again. This may be true even though assurances are given that all responses will remain anonymous" (p 250).

In light of the suggestion above that parents of disabled children are very vulnerable in terms of needs for services, the possibility that responses may have been biased to the positive may well be a reasonable comment on the present study. However, again, it may be partly negated by the additional qualitative comments obtained from respondents.

5.2 Comments on Results

5.2.1 Service Utilisation

5.2.1.1 Children

Respondents for children identified 13 types of services that were used by the person with the disability or the family. Schools, general practitioners and specialist medical services were the most frequently used services; being used respectively by 93%, 90% and 88% of respondents. No other service was used by more than 66% of participants.

As children under five years were excluded from the study, it would be expected that virtually all children who participated would be attending school. Similarly, it would be expected that
most children would utilise the services of a General Practitioner. The usage of specialist medical services though is considerably higher than in other Australian studies (Foreman & Neilands 1991, Baxter 1987) and there is no obvious reason for this. Perhaps, as suggested by Paul and Beckman-Bell (1981), it is related to local referral practices.

Respite accommodation services were used by 27% of respondents in this study and this is very similar to the 32% utilisation rate reported by Salisbury (1990). These results support Salisbury’s contention that respite care services are not used as much as is often assumed and that a utilisation rate of around 30% is fairly typical.

Other results worthy of comment here are the very low levels of usage of advocacy and support groups. The former was used by only one respondent and the latter by two. Lack of use of advocacy services is probably not surprising for children, but the lack of use of support services is very surprising. Such services do exist in the Illawarra area, but it may be that families are not aware of either their existence or their purpose.

5.2.1.2 Adults

Results for adults were very similar to those for children. Most used services were General Practitioners and specialist medical services (84% each) and least used were advocacy and support groups (8% each). High utilisation of medical services is consistent with the results of Minihan and Dean (1990) and McDonald (1985).

Use of respite services was slightly higher than for children (41%), yet lower than the 65% reported from a similar study by Marcenko, Herman & Hazel (1992).

The other significant finding here is that 32 adults were using children’s residential services. This is not an unexpected finding and would be seen in many areas of NSW, where services for people with disabilities are simply not able to cope with demand. Thus, there is frequently
no available adult accommodation service for many clients when they reach the age of 18 years and it is not uncommon to find adults from 18 to over 30 years in children's services.

5.2.2 Service Ratings

Mean ratings for services for children ranged from 5.5 to 7.0 on a 7-point Likert scale. For adults, the corresponding figures are 4.8 and 6.3. These high ratings are consistent with the results of some other consumer evaluation studies in the disability area (e.g. Foreman & Neilands 1991, Brown & Ringma 1989, Justice & McBee 1978) but inconsistent with the low ratings identified in others (e.g. Gribich & Sykes 1990, McKay & Hensey 1990).

However, it is important to note that other studies that report high ratings for services also virtually always report comments from participants that indicate substantial areas of dissatisfaction with services and this is consistent with the findings of this study.

Results of comparisons of staff ratings with those of family respondents revealed some significant differences between these two groups for adults, but not for children. Family respondents for adults rated adult residential services, respite accommodation services, equipment services, non-government placement centres, hospitals, and social/recreation services significantly more highly than staff respondents.

The tendency for family members to rate services more highly than staff is consistently reported in other consumer evaluation studies (e.g. Kurata et al. 1992, el-Guebaly et al. 1983, Kadzin, French & Sherick 1981). It is generally attributed to the different criteria applied by each of these groups in judging services (Goering et al. 1992, Caradoc-Davies, Dixon & Campbell 1989, Spivack et al. 1975).

It is reasonable to suggest that this is the reason for the differences in results found in this study. Parents of disabled adults, as suggested by other studies (e.g. Goering et al. 1992,
Caradoc-Davies, Dixon & Campbell (1989) are very likely judging services on factors such as social function, psychological and emotional benefits to the parent and quality of personal interactions with staff. These same studies would suggest that staff are more likely to judge services on changes in functional capacities and skill levels of clients.

These differences in criteria by which services are judged may account for differences in ratings for several of the services identified above. Others, specifically social/recreation services and equipment services may simply be of less relevance or importance to staff.

It is difficult to hypothesise why differences between staff and family member ratings of services did not occur for respondents for children. Perhaps the most reasonable explanation is the particular local circumstances in children's disability services. Such services in the Illawarra area have, for several years, been partially dominated by political conflict and considerable division amongst parent groups. These problems do not exist in relation to services for adults.

Services for children in the Illawarra area are also considerably behind those in most other areas of the state in that there are still no community-based accommodation services. All children with disabilities in this area who require either permanent or respite accommodation services are placed in institutional facilities.

Thus, it may be, that despite the overall high ratings for services given by these parents, they were somewhat reduced by these local factors and therefore not significantly higher than staff ratings.

5.2.3 Sources of Satisfaction and Dissatisfaction

Winter and Keith (1988) discuss the problems involved in deriving meaning from the high rates of satisfaction commonly identified in consumer evaluation research. They comment: "Although it might be argued that satisfaction surveys have little utility, given the consistently high levels
of satisfaction reported, there are several benefits from conducting them when separate issues in satisfaction are investigated." (p 136)

This study pursued these 'separate issues in satisfaction' by asking respondents to describe factors that were important to them in determining how they rated services, i.e. sources of satisfaction and dissatisfaction. As Winter and Keith describe it, "a greater depth of information was acquired" (p 137) by this mechanism.

The sources of satisfaction/dissatisfaction identified by the respondents in the present study are very similar to the common service dimensions described by Pascoe and Atkisson (1983). These authors perceive these dimensions as common to most health, welfare and related services. They comprise accessibility, availability, physical environment, information resources, interpersonal quality of client-staff exchanges, technical skills of providers, service relevance and outcome or effectiveness of services.

This study identified nine sources each of satisfaction and dissatisfaction. Four of these, i.e. availability of service, staff expertise, availability of support to the family and the client liking/disliking the service, were sources of both satisfaction and dissatisfaction.

Further issues related to staff were also identified as sources of satisfaction or dissatisfaction, although the specific concerns were different. Lack of staff and negative staff attitudes caused dissatisfaction, whereas staff who were perceived as caring were a source of satisfaction.

Other sources of satisfaction were identified as the provision of information, the service understanding the client, the client's individual needs being met and the client improving after attending the service. Final sources of dissatisfaction focused on poor quality of service, inappropriateness of service and inconvenient location of service.
Relating these sources of satisfaction/dissatisfaction to the common service dimensions of Pascoe and Atkisson (1983), it is easy to identify a high degree of commonality. Availability of service is specifically mentioned as a source of satisfaction, as is the provision of information. Technical skills of service providers correspond to staff expertise, another identified source of satisfaction.

Interpersonal quality of client-staff exchanges can be seen to correspond to client liking/disliking the service, caring staff, support to the family and negative staff attitudes. Inconvenient location of service is a component of both physical environment and accessibility.

Improvement in the client after attending the service can be seen both as a measure of outcome and of effectiveness of service. Service relevance is reflected in the service understanding the client and the client's individual needs being met.

Thus, the respondents in this study have identified sources of satisfaction and dissatisfaction that span the full range of service dimensions, as defined by Pascoe and Atkisson (1983). This breadth of response has implications for service providers in terms of the need to be aware that judgements of consumers about services may incorporate all such dimensions.

5.2.3.1 Comparision of Results of This Study with Results of Previous Studies

Published consumer evaluation studies in the disability field have tended to have a different focus to the present study. They have basically asked (usually) parents to rate their satisfaction with services on a scale in a similar way to the present study then asked respondents to comment on services generally. This in turn, has tended to produce a list of perceived inadequacies, gaps and deficits in services and these will be discussed in the next section.

No studies that asked respondents to identify sources of satisfaction and dissatisfaction that contributed to their ratings of services in the way that the present study did were able to be
located. There is therefore, very little comparison that can be made between this aspect of the present study and previous research.

Probably the most striking factor about the previously published studies is that the information obtained from parents is almost totally focused on the negative. As previously discussed, most of these studies report high mean ratings of satisfaction, yet this appears totally inconsistent with the comments made by the same parents.

The most logical explanation appears to be that whatever factors people perceive as positive about services are not being identified in these studies. It appears that the appropriate question that would elicit this information is simply not being asked. Further, whilst it is reasonable to suggest that people rate services highly partly because of gratitude for the existence of any service, it is not reasonable to suggest that this is the sole reason.

This study identified the most commonly occurring sources of satisfaction as the individual needs of the client being met (60%), the caring attitudes of staff (53%), the client liking the service (26%) and the availability of the service when needed (24%).

Whilst there were some minor differences between the responses of various categories of respondents, the overall tendency was for fairly consistent responses between respondent categories. However, family members generally identified more sources of satisfaction than staff.

The only other study identified as providing relevant data about sources of satisfaction is that of Krahn, Eisert and Fifield (1990). These authors attempted to develop an assessment tool to "measure parental perceptions of service delivery outcomes" (p 763).

This tool was based on the Client Satisfaction Questionnaire developed by Larsen et al. (1979) and identified four factors of significance in determining satisfaction. These were general
satisfaction (which included physical surroundings, quality and quantity of service, staff helpfulness, usefulness of information, outcomes and availability of services), clarity of communication, pre-appointment wait and information, and efficiency. These factors accounted for 34%, 8%, 6% and 5% of the variance respectively.

Whilst many of the factors identified by Krahn, Eisert and Fifield (1990) are similar to the sources of satisfaction found in this study, it is not possible to make any further comparison. There are no other published studies that were able to be identified, with which to make meaningful comparisons about sources of satisfaction. Perhaps the most pertinent comment that should be made here is that this is an area where more research is clearly needed.

Consensus on sources of dissatisfaction in the present study was much less apparent than for sources of satisfaction. The most frequently mentioned sources of dissatisfaction were inappropriateness of service (27%), poor quality of service (23%), lack of staff expertise (19%), shortage of staff (17%), negative staff attitudes (16%) and lack of availability of the service (14%).

Again unlike sources of satisfaction, there were considerable differences between respondent categories for sources of dissatisfaction with no obvious single factor able to explain these differences.

Studies by Phan (1994), McKay and Hensey (1990), Hubert (1990), Dittmer and Romans-Clark (1986), Steinberg (1983), Rees (1983) and Waskowitz (1978) also identified negative staff attitudes in some form as an important factor for parents in determining level of dissatisfaction with services.

Parents in the studies by Hubert (1991) and Grbich and Sykes (1990) identified a lack of adequately trained professionals as a source of dissatisfaction. Respondents in Hubert's study also noted staff shortages as an issue.
Again, as with sources of satisfaction it is not possible to make any further comment on similarities or dissimilarities between the findings of this study and previous research. Most data obtained from other studies tends to document gaps and deficits in the actual provision of services, i.e. the lack of availability of needed services, rather than identifying what people may be dissatisfied with about services that they or their disabled family member are actually using.

5.2.4 Perceived Deficits and Gaps in Services

There was substantial agreement amongst respondents in all categories that services are deficient in number and type, and are generally unable to meet the needs of the client population and their families.

Eight specific types of services were named as being needed but not available in sufficient numbers. These are therapy, retirement accommodation, group homes, activity centres, day care centres, information, transport and family support. It should be noted again that the term 'retirement accommodation' is used to describe the need for suitable accommodation for disabled adults with aged or ageing parents. Greater affordability of existing services and more funding generally were also seen as needed.

The most frequently identified of these services were group homes (34%), information (24%), activity centres (22%) and more funding for services (18%). Therapy services, retirement accommodation and family support services were each nominated by 15% of respondents.

There was considerable consistency of response between respondent categories, with some important exceptions in relation to retirement accommodation, provision of information and family support services.

Some specific aspects of the deficits identified by respondents will now be discussed.
5.2.4.1 Permanent/Respite Accommodation

Many previous consumer evaluation studies in the disability area have identified deficits in the provision of permanent and/or respite accommodation services (e.g. Sands, Kozleski & Goodwin 1991, Castellani et al 1986, Janicki & MacEachron 1984, Suelzle & Keenan 1981).

The particular concern of the family respondents in this study was for more permanent group home placements. Parents were concerned with safe, long-term living arrangements for their children and nominated the current favoured model, i.e. the community group home. As this model is heavily promoted by the NSW Department of Community Services as the most appropriate and parents given little information on other possible models, it is reasonable that they would nominate this.

There are extensive waiting lists for permanent accommodation and generally many applications for places that become available. The general perception in relation to these places is that families have to be absolutely 'desperate' and 'in crisis' to obtain one.

Many parents of children living in the area's institutions are also understandably anxious that their children be moved to more appropriate accommodation. Again, it is reasonable to expect that these parents would nominate more group homes as needed and 60% of those interviewed for this study did so.

Staff members are also very aware of deficits in the availability of permanent accommodation for people with disabilities. Again, like parents, they have been provided with little information on other possible accommodation models and it is not surprising that they named this model.

Very few parents identified the need for more respite services. However, some staff saw this as needed. The explanation for this would seem to lie in the differing philosophical perspectives, discussed in Chapter 1.6.3. Rowitz, in 1989, predicted that parents in the 1990s would
continue to seek permanent residential placement for their disabled children, whilst policy makers would continue to promote concepts such as normalisation and community integration.

This study tends to support Rowitz's prediction. Parents interviewed for this study were still very much seeking permanent accommodation for their children (albeit in this case, in community-based services) whilst staff remain convinced that people with disabilities can and should live in the family home, with adequate support services such as respite care.

Overall, the message in relation to accommodation (particularly permanent accommodation) for people with disabilities from the respondents in this study is clear; there is simply not enough.

5.2.4.2 Retirement Accommodation

Informal conversations with parents of both children and adults with disabilities frequently reveal a great deal of concern and anxiety about the long-term futures of the disabled people involved. Parents are worried about what will happen to their child when they die or are no longer able to provide the care that the disabled child requires.

They verbalise their concerns about where their child will live and the long-term security of any such placement. They worry that this responsibility will simply fall to other family members, such as siblings of the disabled child, and that they may not be able or willing to undertake it. It is not unusual for parents to express the hope that their disabled child pre-deceases them, so that their future care is not an issue and the parent feels that he or she can die 'in peace'.

The findings of this study support these observations and indicate a great deal of concern on the part of parents about their children's prospects for the future. This concern was expressed by parents of all ages and with their children living at home and in care. Overall, 20% of family respondents indicated that retirement accommodation was needed and that this issue was not being adequately addressed.
Some 10% of the family respondents for children, 19% of family respondents for adults 40 years and under and 50% of family respondents for adults over 40 years identified lack of retirement accommodation as of concern to them. Clearly these percentages increased with the age of the child, but nevertheless indicate a source of concern for many parents throughout the life-span of their child.

Only 5% of staff named adequate retirement accommodation as a gap in existing services. Again, it is reasonable to see this difference between staff and family responses as a manifestation of different needs and priorities. However, it is probably also reasonable to question whether many staff have a great deal of understanding of the needs and concerns of families or if they are able to see families' perspectives.

Family respondent comments on this issue are encapsulated in this comment by one mother in relation to her disabled daughter: "I really wish, although it's selfish, that she would die before me. Then I would not have to worry about......her quality of life deteriorating......And I think that is what most of the mothers want because they are all getting old. Some of them are 80, I'm 68 and not getting any younger. So where are our kids going"?

Surprisingly also, few other studies have identified this deficit in services. Seltzer (1988) found large numbers of aged and ageing people with disabilities who required additional services or who were on waiting lists to access services. It is reasonable to assume that at least some of these people required accommodation and basic care services that their families were no longer able to provide.

5.2.4.3 Information

The provision of information was another aspect of service delivery that was very clearly indicated by respondents as being inadequate. A total of 30% of family respondents nominated
it, as did 16% of staff respondents. However, there was great variation between categories of respondents in relation to this issue.

A large majority (63%) of family respondents for children identified inadequacies in the provision of information. In complete contrast to this, no staff respondents for children mentioned it. For adults 40 years and under, 22% overall of respondents identified this deficit, with some difference between staff and family respondents; approximately 30% of staff and 20% of family respondents. For adults over 40 years, only 6% of family respondents and no staff respondents named this deficit.

Many previous researchers (e.g. Williams & Calnan 1991, Brown & Ringma 1989, Shields, Morrison & Hart 1988, Baxter 1987, McDonnell et al. 1985, Coffman 1983, Holden & Levine 1982) have identified lack of appropriate information as a deficit of service delivery systems, both within the disability area and a range of other health and related services.

Inadequate provision of information has been identified by respondents in consumer evaluation studies for over 30 years. It was reported in both the earliest (Barclay et al. 1962-3) and most recent (Phan 1994) disability consumer evaluation studies reviewed in Chapter 1.4 and appears consistently in studies over the whole intervening time period.

Despite this evidence of perceived inadequacy by consumers, there would be little dispute with the comment of Mesibov and La Greca (1981) who refer to "......parents' rights to have all available information about their child presented to them as clearly and directly as possible" (p 169). To this, it could be added that parents have a right to information about services and resources available to them.

Also pertinent to this issue are the comments of Caradoc-Davies, Dixon and Campbell (1989) that "(t)here is a very poor correlation between the patient and health team perception of
education. The health team frequently felt that patients had been fully informed, while the patients felt only partly informed" (p 27).

Thus, it may be that service providers feel that they have provided full information to family members, yet those same family members do not feel adequately informed or perhaps do not understand the information that they have been given.

Sometimes, too, it seems that the simplest strategies are not being employed. One mother in this study made the comment that she thought it ".......would be good to have a directory of all the services that are available ......". On being informed by the interviewer that such a document was in fact available from the local council, she responded: "(o)h isn't that wonderful, you do have one". This woman's son was 23 years old at the time of the interview and the directory of services from the council had been available for many years.

It is difficult to hypothesise why such disproportionate numbers of family respondents for children indicated inadequacy in the provision of information and there is nothing in the literature to suggest why this finding might have occurred.

It does seem reasonable to expect that parents of children may have a greater need for information about their child's disability than parents of adults. It is also perhaps reasonable to suggest that they are more insecure in their role as parents of children with disabilities and thus seek more information on the fulfilling of this role. Similarly, they would be less familiar with service delivery systems and may need more information in how to negotiate these systems. However, the figure in this study still seems extreme and may again indicate the presence of the difficulties in children's disability services in the Illawarra area, referred to above.

The general issue though of perceived inadequacies in the provision of information to consumers of disability services is clearly a long-standing and widespread problem. It appears common to a range of service types, for a variety of consumers and over a long period of time.
The present study merely adds to the already considerable weight of evidence that this is a substantial problem. The challenge for service providers lies in finding innovative solutions that will give consumers and their families the information to which they are entitled in a meaningful, organised and positive way.

5.2.4.4 Other Aspects of Service Delivery

Provision of activity centres was identified by 22% of respondents as inadequate. Most of these responses were for adults 40 years and under. This is not an unexpected finding and supports previous findings (e.g. Grbich & Sykes 1990, Black, Molaison & Smull 1990). Clients with severe and profound levels of intellectual disability in NSW often have difficulty in finding suitable day placements once they are past school age and this is only one aspect of a broader issue of inadequate support services generally for families of these clients.

Inadequacies in the provision of other types of day placement services, lack of family support services, transport deficiencies and lack of therapy services were all identified as problems in the present study. Grbich & Sykes (1990) make the general point that more support services are required if the strains on families are to be lessened. These support services include all the types of services identified here as inadequate in some way. Similar points relating to the need for adequate and appropriate support services are made by Caserta et al. (1987) Steinberg (1983) and Suelzle and Keenan (1981).

It is interesting to note that respondents in this study did not specifically identify health care provision as inadequate. This appears inconsistent with the literature reviewed in Chapter 1.5.4.1 where many health services for this population are described as lacking or of poor quality.

It is perhaps relevant that most of the studies discussed in that chapter involved assessment of health needs and adequacy of service provision by professionals, not clients or their
representatives. It is also relevant, in terms of the present study, that many staff working in a
direct care role in disability services (and this includes staff who responded on behalf of clients
in this study) no longer have medical, nursing or paramedical qualifications.

A small number (6%) of respondents in the present study did comment on the lack of nurses
providing direct care to these clients and some were critical of their interactions with medical
staff. However, there was no identifiable theme of perceived inadequacy of health care
provision.

5.3 Important Issues

There are two important issues that should also be taken into account when considering the
results of this study. The first of these is what could be described as the vulnerability of the
client group (including family members). The second is the meaning of the concept of choice
within the context of the relevant service delivery system.

5.3.1 Vulnerability of Client Group

The group of clients and their families being discussed for this study constitute a vulnerable
group for several reasons. The clients themselves have severe and incapacitating disabilities
which make them dependent on others for even basic care. They have few communication skills
and are unable to advocate for themselves in any way.

Their direct family members, particularly parents, are similarly vulnerable. They are severely
emotionally challenged by their children's disabilities and often overwhelmed by the day-to-day
problems of providing care. Long-term planning for their children's futures often generates
enormous anxiety and they struggle constantly to find suitable and adequate services. They tend
to be heavily reliant on services and thus very much 'at the mercy' of service providers.
The vulnerability of this client group is a pertinent factor in considering the high ratings for services given by respondents in this study. Many writers (e.g. Sands, Kozleski & Goodwin 1991, el-Guebaly et al. 1983, Justice & McBee 1978) suggest that high ratings in consumer evaluation research may be partly due to fear that services will be withdrawn or not available in the future if criticisms are made.

Approximately 9% of family respondents in the present study were clearly reluctant to criticise services. There may well have been others who did not make their reluctance apparent. In the light of the vulnerability of this client group, it has to be suggested that high ratings were at least partly produced by a fear of loss of desperately needed services if too much criticism was made.

The comment of Sands, Kozleski and Goodwin (1991) is also pertinent to this issue: ".......it could be interpreted that the degree of satisfaction is linked to participants who may have been enculturated by a service delivery system that has the potential to create a sense of dependency and compliance" (p 312).

Thus, these authors are indicating that clients of disability services (and arguably many other service delivery systems) are at risk of being made dependent and compliant by the services they use. These people are then going to be very unlikely to criticise the services they receive. Brown and Ringma (1989) also discuss the sense of inadequacy that many clients in their study expressed in terms of making decisions and choices for themselves. Like Sands, Kozleski and Goodwin (1991) they are suggesting that the service system tends to foster dependency.

5.3.2 The Concept of Choice

Implicit in any discussion of issues relating to utilisation of services and how consumers perceive the services they use is the concept of choice. That is, it is assumed that consumers
collect information on available services and then make informed judgments about which of the available services would best meet their needs.

The results of this study though and much previous research indicate that this is not the process that occurs. As Sands, Kozleski and Goodwin (1991) describe it, the "(r)eality for consumers of developmental disabilities systems is that they may more closely resemble a world of restricted 'love-it-or-leave-it' options that offer little individualisation" (p 298).

Brown and Ringma (1989) express a similar view and state that "......consumers exercise limited choice in a narrow field of available service options" (p 43). Some consumers in the Brown and Ringma study clearly indicated that they only used some of the services that they did because there was nothing else available.

Some respondents in the present study were also able to articulate the problem of lack of choice. One mother said: ".....the child would have to battle on with whatever services they do provide, whether they were the right ones or not. .........we haven't got a full choice, or much choice at all". A father commented: ".....there is something wrong with the morale at that centre but because we need a break we really are thrust into circumstances where we are sending our child along to a situation where we are not totally satisfied".

Thus, the concept of choice within the context of the current service delivery system seems fairly meaningless. Consumers largely use the services that they do because they have a desperate need for services to support them in caring for a family member with a disability and will use, and often be grateful for, anything that is available.

5.4 Significance and Implications of Findings

This study has added weight to the many previous studies that have identified that disability service consumers and their families generally report a fragmented and inadequate service
delivery system that does not adequately meet their needs. Sands, Kozleski and Goodwin (1991) refer "...to the failure of local, state and federal governments to provide sufficient or appropriate resources and support to persons with disabilities and their families" (p 297).

These findings remain dominant despite the high numerical ratings for services generally given by these consumers. High numerical ratings are common to most consumer evaluation research and occur for a range of reasons. In disability service areas they occur at least partly because a very desperate and vulnerable group of consumers is reluctant to criticise any available services for fear of losing even that.

This study has again demonstrated the value of obtaining and analysing qualitative data, i.e. comments from consumers or their representatives. Carstairs (n.d., cited in Locker & Dunt 1978) suggested that the volume of critical comment given by respondents is a more realistic guide to client or patient opinion than general expressions of satisfaction (e.g. ratings). This comment still appears valid.

The results of this study also showed that people judged services on a wide range of aspects of those services. Sources of satisfaction and dissatisfaction were numerous and varied. Similar research on such sources is scarce and this appears to be an area where more research is needed, to better understand the contributing factors to people rating services as they do.

There also appears to be a need for staff and service providers to better understand the perspective of parents rather than merely attempting to impose ideologies and practices on them. This issue was particularly illustrated in this study in relation to accommodation. Parents were seeking permanent placements for their children whilst staff and service providers were promoting the notion of respite care and the child remaining in the family home.

The widespread reporting of inadequate provision of information occurred in this study, as it has in numerous previous ones. This problem appears to be one of the most reported, longstanding
and intransigent of those identified. There would appear to be an urgent need for service
providers to address this issue.

5.5 A Concluding Comment

Developed Western societies, such as Australia, tend to pride themselves on how they treat the
most devalued and disadvantaged of their members. Indeed, it is often commented that all
societies will ultimately be judged by their willingness and capacity to deal humanely and fairly
with such members.

People with severe disabilities, such as those who participated in this study, belong to the
devalued and disadvantaged section of Australian society. The results of this and similar
previous studies indicate that whilst considerable progress has been made in recent times
towards the goal of equal and appropriate treatment of such people, there is still a great deal of
progress that needs to be made.


Flynn, M. C. 1985, 'Adults who are mentally handicapped: issues and guidelines for interviewing', Journal of Mental Deficiency Research, 30, pp. 369-77.


Ware, J. E. 1978, 'Effects of acquiescent response set on patient satisfaction ratings', Medical Care, 16 (327), pp. 649-53.


APPENDIX 1
DEFINITION OF DEVELOPMENTAL DISABILITY

The term "developmental disability" means a severe chronic disability which:

a) is attributable to an intellectual or physical impairment or combination of intellectual and physical impairments,
b) is manifested before the person attains age 18,
c) is likely to continue indefinitely,
d) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency,
e) reflects the person's need for a combination and sequence of special inter-disciplinary or generic care, treatment or other services which are of life-long or extended duration and are individually planned and co-ordinated.

For practical purposes this includes persons with intellectual handicap, severe epilepsy, cerebral palsy, brain damage acquired in childhood and those with other neurological disorders needing similar provision.

NSW Department of Health 1985
**APPENDIX 2**

**CATEGORIES OF INTELLECTUAL DISABILITY**

<table>
<thead>
<tr>
<th>Category</th>
<th>IQ Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild intellectual disability</td>
<td>IQ 52-67</td>
</tr>
<tr>
<td>Moderate intellectual disability</td>
<td>IQ 36-51</td>
</tr>
<tr>
<td>Severe intellectual disability</td>
<td>IQ 20-35</td>
</tr>
<tr>
<td>Profound intellectual disability</td>
<td>IQ below 20</td>
</tr>
</tbody>
</table>

Gething, 1992
APPENDIX 3

CONSENT FORM

The University of Wollongong
Department of Nursing

Research Project

Service Provision for People with Severe and Profound Intellectual Disability

Researcher: Margaret Gerry

This project is concerned with people with severe and profound intellectual disabilities and with the planning and delivery of services to these people. As part of the project I wish to determine the effectiveness of these services, as perceived by clients, families, care-givers and advocates.

Participants will be required to be individually interviewed and the interview will be recorded.

The information obtained will be confidential and no individual participant will be identified. If you are willing to participate in this research, will you please sign the Consent Form below.

CONSENT FORM

I am aware of the purposes of this interview and give my consent for the data to be used by the researcher listed above.

I understand that strict confidentiality will be maintained, that I am free to withdraw from the study at any time and that withdrawal from the study will not affect services being provided to me in the future.

Name: ________________________________

Signature: ________________________________ Date: ______

Name: ________________________________

Signature: ________________________________ Date: ______
APPENDIX 4

QUESTIONNAIRE

1) Sex: ( ) Male ( ) Female
2) Age: ( ) Under 25 ( ) 26-35 ( ) 36-45 ( ) Over 45
3) Place of Birth: ( ) Australia ( ) Overseas, specify
4) Parents: ( ) Contact with son/daughter
( ) Parents unknown, specify
( ) Parents deceased, specify
5) Parent's Place of Birth:
(a) Father
( ) Australia
( ) Overseas, specify
(b) Mother
( ) Australia
( ) Overseas, specify
6) Current Marital Status of Parents:
( ) Single ( ) Married ( ) Separated/Divorced ( ) Defacto
7) Number of Children (of parents): ( )
8) Parent's Highest Education Level:
(a) Father
( ) ( ) Primary and/or Part Secondary
( ) ( ) Completed Secondary
( ) ( ) Tertiary (other than university) e.g TAFE, Nursing or Teachers' Certificate, Diploma
( ) ( ) Tertiary (University degree or higher)
(b) Mother
( ) ( ) Primary and/or Part Secondary
( ) ( ) Completed Secondary
( ) ( ) Tertiary (other than university) e.g TAFE, Nursing or Teachers' Certificate, Diploma
( ) ( ) Tertiary (University degree or higher)
9) a) Where does your son/daughter/client currently live? Group home ( )
Institution ( )
Home with parents ( )
b) Where is this place of residence?
10) I have here a list of services that people with disabilities and their families use. I'll read out the general service areas to you and if you could just tell me which services, if any, you or your son/daughter/client have used in the past five years from these areas.

**SERVICE AREAS.**

* Accommodation, e.g. Adult Developmental Disabilities Residential Service; Baringa; respite care services; Cram House.
* Home Care Services, e.g. help with housekeeping, general repairs and personal care.
* Aids and Equipment, e.g. Homeleigh, Wollongong Community Rehabilitation Centre. (Equipment loan service).
* Counselling and Support Services, e.g. Illawarra Child Development Centre; Illawarra Developmental Disabilities Service; hospitals.
* Day Placement Centres, e.g. Northbeach Activity Centre; Individual Development Centre; schools.
* Information and Resource Organisations, e.g. Citizen Advocacy; Developmental Disabilities Service; Disabled Persons' Trust.
* Health Services, e.g. general practitioners; community health centres; hospitals; specialists; dentists.
* Social, Recreational and Leisure Services, e.g. Riding for the Disabled Association; Parameadows Ex Students' Association; Crossroads; The Coffee Shop; Harmony Group.

11) I've written down the services you mentioned on this sheet. Could you rate these on how satisfied you were with each service.

12) What is it about these services that is important to you when you are rating your satisfaction?

13) Are there any other services or information that you felt you needed for yourself or your son/daughter/client that weren't available?

14) Do you have any other comments you wish to make about services or lack of, for people with developmental disabilities and their families, carers and advocates.
# SERVICE RATINGS

Please rate these services by circling your most appropriate response as to how satisfied you were with each service.

1 = extremely unsatisfied  
4 = average  
7 = extremely satisfied

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