# A Study of Deinstitutionalization of the Moderately, Severely and Profoundly Retarded Populations of the Three Major Institutions in British Columbia

by

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## Abstract

This study assessed the effect of deinstitutionalization on the health status and daily living skills of a population of persons with moderate, severe, and profound mental retardation. The original data were developed for the British Columbia Ministry of Health, six months prior to the closing of Tranquille Hospital in June/July of 1983. These data were used as the basis for comparison of former Tranquille Hospital residents with sample populations of people who were residents of Woodlands School or Glendale Lodge and remained in the institution.

Individuals discharged from Tranquille Hospital into the community were matched with present institutional residents of Woodlands School and Glendale Lodge on the basis of the level of retardation, sex, age, length of stay in an institution, adaptive behaviour score, and psychological function score. The instrument used to measure these variables was the Wilcox Client Data Scale and measures were taken over two periods in time.

The move to the community did not appear to have made a significant difference in the moderately, profoundly and severely retarded subjects moved to the community. On the

other hand, it was shown that the subjects moved to the community had not deteriorated significantly by their experience. The subjects remaining in the institutions were found to have changed generally as much and in the same way as had the subjects who were moved to the community. The move to integrate the Tranquille Hospital population into the community was not as beneficial as deinstitutionalization philosophy would have predicted.

Since the residents remaining in the institutions were shown to be more severely disabled on most of the variables than those subjects moved to the community, recommendations for future research are offered to enhance understanding of the special needs of severe and profound populations.

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## Dedication

My love and deep gratitude to my husband for his patience, encouragement, generosity and support in enabling me to finish this degree, and helping me to keep a sense of perspective and time; to my darlings Lisa and Geoffrey for their loving gifts of humour, love and responsibility which allowed me to lay aside the demands of motherhood at times and be a student, for teaching me their understanding of confidence and for keeping me real.

## I. Introduction

This study is part of an ongoing assessment of the effect of deinstitutionalization on subjects in the moderate, severe and profound range of retardation. It compares the past and present health, psychological status and living skills of a deinstitutionalized group of adults with those of a group of matched subjects of still-institutionalized residents. The subjects are the entire institutional population in a provincial service jurisdiction at the beginning of the major deinstitutionalization effort in British Columbia. The study had seven original objectives, the first four of which will be examined in this paper. The objectives were to:

1. examine change over time in adaptive behaviour (including personal and social) and psychological function of persons transferred from an institution with that of matched individuals who had remained in an institution;

2. assess the change over time in the number and type of medications taken;

3. analyze the current and projected need for, and receipt of professional care services;

4. determine the differential change in the incidence of extraordinary pathology;

5. examine and compare the concurrent validity of the adaptive behaviour scale of the study's assessment tool with that of the Revised Vineland Adaptive Behaviour Scale;

6. present an exploratory analysis of the social/physical/ attitudinal characteristics of community homes and care givers supervising deinstitutionalized individuals; and

7. propose a new model for describing moderately, severely and profoundly retarded individuals.

Since the early '70's, there has been an effort throughout North America to reduce the population of institutions for the mentally retarded, and to encourage the development of independent living. The goal of reduced institutional populations has been achieved variously throughout North America by decreased admissions and concerted efforts to develop individual community placements. In some cases, change has been rapid, often spurred by litigation in the United States. A report on the closure of U.S. state institutions for the retarded since 1970 noted that almost three-quarters of the 24 closures

had taken place since 1982 (Braddock and Heller, 1985). Rarely had the closures been evaluated by responsible state agencies. Institutional residency fell from a peak in the mid '60's to a low in the early '80's, paralleled by an equal but opposite trend in the number of community facilities and residents (Bruininks, Hauber and Kudla, 1980; Emerson, 1985).

Earlier, Braddock (1981) indicated that the move to deinstitutionalization for the mentally retarded had both started later and proceeded more gradually than it had for the mentally ill. Although the number of institutional admissions dropped in the 1960's and 1970's, the proportion of severely/profoundly handicapped institutional residents grew from 60% in 1964 to 77% in 1979, as the less disabled residents were placed in community settings. Richardson (1984) references data showing institutional facilities to have a population of 75% severely/profoundly retarded compared with community residences that average 66% mildly/moderately retarded. Bruininks, Hauber, and Kudla (1980) reported that the number of community residential facilities for the mentally retarded doubled between 1973 and 1977. While 30% of residents were borderline or mildly retarded only 10% were profoundly retarded. As a result, further depopulation has become more difficult.

## II. Background

In 1981, the government of British Columbia mandated the, then, Ministry of Human Resources (subsequently to be referred to by its new name - Ministry of Social Services and Housing) to close the three provincial institutions for the mentally retarded over the next ten years. The residences were old and would have required extensive and costly renovations and maintenance to meet acceptable standards. At the time, there were 1340 residents in these three major provincial facilities. The Glendale Lodge facility, located in Victoria on the southern tip of Vancouver Island, housed 312 residents. Tranquille Hospital, situated in Kamloops in the interior of the province, totaled 322 residents. Woodlands School, located in New Westminster in the south mainland coastal area, held 704 residents. Initial planning involved the gradual depopulation of all three facilities through community placement of individuals and a policy of restricted admissions. Tranquille Hospital, closing at the end of 1983, allowed little time in one year for the planning or preparation of necessary services in the community. The other two facilities are being gradually depopulated, and currently are slated for closure in 1989 and 1991.

In mid-1983, the author was hired by the Ministry of Health to develop a tool for the assessment of health and psychological status, behavioural function and living skills (Appendix A) and to conduct an assessment of the residents of all levels of retardation then living in the three institutions. In all, 1338 assessments were completed for the Ministry of Health: 704 at Woodlands School, 322 at Tranquille Hospital, and 312 at Glendale Lodge. An additional population of 102 community-based children and adolescents, potentially eligible for placement in extended care facilities, were assessed at the request of the Ministry of Social Services and Housing. The grand total of subjects was 1440. Of these residents, 86% were identified as being severely or profoundly retarded, 12% moderately retarded and 3% in the mildly retarded to normal range. The remaining percentage was unclassified. The goal was to determine the behavioural, personal and social functional levels and health of the residents, the service being received by them in institutional care, and their required health service(s) if and when placed in the community.

In 1986, the author was granted the approval of the Ministries of Health and of Social Services and Housing to conduct a follow-up investigative study (Appendix B1 and B2) upon achieving grant support from the British Columbia Health Care Research Foundation (Appendix C). Informal

support to facilitate the contacts necessary for the study was verbally sought from and extended by the Association of British Columbians for Mentally Handicapped Persons.

Recent literature in retardation both in Canada and the United States has focused primarily on assessing the perceived benefits of community living on individuals with mild retardation only. This group, forming the largest population of retarded persons, has few physical impairments and usually ranks in the lowest socio-economic category (Grossman, 1983). Studies determining the effects of similar community living conditions on persons being moderately, severely and profoundly retarded are comparatively few (Gollay, 1977).

This study focused on subjects in the moderate, severe, and profound range of retardation, which, according to Grossman (1983) form a clinical typology not shared by individuals with mild retardation, demonstrating central nervous system pathology commonly associated with physical concomitants and usually diagnosed from birth. The data developed by the investigator in the 1983 study for the Ministry of Health on these subjects form the baseline for comparison. The correlation between frequency of physical sequelae and lower intelligence is very high, as it is with limitations in self-care ability, competence in expressive or receptive language, mobility, and the capacity for self-

motivation, independence, and economic direction. This relationship was shown to be consistent in the population of this study as shown in the data. The discussion and conclusions as presented address outcome potentials for subjects of moderate, severe and profound levels of retardation only. Reference to individuals in other categories of retardation is deliberately excluded.

The study was originally designed to assess three groups over two points in time:

1. Tranquille Hospital residents (1983) before deinstitutionalization and afterwards (1986);

2. Woodlands School and Glendale Lodge residents who remained in the institutions (1983 and 1986);

3. The extended care eligible children and adolescents in the community (1983) and remaining in the community (1986).

This last population was excluded in 1986 at the request of the Ministry of Social Services and Housing, changing the design to two groups over two points in time. Persons living in Tranquille Hospital in 1983 and moved to community residences are contrasted before and after the move. They are compared with matched subjects resident in Glendale Lodge and/or Woodlands School in 1983 and still

resident there in 1986-1987. The follow-up data are analyzed statistically, and interpreted. The discussion and recommendations offer considerations for future planning of the care of moderately, severely and profoundly retarded individuals.

## III. Historical Perspective

Over many centuries, the care of the mentally retarded has traditionally changed within the context of transient societal values and mores (Zigler and Muenchow, 1979). A brief summary of the selected history presented by Grossman (1983) follows. Mental retardation was described as early as 1500 B.C. in Greek literature. Among the first definitions was that of Hippocrates in 500 B.C. During the Middle Ages, the mentally retarded were variously tolerated as fools in royal courts, persecuted for suspicion of being commanded by evil spirits, sexually abused or tolerated as innocents. During the 16th and 17th centuries in England, there were attempts to differentiate between mental retardation and mental illness. Study of mental retardation by individuals like Fitz-Hubert in 1534, Willis in 1672, John Locke in the 1800's and Pinel in the 19th century lead to progressively more sophisticated definitions reflecting the thinking of the time.

Institutional care began in the early 1800's. Communities for the mentally retarded began in the U.S. after 1850 (Little and Johnson cited by McCarver and Craig, 1974). Prior to that time, the retarded were essentially at the mercy of charity. The initial goals of these institutions were to cure retardation and return these

individuals to community living (Baumeister, 1970) helped by short term training (Gollay, 1977). These ideals turned into a reality of custodial care as it became clear that retardation could not be markedly altered in a short period of time. Having been established, institutions were heavily pressured to expand (Wolfensberger, 1976). There was essentially no education for the disabled prior to the 19th century. Opportunities for placement of the retarded in the community increased during the second world war possibly because of the heightened demand for labour (McCarver and Craig, 1974).

By the beginning of the 20th century, intelligence tests were being developed in France and the U.S. Work on intelligence tests was furthered during World War I, with the early version of the Stanford-Binet being used by 1925. Better description of the retarded population was possible as a result of this operational definition. The introduction of behaviourism to psychology in North America led to an increasingly strong belief that the mentally retarded would respond positively to stimulating programmes (Thompson and Carey, 1980). In recent decades, mental retardation advocacy groups, professionals, parent organizations, and society as a whole struggled with changing perspectives about service structures for the mentally retarded, leading governments to

struggle with related budgetary dilemmas (Bradley, 1976). Community groups applied almost equal pressure in diametrically opposed philosophies urging that the quality of care within institutions be improved or, alternately, to eliminate them entirely. The response of parents and families varied as to their needs. Some desired to care for their family member and lobbied for the support of increased community services. Many preferred their family member to continue in institutional care (Meyer, 1980). Communication between and among the various factions involved in the decision making, advocacy and implementation of care became difficult. The principle of normalization became the keystone of the crusade for deinstitutionalization, springing from the values of the civil rights movement during the sixties.

## IV. A Look at the Issues

### Cause of Depopulation

Although deinstitutionalization of the mentally ill and mentally retarded had been the practice on a small scale since the early 1900's in both Canada and the U.S., Wolfensberger's ideology renewed the effort to place these populations within the community. The impetus for the community transfer of psychiatric patients in the U.S. preceded that of the mentally retarded by approximately 10 years, due to the introduction of antipsychotic medication and to federal legislation then passed. After the breakthrough of psychotropic medication in the '50's, the transfer of many mentally ill persons occurred in the '60's with the shift in public attitude to greater receptivity for minority groups. This move was criticized as being premature and hampered by inadequate community services, exchanging "warehousing" for "community dumping" (Gibson and Field, 1983). Similar concerns of poor community readiness have been expressed by Conroy (1977) who stated that public pressure behind the movement led to rapid and premature deinstitutionalization.

Community placement of the mentally retarded had different initiatives (Braddock, 1981). The relocation of

mentally retarded persons was spurred by litigation over the issue of their right to habilitation (Willer, Scheerenberger, and Intagliata, 1978; Willer and Intagliata, 1982). The number of new admissions to institutional facilities in Canada and the United States has generally decreased, though the number of readmissions has at times increased more rapidly than the number of discharges to community placements (Conroy, 1977). Scheerenberger (1981) stated that 79% of the public residential facilities reported a recidivism rate (excluding returns for respite) of 1.9% of individuals placed in community settings. In comparison, Willer, Scheerenberger, and Intagliata (1978) referenced Willer, Atkinson and Intagliata (1977) as reporting recidivism rates as "7% for community care facilities, 48% for family care, and 36% for natural family placement" (pg. 8). They further referenced Wyngaarden and Gollay (1976) as reporting a reinstitutionalization rate of 10%. Kuhlman (1940) stated that U.S. institutions in 1925 held 50,000 mentally retarded residents (3% of the retarded population). Heal, Sigelman, and Switzky (1978) recorded that the 237 public residences in 1967 held 200,000 inmates.

Scheerenberger (1981) gathered data on the trends and status of public residential facilities in the United States. He found that 278 public residences held 155,902

people in 1978-1979. He reported average daily census, sex, age, level of retardation, level of adaptive behaviours and of physical disorders. He also presented data to reflect the movement of the population, the programmes offered, the amount of family contact, service available, administration budget and cost issues. The population was described as being 56% male, 44% female; 30% under 21 years of age; 77% severely-profoundly retarded; 60% mobile; 56% dressing independently; 74% eating independently; 81% able to understand some language; 59% speech; 86% toilet trained; 25% severely emotionally disabled; 33% with one or more physical handicapping conditions. Comparable national and/or provincial Canadian data were not found. Statistics Canada produced a reference to a "one time only study", Statistics Canada publication #82-555E. Although this publication contained mental retardation data on classification, problems with transportation, disability grouped by income, age and sex, the particulars were scant. Only one other reference of any detail was found (Statistical Supplement 50th Annual Report, 1981). This report contained general detail on facility resident movement and status, days of care, age and sex, diagnosis, admission and discharge by age and diagnosis, and reason for admission. It appears that these data were for residents of facilities under provincial jurisdiction only.

The system for reporting health statistics in Canada relies primarily on voluntary reports from individual facilities which report morbidity and birth rates, admission, discharge and financial detail. Special care facilities report selectively on a diverse number of variables.

Detail in the available literature suggests that the population of Canadian facilities at the beginning of the move to deinstitutionalization tended to involve more severely retarded individuals than that of the United States. It appears that more mildly retarded individuals were either never placed in the institutions initially or the trend to community placement in the period after the Second World War was more extensive. It is reasonable to assume that Canadian institutional populations are now comparable with those in American institutions since the impetus in the 1960's and 70's in the United States to move out the mildly and borderline retarded, though the lack of Canada wide data makes it difficult to be sure.

## Controversy of Ideology

Society is divided in opinion concerning whether the severely and profoundly retarded are best cared for in institutions (Miller, 1978; Felce, Kushlick, and Mansell, 1980). Gollay (1977) presented the dilemma precisely when

she said "Persons of many different perspectives are concerned about the future of the deinstitutionalization movement, some because they are unsure of the abilities of mentally retarded persons ever to succeed outside of a protected environment, others because of questions about the cost benefits of such efforts, and still others because of a fear that a sound concept will be undermined by inadequate planning and poor implementation" (pg. 138). The constitutionality of commitment to institutions and appropriate placement for mentally retarded residents has been argued in many courtrooms, especially in the United States, since the inception of the principle of normalization. As an example, the standards for the care of the mentally retarded set by Partlow School (1971) have been addressed at length by McGee and Menolascino (1981), Ellis (1979), and Roos (1979). Despite the legal judgements generally in support of deinstitutionalization, controversy over what defines the best environment for those with mental retardation persists. As the philosophy supporting deinstitutionalization gained both political and philosophical momentum, controversy about its real value increased.

The ideology of normalization developed from a movement for the rights of minorities to a consumer advocacy for the rights of the retarded (Emerson, 1985). This movement was based on a belief that the mentally

retarded must be exposed to a normal environment in order to have access to a normal life. It can be traced to its origins in Scandinavia where Nirje (1969) described the concept of normalization as a life pattern for the retarded closely approximating that of others in society. The concept evolved from the belief that service for mentally retarded people is less biased and more effective in settings integrated in the community than in segregated institutional facilities (McCord, 1982). Wolfensberger (1970) interpreted normalization to mean that deviant persons should be exposed to experiences that are culturally normative and so are likely to elicit or maintain normative behaviour. The classic definition of normalization was set by Wolfensberger and Menolascino (1970). They defined the term, operationally, to mean that handicapped persons should be presented to society in such a way as to emphasize their similarities rather than their differences; service should be provided in the least restrictive environment; and mentally retarded people should have a right to the same social and physical environments as do normal individuals. Later, Wolfensberger (1983) promoted the use of the term "social role valorization" instead of the phrase "the principle of normalization" because of his concern that few people really understand the true meaning or aim of normalization.

He believed this new phrase more adequately describes the goal of the movement.

Leaders in this philosophy, like Wolfensberger and Scheerenberger, stress the normalizing effects of community living in enhancing the quality of life. Proponents of normalization believe institutions do not adequately serve the mentally handicapped because of excessive drug use, impersonal and physically secluded environments, crowding, failure to provide comprehensive evaluation, developmental programming and follow-up, and lack of sufficient care because of insufficient numbers of qualified staff (Menolascino and McGee, 1981a). They defined deinstitutionalization as "an array of residential, educational, vocational, and leisure time services based on each mentally retarded person's needs" (Menolascino and McGee, 1981b). In a review of the recent literature, McCarver and Craig (1974) defined four issues of concern about institutions:

1. The emotional needs of individuals are not adequately met;
2. essential social training is not available;
3. life in institutions may adversely affect intellectual functioning;
4. institutions are impersonal and regimented.

There often is a sense of urgency implied in the need to organize community placement. Sometimes, as reported by Richardson (1984), "the people in charge felt they could

not delay even long enough to organize the network of community service the new residences would need" (pg.333). Success or failure in placement is frequently practically defined by whether or not an individual returns to an institution. However, another way of defining successful placement would include a measure of the well being of the individuals after placement.

Others oppose this perception of the meaning of community life. These conservatives believe there is a potential lack of a full spectrum of necessary services and companionship with peers in the community and that the concept of deinstitutionalization is over-liberal, too all-encompassing and ideologically biased to serve the best interest of all mentally retarded persons. Individuals with severe and profound retardation may better be served in specialized institutional facilities. The community may prove more restrictive than institutional life because of the lack of opportunities or ability to access resources (Warren, in Hendrix, 1981). Butterfield (1977) perceived the institution to afford more humane treatment for some individuals than a community residence would. Burkhard (1982) proffered a belief that the retarded have the right not to be thrust into an environment they cannot master. Throne (1979) maintained that in uniting against institutions, proponents of community living miss the essential issue: that of determining the kind of facility

that would best serve the needs of the retarded and nonretarded alike. Epstein (1982) referred to Throne as arguing that mentally retarded individuals require more than "normal" techniques of training and care in order to progress. Appropriate placement must be based on realistic planning and include options to live with peers in protected environments if this is preferred for social and emotional reasons (Hendrix, 1981). The Wyatt-Pennhurst case decision reflected a belief that institutional life may actually be the optimal placement for some severely and profoundly retarded persons (Vitello, 1981). Roos (1970) questioned the humanity of allowing retardates freedom to choose an anormal pattern. Conversely he questions the advocate's right to limit the options of choice to protect the retarded from the decision. Emerson (1985) presented a literature review to show that mentally retarded individuals in the community still have selective interactions with the staff and society, are lonely, socialize more frequently with peers than with others, show little independence and are still involved with repetitive, inconsequential activity. Lakin, Bradley, Hill, Hauber, and Bruininks (1983) stated that institutional facilities serve an essential role as a stable environment when community placement fails, as a transition from the natural home to community placement and as an environment for low functioning individuals (although they concede that this

function is in transition). Though the intent of the deinstitutionalization movement is normalization, it is realized more in the theoretical than in the practical sense (Flynn and Nitsch, 1980).

Landesman-Dwyer (1981) stated that the terminology used in discussion around the issues of deinstitutionalization has become value-laden and its ability to discriminate objectively among the various component elements is reduced. Fiorelli (1982) referenced Willer as stating that "normalization will become less popular during the next decade, yielding to concepts such as quality of life" (pg. 14). He further cited Bruininks as predicting an increased need to "institutionalize developmentally disabled individuals based on demographic trends projected for the remainder of this decade" (pg. 14). Conroy (1977) predicted that the move to community based facilities had reached a plateau in many of the United States and that readmissions will either continue or increase at a very high rate. McCarver and Craig (1974) comment that "in view of such careful selection, one might expect that the (retarded) physically handicapped would be as successful, or even more so, than the non-handicapped (retarded), in their community adjustment" (pg. 175). They remark further that "since the problems that these retardates presented in their homes and/or communities were sufficient to result in institutionalization, it seems

likely that returning them to the community would be futile unless the presenting problems were somehow removed" (pg. 152).

The available data suggest that reality lies somewhere between these two stances. Richardson (1984) urged evaluation of individual needs and quoted Nirje's statement that "the application of the normalization principle will not make retarded people normal", saying that "the concept of deinstitutionalization, although poorly defined operationally, has been of great value in provoking widespread activities directed toward changing forms of care for those in institutions" (pg. 362). Epstein (1982) stated that Nirje defines normalization by its means whereas Wolfensberger defined it in terms of its process and goals. Epstein proposed that normalization has as its goal enabling individuals to achieve defined goals rather than to prove a defined philosophy. The first can be measured empirically; the second is purely subjective. Kleinberg and Galligan (1983) presented a review of literature which supported their interpretation that functional ability develops in a continuum whether in the community or in the institution. They found "no behavioural domain in which all investigators found the same change taking place" (pg. 24). They concluded that functional ability was not a newly learned behaviour but one that

would develop if nurtured carefully in whatever environment the individual is placed.

## Cost of Care

Braddock (1981) commented that reasons of simple economy put the success of community placements of the retarded at risk and that the necessary service and supervised care requirements of the mentally retarded will be expensive. He counsels that there is a lack of existing support because of the high cost of successful programming and that the move to community placement may be in jeopardy if federal policy changes because of financial pressure. Fiorelli (1982) referred to the "unprecedented cuts and regression proposed in social and entitlement programs" (pg.14) at the federal level which are reflected at the state level. He viewed these as threatening to eliminate or cut back service programs. These developments in the United States are potentially, if not yet actually, to be paralleled in just as Canadian economic and social tides tend to follow American trends.

Lower costs of care in the community, relative to that of institutional life, are proffered as support for advocating community settings. However, Bensburg and Smith (1984) concluded that comparisons of community group home costs versus institutional costs reflects discrepancies in the interpretation of cost data such as rent versus

purchase or new construction costs, offset revenue, and costs amortized across the average census instead of one high census. Emerson (1985) commented on the negative reaction as the cost of maintaining the institutions increased as the number of residents declined and the proportion of severity intensified leading to higher per client costs. Heal, Sigelman and Switzky (1980) commented that the remaining institutionalized residents require more intensive levels of programming and, presumably, more extensive and expensive levels of programming for the community placement of these more severely disabled individuals. Objective adjudication of the pros and cons of cost issues is blurred by subjective investment in philosophic belief. Lack of clarity as to outcome data on deinstitutionalization still exists. Decisions pertaining to the allocation of funds were torn by pressure from opposing advocacy groups, differing in political, economic and social expectations (Richardson, 1984). Labor unions in British Columbia even campaigned in the media that deinstitutionalization was a threat to employment and had potential economic implications. The belief that community facilities cost less may actually reflect false economics. Such a belief may have risen from discrepancies in data between the projected need for services and the actual availability of resources (Bruininks, Hauber and Kudla, 1980). The problem lies in relating and observable

difference reported in the tax or mill rate, or any part of it, to institutionalization costs. The limited availability of cost data and uniform costing procedures makes interpretation of this issue difficult.

## Problems of Implementation

Though the ideology behind normalization appears ethically sound, its implementation has reportedly been problematic, reflecting as it does the sometimes vague processes of litigation, politics and the crosswinds of pressure by special interest groups. The mean success rate of deinstitutionalization over the years reported by McCarver and Craig (1974) (accepting the distortions inherent in the data due to variability in outcomes, definitions, subject selection, sample sizes and similar variables) shows a peak success rate of 74% during the period of 1935 to 1954, with decreasing success rates over time, falling to about 50% in 1970. They interpreted this peak to be due to the increased demand for labour during the war years and a reduced emphasis on eugenics. Conversely, they considered the decreased success rate to be partially due to the gradual increase in the proportion of more severely retarded individuals in the institutions, making the task of deinstitutionalization more complex. They suggested that the improved quality of recent rehabilitation programs is offset by an increased need for

survival ability created by demands of the greater sophistication in urban society. Seltzer (1984) reported that public attitude is still negative toward community placement of the retarded especially where property values are high and when the community facilities are nearby, though in general public attitude is supportive of deinstitutionalization as a philosophy. Gollay (1977) identified groups of factors relating to successful adjustment in the community and outlines a plan of action which includes:

1. the launching of enough quality resources that return to the institution is an unnecessary alternative;
2. further release of disabled people; and
3. promoting successful depopulation by readying the institution to release client, readying clients to be transferred and preparing the community to receive these people.

Heal, Sigelman and Switzky (1978) observed that the energy committed today to developing community alternatives is matched historically by a commitment in 1899 to finding the ideal institution. There is the same zealous investment of hope and belief invested in future potential but "empirical investigation is lacking" (pg. 214). By comparison, parents of depopulated individuals are seldom directly involved in the decision regarding the deinstitutionalization placement (Miller, Miller and Repp, 1978). They interpreted this to mean that families rescind

their decision-making power and stop monitoring the decision made on behalf of their retarded family member. Lippman (1977) cautioned that the terms normalization, deinstitutionalization and mainstreaming may too easily be only symbolically applied. He fears people may react automatically to the ideological concepts rather than define meaningful change for the individual. Miller, Miller and Repp, (1978) observed the law and reality to be at odds. It was their opinion that mainstreaming reduces opportunities for the least restrictive environment to a reality of the most amicable environment, as a solution to the lack of finances to support improved services. The problem seems to lie in the argument that exposure to cultural norming affords the opportunity for the development or maintainance of normal behaviour but does not define what is normal behaviour, adaptive skill and psychological function for severely and profoundly retarded people.

Shafter (cited by McCarver and Craig, 1974) delineated a model of selection.

Method 1. The merit process selected subjects on the basis of their earned and/or demonstrated ability to graduate through a series of steps toward release;

Method 2. Objective choice candidates are chosen on the basis of rated ability on a defined number of variables considered to be predictive of ability to succeed in the community; and

Method 3. The subjective process combined the other two processes and added unique variables of the specific political, economic and/or social factors influencing a move.

Shafter concludes that the subjective method is applied most frequently. This method appears to have been applied in the deinstitutionalization of Tranquille Hospital. The reported lack of an objective process in selecting subjects for the move introduced the possibility of bias in the selection of subjects for transfer to the community and further for the current study.

Gollay (1976) stated that intelligence should not be a criterion for selecting individuals for transfer to the community, because even the severely retarded will succeed in the community with adequate support. Gollay's assumption that adequate services are available, needs to be examined. "All too often community services conspire to re-enact the very same institutional processes of ensuring the physical and social isolation and stigmatization of handicapped persons, maintaining the degrading asymmetrical power relationships between residents and staff and encouraging dependency and regimentation" (pg. 282, Emerson, 1985). The most commonly reported lack of services are vocational, recreational and mental health (Intagliata, Kraus and Willer, 1980). In reviewing the literature to discover a definition of the characteristics of the ideal community

setting, the variety of available resources reported (or lack of same) was noteworthy. Studies varied on every conceivable factor including the staffing ratio and population density; programme content; philosophy; duration, and number and nature of residents (Schalock, Harper and Genung, 1981; Campbell and Bailey, 1984; Hull and Thompson, 1981; Repp and Barton, 1980; Felce, Kushlick, and Mansell, 1980; Howell and May, 1980; Reuter, Archer, Dunn and White, 1983; Alexander, Huganir and Zigler, 1985). The environmental and service components required for successful placement are defined differently depending on the criterion used to define success (Crawford, Aiello and Thompson, 1979). The "success of placement was seen to depend primarily on the quality of the community support system rather than the characteristics of the individuals themselves" (pg. 243, Heal, Sigelman and Switzky, 1978). In order to determine the characteristics needed for the community setting, many aspects of available services are being examined including: the degree of cultural normativeness, the services and the continuum of care necessary for developmental growth, the required level of service for each level of retardation, an adequate standard of service compared with a necessary level and possible licensing principles, the measure and interpretation of an individual's interaction with the environment. Lack of sufficient care, lack of appropriate services or lack of a

full spectrum of services may effectively damage the potential for the success of community placement. The alternative of institutional life may prove to be better in such cases. The type and level of services are not attitudinally separate from the individual. As a result, it is difficult to identify factors which promote integration and norming standards while addressing the individual's needs.

The phrase "least restrictive environment", arose from a courtroom decision reported by Scheerenberger (1976). It refers to the right of mentally retarded persons to an environment that provides the minimum of supervision and the highest integration possible within a given environment. It is important to remember that the actual statement from the court proceedings defines deinstitutionalization as "the least restrictive environment from which the individual can benefit". These words qualify the concept of least restrictive environment. From this perspective, deinstitutionalization takes on a new meaning in which the individual has the right to be placed in an environment that is restrictive only to the extent that the individual is still able to benefit from that environment. The focus becomes the need to accurately assess the individual's needs, to accurately interpret the assessment, and to determine the services and facilities that best meet these needs. Vitello, Atthowe, Cadwell

(1983) found that criteria for the selection of those to be placed in the community related to intelligence and adaptive behaviour. These variables were used as predictors of function in the community. Individuals with pathological behaviour, or who are considered to be medically fragile were not transferred (DeSilva and Higenbottam, 1981; Intagliata and Willer, 1982). Selection by these factors would bias the process of selection for community placement against the physically disabled and the non-mobile. Such selection may produce, or be further influenced, by a lack of adequate community based services or insufficient transportation to these services (Barnes and Toews, 1983).

Lack of clear guidelines for classifying mentally retarded individuals over the past decade has fed the deinstitutionalization controversy (Heber, 1961; Cronbach, 1975; Adams, 1973; Zigler, Balla, Hodapp, 1984; Barnett, 1986; Hodapp, Zigler, 1986). Although this controversy continues, current policy aimed at the deinstitutionalization of the mentally retarded cannot be entirely rationalized on the basis of well-established, unequivocal, reliable, valid and bias-free research (Baumeister, 1981). While normalization has been adopted in theory, implementation has been difficult (Flynn and Nitsch, 1980).

**Practicalities of Research**

Until the last decade, little systematic research was available that investigated the consequences of community placement of retarded populations in the moderate to profound range of retardation. Research in this field frequently creates two questions from one. Prior to the last decade, there was little evaluative research on the consequences of deinstitutionalization. Bachrach and Lamb (cited in Emerson, 1985) criticized previous attempts at evaluation as biased and leading to misunderstanding. Since the late 1960's, spurred by available financial support and the focus of social conscience, research has attempted to evaluate the effect of political and social initiatives on minority groups.

The very nature of research in this field invites the use of survey and questionnaire methodology with the inherent risk of bias both of the interviewer and from the interviewee as described by Babbie (1973). Much of the available research lacks replication and contains ambiguous results that threaten to weaken the impact of further research into the best placement for the development of mentally retarded persons (Bulmer, 1982). Research in this field is a product of public policy and as such is at risk of being fragmented by the economic, political and social state of society (Baumeister, 1981; Schroeder and

Henes, 1978).

Often the design of research in this field is weak. McCarver and Craig (1974) suggest that many weaknesses of studies in the field of retardation would be improved by a better understanding of basic experimental design. Emerson (1985) recommends that better methodology and design criteria for research in this area be developed. These studies frequently assess only one point in time, have no prelocation data or comparison group, use a nonrepresentative sample, or employ tools of unknown validity or reliability. Such weak design produces results of "poor communicability and accessibility of research data, divergent research process, methodological inadequacies in research design" (pg.279) plus conclusions that too frequently reflect "the inherently political nature of the policy-making process itself" (pg.279, Emerson, 1985). Emerson commented that much work is necessary to increase the effectiveness of research. Time lags between research and policy decisions must be reduced. The empirical data discovered by research must be reflected in future planning. Research must be allowed and must demand the freedom to ask critical questions, create ambiguity, raise controversy, and refine its measures.

Discussion of the beneficial and adverse effects of time spent in an institution seems to be fairly strongly dichotomized. Schroeder and Henes (1978), in a small matched comparison, found significant gains in communication during one year of group-home life when compared to institution residents but the gains in self-help and socialization scores were not significant possibly because the pre-test was conducted up to two years after the initial placement in group homes so that early gains were not noted. Conroy, Efthimiou and Lemanowicz (1982) matched clients on the basis of sex, level of retardation, years in institutions, self-care, skills and age. In this study, they found significant increases in adaptive behaviour for the 70 "movers" after two years in the community as compared with the 70 "stayers", while they found no change in either groups in maladaptive behaviour. Though information on pre-move medical needs was collected, the post-move needs of neither group were reported. Some of the studies reported by McCarver and Craig (1974) supported the hypothesis that a period of institutional life of two or more years was predictive of greater success in the community because the subjects were more matured, more settled and less likely to show post-discharge delinquency. Other studies recommended reducing the length of institutional life to a minimum because no relationship was found between recidivism and length of stay. Still others

promoted the elimination of any institutional life whatever. McCarver and Craig (1974) concluded that a very complex relationship exists between length of stay, the period of adjustment to the community and success in the community. Results about these questions are clouded by the philosophy of the individual researcher.

Data on the relationship of predischarge training to success in the community are also shown to be confounded in the literature (McCarver and Craig, 1974; Gollay, 1977). Though training in some of the studies was positively related to greater success in the community, other studies observed a negative relationship, possibly due to the unrealistic environment of training in the institution. Although some of the subjects in the present study had been involved in aspects of training either for vocational opportunities in the community or for future community placement, most of the subjects had not received such preparation at the time of the closing of Tranquille Hospital. Planned, methodical preparation for the subjects for the transition to the community is recommended (Gollay, 1977; Heal, Sigelman and Switzky, 1978). Gradual transition through approximations of readiness appears as important as the content of the training (Heal, Sigelman and Switzky, 1978).

## V. Reasons for the Controversy

There are some basic reasons for the continuing controversial nature of the question of what is the best environment for the mentally retarded (Baumeister, 1981). There is confusion over the essence of the primary issue, which may really be more one of therapeutic versus custodial placement (Flynn and Nitsch, 1980, Kleinberg and Galligan, 1983). Many of the issues are only imperfectly reflected in the literature at this time. "Most of the studies available are post hoc surveys rather than true experiments" (pg. 194, Windle cited by McCarver and Craig, 1974). McCarver and Craig (1974) stated that choice of design is predicated largely by the agenda of the experimenter. At times, the goals appear to have been predefined, or else preselected populations are used. Frequently a lack of sufficient numbers of subjects limits the applicability of the conclusions.

### Confusion Regarding Definitions

A serious problem in attempting to describe subjects in research on mental retardation is the difficulty of presenting a clear definition of a population that is homogeneous on some variables but heterogeneous on other diverse dimensions. It is difficult to establish all the

associations in the complexity of descriptors of retarded subjects. Attempts may default either to a description of the mean of the population in order to reduce the extreme variability of the subjects' characteristics and descriptive dimensions, or to a broad, all-encompassing description that lacks definition and boundaries.

Measures of social adaptation continue to be difficult to define. Definitions of predictor and selection variables are confounded across studies. McCarver and Craig (1974) categorized studies into groups having three primary purposes; prognosis, retrospection or prediction and comparison.

1) Prognostic studies use discharge from the institution as the one important measure of success. McCarver and Craig (1974) studied fifteen characteristics used as factors to predict success and eighteen factors used to select candidates for release. These included intelligence, admission age, sex, and level of education. None of the variables consistently differentiated success or lack of success.
2) Conversely, retrospective follow-up studies used the dichotomy of success or failure in the community as the variable to measure the quality of community programs and placement. McCarver and Craig (1974) refer to several articles and suggest that there is little wisdom in comparing "the results from different studies if different selection criteria were employed" (pg. 159).

3) Comparative studies attempt to compare one group of subjects with another group considered to be relevant on a number of variables. Control groups are variously defined, if at all. In an interesting and in-depth review, these authors examined current literature on a variable-by-variable basis in four categories. In the initial group of variables called the "preadmission years", they included variables from the preadmission state of the individual's home environment, delinquency, and sexual behaviour. The variables in the "institutional years" group relate to the time of institutional life, including the reason for admission, age at admission, behaviour, training, work experiences, and length of stay. In the context of the "release process", the authors clustered variables related to selection criteria, family interest, number of prior community placements, type of placement (including vocational, home, foster home, halfway house, group placement and escape), and community attitudes and supervision. The final grouping is titled "characteristics of subjects", and includes age at release, diagnosis, race/ethnic background, intellectual level, academic ability, personality, personal appearance, physical handicaps, vocational skills, psychomotor measures, social skills and sterilization. Throughout the review, reported studies demonstrated confounded data. Positive findings are countered with equally strong negative findings or no findings at all.

McCarver and Craig (1974) stated that the confounding lay at least partially in the failure to provide

developmental programs or comprehensive evaluation related closely to pertinent variables. They noted that the literature reported confounding by other variables in relation to the selection for and prediction of successful adjustment in the community. These other variables included social skills, psychomotor ability, sterilization, vocational skills, personal appearance, personality and academic ability. Good behaviour is at times defined as institutional conformity and it may well be a poor predictor of community success. Recent studies showed some evidence that subjects with a history of delinquency have less success in community placement (McCarver and Craig, 1974). McCarver and Craig (1974) state that behaviour in the institution seemed more related to selection for discharge than to prediction of success in the community. Variables used to predict suitability for community living are confounded with variables used to assess the outcome (Zigler and Muenchow, 1979). Epstein (1982) suggested that incremental technology may be forcing society to redefine illiteracy and possibly even retardation. The premise of deinstitutionalization is Wolfenberger's argument that exposure to cultural norming affords the opportunity for the development or maintainance of normal behaviour. The difficulty is to determine what is normal behaviour for severely and profoundly retarded people.

Projects are often associated with financial and philosophical controversy (Braddock and Tamar, 1985). Researchers in mental retardation compete among themselves for funding priority. The allocation of funds is swayed by social and political factors. Even where policy issues are clear and formally presented, the interpretation of the outcomes of the project and the conclusions and recommendations for implementation are frequently unclear because of lack of social, political or economic support. Or policy becomes distorted in an attempt to influence a specific local policy decision relating to defined subject populations.

Problems surface from the confusion over interpretation of terms such as normalization, deinstitutionalization, function, and retardation as used in reference to this population. Definitions of these terms are variously operationalized between studies and researchers. The research is compartmentalized and does not achieve the scientific demand of replication. Small, unique groups of subjects are described in many of the studies. Definitions tend to lack operational boundaries (Justen, 1976; Baker, 1979). They are often ill-defined, categorical and applied beyond their intended scope. The aims of generalizability and replicability are restricted in much research in mental retardation by the lack of universal agreement on definitions (Zigler, Balla & Hodapp, 1984).

Alexander, Huganir and Zigler (1985) showed that interpretation of studies of different residential settings is difficult because of non-controllable selection factors such as intelligence level and availability of subjects. As a result, generalizability among individual research studies in mental retardation is limited. Comparisons are further limited by the confusion produced by variable definitions of the meaning of success of integration or deinstitutionalization (Zigler and Muenchow, 1979). The manner of interpreting the outcome, and, subsequently, the value of the research and even the impact of deinstitutionalization, is in question.

The generic use of the term, mental retardation, describes a whole range of complex symptoms both of physical and mental impairment. The term is applied variably to a loss of function spanning from mild to profound severity, and designates differences between levels of retardation. Retarded individuals show attributes of lower intelligence and inadequate social behaviour and vary in the degree of deficit as well as in the presence of concomitant physical anomalies and psychological disorders resulting in marked variance in the needs of the individuals. Each level has varying characteristics in physical, behavioural, conceptual, and associated functions. The application of a variety of operational definitions in specific studies has confused the use and

referents of retardation terminology. In literature review, Tawney and Demchak (1984) referenced the term "severely handicapped" used in three broadly different ways to mean a) multiple handicaps, b) a broad range of handicapping conditions, and c) impoverished behaviour patterns. Variable intensity of different characteristics in the various ranges of retardation produces distinctly different functional limitations and capabilities. There is a range and variety of conditions within each level of retardation. The physical, cognitive, emotional and functional levels of ability create a multidimensional mosaic (Grossman, 1983). Emotional affect varies situationally over time. Characteristics of individuals classified within the four major groups of mild, moderate, severe and profound retardation are widely variant even on defined functions such as serial learning tasks, potential for learning and ability to transfer learning to new situations, judgement, associative learning, discovery and application of learning (Cruickshank, 1971). In this study, serious physical and functional disabilities were found to be frequent concomitants of retardation in the severe and profound ranges, agreeing with Baird and Sadovnick (1985) and Herbst and Baird (1983). Behavioural disorders such as self-abuse, violence to others, and sexual deviance were the predominant concomitants of the mild and moderately retarded. Baird and Sadovnick (1985) pointed out that

observation time is needed before categorizing individuals, and stated that the necessary lag time increases with the more severe categories.

There is much controversy due to the lack of clear definition of the term "quality of life". Emerson (1985) focuses attention to a number of questions. What are the factors which shape an individual's behaviour for good or bad? What individual values and lifestyle interact with which environmental characteristics to shape behaviour? How are community participation, social interpersonal interaction and effectiveness of activity patterns measured -or valued? Is one who does not participate a failure? How significant is the personal satisfaction of the client and how is it measured in severely and profoundly retarded individuals? How are predictor variables chosen? Are expectations of the product to be defined by the service producer or the consumer? Is the consumer the mentally retarded individual or his/her advocate? Do outcome measures reflect the political/social mood for and of the consumer? Can a decision be made as to what justice applies to mentally retarded individuals who offend these standards? These questions and other must be answered before change in quality of life can be effectively measured.

Clearer definitions used in a consistent manner are essential to clarify research and to support replicability. The heterogeneous nature of levels within mental retardation on many parameters makes classification of the retarded a difficult task. Barnett (1986) suggested that retardation defined as cognitive deficiency varies culturally depending on the relative value of a given function in a given cultural context. Zigler, Balla, and Hodapp (1984) stated the purpose of a classification system is 1) to discriminate among different groups and 2) to identify the individuals that belong in each of those groups. The more adequately these functions are met, the more accurately the behaviour of group members can be predicted and their needs planned for.

## Controversy over Labels

Many proponents of normalization criticize the use of any terms as labels because of possible stigmatization and advocate the elimination of labels. Mental retardation terminology holds negative connotations for some people because of social associations acquired through customary usage. Since retardation exists, whether or not it is labelled, the risk of stigmatization by labelling must be weighed against the value of labels in identifying individuals as eligible for special services (Hodapp and Zigler, 1986). Grossman (1983) suggested that the purpose

of labelling is confused with that of classification, which is essential to the study of any phenomenon. He stated that the process of classification is necessary to develop the universal terminology essential for communication in research and to establish criteria for membership in levels of retardation or for inclusion for special needs. The function of classification occurs in all societies and is necessary for the application of societal rules. Mutual dependency exists between classification and research.

Labelling is oriented to personal classification regardless of impersonal data. As such it fails because it focuses on the individual and is limited in reflecting the relative potential of that individual. Labelling frequently errs by over-inclusion or by excessive conservatism resulting in under-inclusion. In the first case individuals may be falsely labelled. In the latter, individuals may forfeit eligibility for special services, funding or support. "Communication about individuals or categories of individuals is not possible without labels for the conditions they manifest" (Grossman, 1983, pg. 20).

**Intelligence as a Predictor**

Intelligence is as weak a predictor of adaptive behaviour as it is of social function (Heal, Sigelman and Switzky, 1978). Zigler, Balla and Hodapp (1984) discussed the relationship of intelligence to adaptive behavioural ability. They stated that the principle of classification by intelligence scores implies that intelligence correlates with a pattern of behavioural abilities and limitations with age specific parameters. Intelligence classification aims at the prediction of the individual's behaviour over time. Because intelligence scores are not constant across age, these authors contend that intelligence is not a strong predictor of social or adaptive ability, and only estimates the rate of intellectual development.

Not all retarded individuals in any level of retardation are placed in institutions (McCarver and Craig, 1984). Some aspect of preselection is assumed to have affected their placement into the institution initially. The decision usually occurs because:

1) there are social or economic limitations in the home possibly due to the age or intellectual ability of the parents;
2) the individual exhibited behaviour which the community could not tolerate; or
3) the socio-economic resources of the community were inadequate to meet the needs of the individual.

**Need for a Classification System**

Accurate representation of the needs of the mentally retarded poses problems. Increasingly, literature examining the effectiveness of deinstitutionalization reveals that the research process, the selection of subjects, the descriptors used and the mode of deinstitutionalization vary on almost every possible dimension across studies (Janicki and MacEachron, 1984; Sherman, Frenkel, and Newman, 1984; Glick, Guyer, Burr, and Gorbach, 1983; Hauber, Bruininks, and Hill, 1984; Pratt, Luszcz, and Brown, 1980; Scanlon, Arick, and Krug, 1982; McDonald, 1985). A satisfactory classification system must be developed to establish a common standard for the comparison of populations across studies.

Several classification systems have been proposed in the literature. The American Psychiatric Association (1982) operationally defined mental retardation as significantly subaverage function in general intellectual skills falling two standard deviations below the mean as measured on an individually administered intelligence test, with incidence prior to the age of 18. Four levels of retardation were defined. Grossman's (1983) multiaxial approach defined retardation as low intellectual function at least two standard deviations below the norm, with incidence in the developmental period before age eighteen, and with

concurrent deficient social competence measured as subnormal function on an adaptive behaviour scale. He further defined social competence as "a rating of adaptive behaviour intended to measure an individual's routine personal, community and social responsibility behaviour as well as interpersonal behaviour" (pg.42). He measured adaptive behaviour by informal appraisal with scores on one or more of a number of standard(ized) behavioural scales. Rutter (1981) defined retardation from a psychiatric perspective as organic deterioration closely related to intellectual malfunction. "Most organic reactions are a result of conditions that have prevented normal development from the outset" (pg. 92). Zigler, Balla, and Hodapp (1984) assumed retardation to be a stable trait of below average intellectual function and divided their population by the genetic or organic etiology of the retardation. They emphasize the etiology of retardation as essential to the adequate classification of retarded individuals.

Functional terminology more adequately describes the social or behavioural ability of a population and generates useful comparisons in terms of abilities or limitations, behavioural competencies and the supportive services required. Grouping subjects according to commonalities in their physical and functional condition enables comparison of the subjects in terms of objective, measurable criteria and avoids the restriction of the preset perceptions. It

assists in classifying the population and determines service needs, and supports the allocation of limited and costly resources.

Sailor and Guess (1983) considered it impracticable, if not impossible, to define this population by individual characteristics because of the great variance. They suggested a service-needs model (defining the population in terms of requisite needs) in order to objectify the description and enhance its functional application. Solomon, Gordon and Davis (1984) recommended a demographic approach in describing subjects in terms of social demographics including clinical characteristics, functional abilities, psychological function and amount of care required and received. Jacobson and Janicki (1983) described their population in terms of age and level of retardation. An operational description of retarded individuals is an infinitely complex and unresolved matter. A definitional strategy is needed to bring order to the description of the mentally retarded to facilitate communication among workers in the field and to aid in defining those individuals who are retarded to better identify them as eligible for services, assistance and preventive aid. Grossman (1985) observes that a system of classification cannot adequately reflect various ideologies and objectively identify recipients as meeting appropriate intellectual and behavioural criteria. Objectivity is

necessarily affected by cultural mores, environmental factors, and the ability and experience of the individual doing the evaluation. The social, behavioural, personal, emotional and environmental variables most affecting developmental and societal success still lack consistent definition.

## VI. Definitions

For the purpose of clarity in this study, terms will be defined as follows:

**Deinstitutionalization** - used to mean the transfer of mentally retarded persons from a facility in provincial or state jurisdiction to community facilities under private or public authority but usually funded at least partially by the province.

**Normalization** - the process of placing mentally retarded individuals in homes in the community such that their care, physical and personal surroundings and the ratio of mentally retarded to normal residents in the home is comparable to the environment of the average citizen

**Mental Retardation** - the full spectrum of individuals with intelligence falling below an IQ of 70. (Where further definition is required, specific reference will be given.)

## VII. Description of the Present Study

The present study began in 1983 when the investigator was employed as a consultant by the Ministry of Health to assess the resident population of the three major provincial institutions for the mentally retarded prior to the move towards deinstitutionalization. Woodlands School, Glendale Lodge and Tranquille Hospital served primarily as regional institutions rather than as provincial facilities because referrals tended to be made to the facility within the client's home locale. There were some differences between the institutional groups on the variables to be discussed. The three populations are, however, treated as equal populations because: a) provincial policy was applied consistently across the three institutions, b) placement was determined primarily by geographical region of origin rather than physical or mental factors, and c) transfer among the three residences for reasons of assessment and medical care caused the populations to become homogeneous.

The study employs appropriate comparison groups and a longitudinal model as recommended by Emerson (1985). Matched control comparisons of institutionalized and deinstitutionalized persons partially solve the problem of uncontrolled selection factors, such as intelligence, referred to by Alexander, Huganir and Zigler (1985). Three

years passed between the initial assessment just prior to the closing of Tranquille Hospital and the follow-up testing, allowing for the post-transfer adjustment prescribed by Cohen, Conroy, Fraser, Snelbecker and Spreat (1977).

The study by Conroy, Efthimiou and Lemanowicz (1982) provides the closest available parallel to the one reported here. Their clients were matched on all variables previously reported to affect client growth, as well as on the pre-move value of the dependent variable of adaptive behaviour. Their study was conducted approximately two years after placement to allow time for the adjustment period. The major relationship investigated was the change in adaptive behaviour for the deinstitutionalized subjects, compared with institutionalized clients. The present study partially avoids concern about the possible lack of generalizability as a major design problem (Conroy, Efthimiou and Lemanowicz, 1982) because the subject pool of the original study was the entire population of moderately, severely and profoundly retarded individuals at each of the three institutions. As well, comparisons of each matched subject group with their respective institutional population examine the degree to which the sample groups representative of their respective institutional.

The defined population of this study consisted of 1245 moderately, severely, and profoundly mentally retarded residents - 647 in Woodlands School, 308 in Tranquille Hospital, and 290 in Glendale Lodge. At the time of the follow-up study, Tranquille Hospital had been completely depopulated by a combination of strategies. Of the original Tranquille Hospital mixed population of 322 individuals, the Ministry of Health reported that 54 residents were transferred to the jurisdiction of the Continuing Care Division in the Ministry of Health. The other 268 retarded individuals from Tranquille Hospital remained under the jurisdiction of the Ministry of Social Service and Housing. No figures were available from the Ministry of Social Services and Housing of the number of people who moved from Tranquille Hospital to Woodlands School or Glendale Lodge, who died in the interim or who were moved to the community though it was later reported that 249 former Tranquille Hospital residents were available for possible inclusion in the study.

Tranquille Hospital was depopulated under the authority of the Ministry of Social Services and Housing, which continues to be responsible for Woodlands School. The operation of Glendale Lodge was transferred to the Ministry of Health. In this study, the deinstitutionalized Tranquille Hospital residents were assessed in their community residences. These individuals were matched with

subjects drawn from residents continuing in Woodlands School and Glendale Lodge. The original proposal to include 102 never-institutionalized children and adolescents with comparable levels of retardation was, unfortunately, not subsequently allowed by the Ministry of Social Services and Housing. As a result, this unique opportunity to compare deinstitutionalized subjects with clients remaining in an institution and those never institutionalized, but remaining in the community for the period of the study, was lost.

## Subject Attrition

The study experienced a large subject loss possibly due to the multiple levels of consent required by the Ministry of Social Services and Housing. The greatest subject loss occurred at the regional and district levels of the Ministry of Social Services and Housing, with small losses at the level of the societies responsible for the client in the community, the caregiver employees of those societies or the families. The Ministry of Social Services and Housing assumed responsibility for requesting consent and contacted the investigator when all levels of consent had been received. It is not known how many consent requests the Ministry of Social Service and Housing originally sent out.

Approximately 20% of the successfully traced subjects were discovered by the assessors when they contacted a society representative to arrange the interview. The representative inquired why they were not being interviewed about the other residents. When told that no consent had been received for those individuals, the representative usually asked the parent directly. In every case, the parents consented. They stated that no consent form had been received by mail from the regional office.

Many consent requests were returned by the regions as being unknown for address of either the client or the person responsible. On several occasions, employees of the Ministry of Social Services and Housing commented to the assessors that selection bias was active at the regional or district level. The inclusion of seven subjects was refused; the reason given was that the subjects were either too severely intellectually or physically disabled or not doing well enough to be included, or the family was too sensitive to be asked to have the subject included. A number of employees at ministry, regional and district levels, with whom the study necessitated interaction, appeared reluctant to part with patient information in spite of the agreement of the Ministries of Health and Social Services and Housing. It is reasonable to assume that this pattern of subject loss introduced a source of bias in the study. This will be discussed in the

interpretation of the data. Some consents were lost because clients might not have been able to give their own informed consent, such consents might not have been valid, or the body having legal authority to give consent for this study or any medical or social intervention on behalf of the client was in doubt.

The Ministry of Social Services and Housing estimated that there were 263 Tranquille Hospital residents moved to the community of which 249 were moderately, severely or profoundly retarded. The Ministry projected a loss of 60 subjects resulting in a potential subject pool of 189. A total of 125 forms were returned of which only 93 could be used. This subject loss of 32 persons had several causes. The Ministry of Social Services and Housing was unable to trace eight subjects or to identify the care provider in five other cases. Four subjects were originally diagnosed at retardation levels above moderate and therefore could not be included. Three subjects had not been included in the original study in 1983. One consent arrived six months after the termination of the study. Care societies refused to allow three subjects to be interviewed stating that subject information now belonged to the society. Two other societies refused to let their residents participate because the data used for the original study (held in confidence by the Ministry of Health) was not available to them . Social workers or caregivers had signed the consents

for seven subjects and it was later decided, by the Ministry of Social Services and Housing, that when no contact could be made with the responsible person or no committeeship had been established, such approval was inappropriate. Four people had returned to an institution or attended day programs in an institution and were considered spoiled subjects.

## Informed Consent

Approval to proceed with this study was obtained from both the Ministry of Health and the Ministry of Social Services and Housing (Appendices B1, B2) and funding support from the British Columbia Health Care Research Foundation (Appendix C). The Ministry of Social Services and Housing required that they assume the responsibility for obtaining consent for subjects for the study. They sent a letter, study abstract, draft letter (client) (Appendix D1), draft letter (person representing client) (Appendix D2), consent form (client) (Appendix D3) and consent form (person representing client) (Appendix D4) to regional and district offices known to be contacts for the deinstitutionalized Tranquille Hospital subjects. Each level of authority with responsibility for each subject was given the clear option to withdraw from the study at any time. At the interview with the caregivers, the purpose of the study was reviewed and clarified as necessary.

All information has been kept fully confidential. Subjects are identified only by means of a number. The names of subjects, the regions, districts, societies, or caregivers are not referred to in the interpretation of the data. Final results are presented as aggregate data only.

The issue of what defined informed consent appears to have been one of the major causes of difficulty in obtaining subjects. The variety of questions encountered included whether retarded people had authority to give consent for themselves, what level of retardation prohibits adequate understanding to make consent impossible, who else has authority to give consent for these individuals and what process of law is required to establish this authority. The legal position regarding authority for informed consent for mentally retarded persons in this province is unclear. The legal responsibilities are poorly defined in the following circumstances:

1) for the family of a mentally retarded individual no longer living at home;
2) if the family does not take the responsibility to give consent for these people; and
3) if the individual's parents are deceased. In most cases, no guardian or committeeship had been appointed by the courts.

Many of the former residents of the institutions are older, if not elderly, and their families have had little

contact with them over the years. Hence, the families (in many cases no longer parents but siblings or more distant relatives) are reluctant to accept the position of consenting on behalf of the retarded person because they do not know them well. There is no legal precedent at this time to define the level of retardation at which an individual is able to understand the legal implications of giving consent. Brenner and Gerken (1986) discussed the enigma of informed consent. They quoted the judge in a precedent setting case as defining informed consent as "Every adult human being of adult years and sound mind has the [legal] right to determine what shall be done with his own body".

**Sampling**

Preliminary analysis indicated that the two institutional groups of Tranquille Hospital and Woodlands School/Glendale Lodge were different in a number of variables. Therefore, the best available match for each Tranquille Hospital resident was identified from the 937 moderately, severely, and profoundly retarded persons resident in Woodlands School/Glendale Lodge in 1983. The match was based on the following criteria:

- level of retardation (moderate,severe or profound);
- adaptive behaviour score - to be described below;
- psychological function score - to be described below;
- years in institutions (0-9, 10-29, 30+);

- age (plus or minus 5 years);- sex - used for matching only as "tie-breakers" when the other criteria had produced two or more identical matches.

The matching variables are equivalent to those used by Conroy, Efthimiou, and Lemanowicz (1982) and Locker, Rao, and Weddell (1984) in a similar study based on a single institution, though the Conroy study used a single self-care score. Only 93 subject pairs were obtained for the Tranquille Hospital-Woodlands School/Glendale Lodge match out of 249 moderately, severely or profoundly retarded former residents of Tranquille Hospital stated to be available for this study.

## The Assessment Tool

The adaptive behaviour assessment instrument used in this study, the "Wilcox Client Data Scale" (Appendix A), was designed by the author for the original research for the Ministry of Health in 1983. It was based on the format still used by the Ministry of Health to assess individuals being considered for admission to long term care settings. Its content validity was judged and approved by a panel representing the Ministries of Health and of Social Services and Housing. Included were a psychiatrist, physician, nurse, psychologist, social worker, statisticians, and a rehabilitation therapist. Carefully worded, standard interviewing techniques were used to

reduce potential error variance in the data. In 1986, scores on the Vineland Adaptive Behaviour Scale (Daily Living Skills Domain) were also obtained. These comparative data provided information on the cross validation of the Wilcox Client Data Scale. Both the reliability and the validity of the assessment tool are discussed later.

An interviewer-questionnaire format was chosen as being the most economical of time and the most efficient in obtaining sensitive information. Babbie (1973) supported the use of an interviewer questionnaire for data collection. The interviewer format is likely to produce a higher rate of response than a mail-in format. It is effective in decreasing the incidence of unexplicit responses. There is opportunity to clarify items on the questionnaire that may otherwise lead to confusion. The direct contact with the subjects or representatives of the subjects gives occasion for observation. Such a technique proved particularly effective in helping caregivers to respond to questions about the subject that were perceived as potentially prejudicial or "labelling". The interviewer format can be criticized as a potentially biased medium. In this study, the interviewers were university graduates hired because of their interview skills although they had no previous experience in retardation. The subjects were identified only by a code number and remained anonymous to the interviewers. Caregivers were eligible for the

interview on behalf of a client if they had worked with that client for a minimum of six months. A third party entered and coded the data into the computer and the investigator interpreted the data. It is believed that the process was essentially bias free.

The Wilcox Client Data Scale consisted initially of four sections developed for computerized data analysis. The characteristics of the population were described on these four parameters (totalling 65 variables) as reported by the resident care-givers. These were:

1. demographic and medical information;
2. personal function;
3. hours of care received; and
4. projected community service requirements.

The first part recorded individual demographic data including place of residence, range of intellectual function, sex, age, and years in care. The medical information included medical background (diagnosis, interventions, birth history,etc.), medications, treatments (defined as capable of application by other than nurse), procedures (defined as requiring application by nurse), allergies, visual and hearing aids, and diet. Intelligence was recorded according to the DSM-III subtypes of mental retardation of 318.0 moderate, 318.1 severe and 318.2 profound. No intelligence scores are reported because of the variability in the reporting of such scores in

the subjects' charts.

The second part recorded the level of function on 24 variables. The ability to function independently was defined operationally on a 5 point scale in terms of 24 descriptors in the areas of personal care, communication, mental status, and life skills. These were: ambulation, transfers, bathing, dressing, grooming, eating, bladder control, bowel control, vision, hearing, speech and/or skill in and means of alternative methods of communication, dental status, understanding of others, general comprehension, self-direction, emotional stability, general behaviour, food preparation, housekeeping, shopping, travelling, telephone use, and responsibility for medications. The measure of individual ability on any one functional variable was the descriptor reported by the primary caregiver to be the best single description of the level at which the individual performed on a regular basis. These scores are assigned to one of two aggregate scores where they are reported as a single quotient. Epstein (1982) referenced literature that supports the use of an adaptive behaviour score as a measure of function in society.

The use of a single quotient is contrary to Grossman's (1983) recommendation that multiple scores are more descriptive of an individual. The single quotient was used

here because it was considered to afford greater specificity in the examination of the data. Although the within-subject variability referred to by Grossman is present, the symptomology of moderate, severe and profound levels of retardation has a smaller range of variability than that of mild retardation. Since the tool was developed specifically to describe the more serious levels of retardation, it is believed that a single quotient describes the limited range of these subjects. Finally, the score was not intended to function as a profile on which to base a decision as to individual programming needs. The single quotient serves at one point in time as a measure of the status of the individual's overall ability on a number of variables as a result of receiving a profile of programs.

The third part of the scale recorded the health services the individual received in 1983 and the amount of staff time required to accomplish these services recorded in hours of care received per week. These included physician (general practitioner, psychiatrist and other specialists), physiotherapist, occupational therapist, psychologist, nurse, and nursing aide.

The fourth section projected the health services that would be required in the future if the individual were to live in a community setting. These included health

counselling (nursing), drug therapy, diet therapy, podiatry, optical care, physical exercise (a formal program as compared with incidental activity), physiotherapy, occupational therapy, audiology, dental care, speech therapy, treatment procedures by nurses, short term relief in hospital, orthotic/prosthetic care, physician care, psychological intervention, schooling and respite care. These service levels represented the level of care required if ideal levels of service were available and did not serve as predictors of success in community placement.

Additional variables of care approaches practiced by the private societies, characteristics of care givers and residence, and availability of health and social services beyond the primary residence, were documented in a revised 1986 version of the Wilcox Client Data Scale and are discussed in another paper.

Several concerns attend the use of adaptive behaviour scales in the assessment of mentally retarded individuals. The assessment of adaptive behaviour is a costly process requiring prolonged observation and/or in-depth interviewing. Assessments are usually based on either a caregiver report or direct observation by a trained assessor. There are limitations to both choices. Personnel working with a subject may be familiar only with one aspect of the subject's life pattern such as daytime versus night

time behaviour. Staff may be reluctant to give input because the assessment is perceived as an additional burden to an already busy schedule. The staff person may consider the assessment potentially intrusive or threatening to the lifestyle of the subject or possibly judgemental of the quality of care. Interpretation of adaptive behaviour ratings is difficult at best. The information recorded usually reflects a subjective judgment on the part of either the caregiver and/or the assessor. Interpretation of an adaptive behaviour tool requires skilled professional judgement. There is little agreement on the best variables to measure. Some scales measure adaptive behaviour whereas others measure maladaptive behaviour. Some scales record observation whereas others record reported detail. There is much variety in the scale's intended subject use, and in their projected outcome measures. Their validity is variable and many of the scales are poorly normed (Grossman,1983).

The reliability of the Wilcox Client Data Scale was tested by assessors trained by the investigator to use the appraisal form for the initial assessment in 1983. Because the scale was developed for use by the Ministry of Health for the assessment of the entire population of moderately, severely and profoundly retarded individuals in the province of British Columbia in 1983, no norming data were available initially. Inter-rater reliability was tested

after training and retraining until the testers demonstrated an error rate of one point difference on the sum of the scores on the 24 ability functions in the second part of the scale (approximately 98% agreement).

Testing of the concurrent validity of the Wilcox Client Data Scale was carried out by a comparison of the scores on the Wilcox Client Data Scale items 20-29 and 39-42 to scores on the Daily Living Skills Domain of the Expanded form of the Vineland Adaptive Behaviour Scale (Sparrow, 1984) on the same subjects. The assessors were trained in the use of the Vineland by a registered psychologist. The results of this comparison will discussed in a later paper.

**Adaptive Behaviour and Psychological Function Score**

Scores on any one of a number of single abilities in themselves can reasonably be expected to provide at least a weak projection of the functioning of an individual. A more reliable measure of the individual's ability is the mean of a combination of scores on several similar parameters. Two special scale scores were developed from the items in the second part of the Wilcox Client Data Scale.

The Adaptive Behaviour Score describes a dimension of ability to function independently. It is an aggregate score derived from the scores on fourteen individual items of the

Wilcox Client Data Scale (items 1-10 and 20-23) including the variables ambulation, transfer, bathing, dressing , grooming, eating, bladder control, bowel control, vision, hearing, food preparation, housekeeping, shopping, and travelling. Scores can range from 14 (1 x 14) to 70 (5 x 14) where 1 represents the most independent ability and 5 represents the most dependent. The maximum score of 70 represents the lowest level of adaptation.

The Psychological Function Score describes a dimension of awareness of self in the environment and ability to interact with it. It is derived from six items of the Wilcox Client Data Scale (items 11, 12, and 16-19) and includes speech, understanding of speech, general comprehension, self-direction, emotional stability, and disordered behaviour. Scores can range from 6 (1 x 6) to 30 (5 x 6) where 1 represents the highest competence and 5 represents the greatest disability. A score of 30 represents the lowest level of psychological function.

**Other Grouped Scores**

A number of scales were created from the daily living skills variables by grouping the scores on two or more of these variables to produce another parameter that would reflect an expanded, more complex measure of ability. These scales measured ability in nine different areas.

1. General ability or independence in mobility integrated the scores on ambulation and transfer ability.
2. The selfcare variable included scores on bathing, dressing, grooming, eating, and the ability to take one's own medication.
3. The scale indicating toilet habits included measures of ability to control both bowel and bladder function.
4. The sensory function scale combined scores on vision and hearing.
5. Communication represented a consolidated score on ability in spoken language (speech), understanding of heard language, and perception of the non-verbal aspects of expression.
6. Awareness included scores on general comprehension and self-direction.
7. (Un)disturbed behaviour reflected ratings in emotional stability and behaviour.
8. Living comprised scores on housekeeping, food preparation, shopping, travel and telephone use.
9. A measure of ability (in)dependence was developed from grouped scores on the four ability scales of selfcare, communication, awareness, and living ability.

## VIII. Presentation of Predictions

As an outcome of investigating the literature, the following hypothetical predictions will be tested:

1. Uniform criteria for admissions were applied to the three provincial institutions of Woodlands School, Glendale Lodge and Tranquille Hospital. Placement was determined primarily by geographical region rather than for reasons of physical or functional ability. Transfers among the three residences for assessment and special medical care or programmes caused the populations to be homogeneous and care standards were applied consistently. To investigate the extent of this homogeneity in 1983, specific comparisons were made between the Woodlands School/Glendale Lodge (Woodlands/Glendale) group and the Tranquille Hospital (Tranquille) group, the Tranquille-matched group and the Tranquille group, and the Woodlands/Glendale-matched group and the Woodlands/Glendale group on the personal demographic, functional measures and service levels assessed by the Wilcox Client Data Scale.

2. Changes were expected in the scores on adaptive behaviour and psychological function from 1983 to 1986 within sample groups of both the Tranquille matched

subjects and the Woodlands/Glendale matched subjects because of either the effects of maturation over time and/or as a result of the care which these individuals receive in community and the institution. The deinstitutionalization philosophy predicts that both adaptive and psychological functions in the community group will show more improvement than in the institutionalized group.

3. The number and type of behavioural medications received by the subjects are predicted to change from 1983 to 1986 within the Tranquille matched and Woodlands/Glendale matched samples. Deinstitutionalization philosophy suggests that Tranquille subjects in the community will have their medications reduced more than those subjects remaining in Woodlands/Glendale.

4. As a response to the increased consciousness of the need for more and better services for the mentally retarded, it is expected that more health services will be provided for both matched groups in 1986 compared to 1983. Moreover, caregivers should report higher levels of projected need for health care than was actually received in either 1983 or 1986 for both groups. The Tranquille matched subjects in the community will be reported to receive more health

services than individuals remaining in Woodlands/Glendale because receipt of adequate services is reported to be a factor in the success of community placement. For the same reason, Woodlands/Glendale subjects will be reported to have a higher projected need for health care services in 1986.

5. The incidence of extraordinary pathology should be similar between the two matched groups in 1983. However, deinstitutionalization philosophy would suggest that the extent to which pathology will be reported should decrease more in the Tranquille matched subjects in 1986 than in the Woodlands/Glendale matched subjects in 1986.

## IX. Results

There were 1245 individuals diagnosed as moderately, severely or profoundly retarded residing in the provincial institutions in 1983. Approximately 25% of these people resided in Tranquille, 52% in Woodlands, and 23% in Glendale. The populations of Woodlands and Glendale in 1983 were combined as Woodlands/Glendale (W/G) for the statistical comparison in this study. Matched subject pairs were identified for follow-up from the moderately, severely and profoundly retarded populations of Tranquille, and W/G. Many of these people were moved to the community. Of the people moved from Tranquille to the community, 93 subjects were available for matching. Similarly, 93 matched subjects from Woodlands/Glendale were identified.

**Table 1**
**Population Grouped by Institution Code in 1983**

| | Group | | | | |
|---|---|---|---|---|---|
| | T | W | G | Tm | W/Gm |
| f | 308 | 647 | 290 | 93 | 93 |

Note: T = Tranquille subjects; W = Woodlands subjects; G = Glendale subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

Specific groups were compared to test the predictions outlined above. An overview of these comparisons is presented next and shown in Table 2 below. The 93 subjects identified in Tranquille for the purpose of matching are coded (Tm). Likewise, the matched subjects in Woodlands/Glendale are identified as (W/Gm). The subjects remaining in the Tranquille group after the removal of the Tranquille matched (Tm) group are designated (T) and those remaining in the combined Woodlands/Glendale group are coded (W/G).

1. Comparisons were made between the 93 subjects in Tm and the 215 subjects remaining in T after the matched subjects were removed. These comparisons evaluate possible differences between these groups prior to deinstitutionalization.

2. Similar comparisons were made between the 93 W/Gm subjects and the remaining 844 W/G subjects.

3. Comparisons between Tm and W/Gm in 1983 were carried out to evaluate the success of the matching procedure, and to investigate possible differences on variables not included in the matching process.

4. Comparisons across time from 1983 to 1986 were made for the Tm group.

5. Comparisons across time from 1983 to 1986 were made for the W/Gm group.

6. Finally, the Tm and W/Gm groups are compared in 1986.

**Table 2**
**Pattern of Comparisons**

| Year | Population |
|---|---|
| 1983 | <-------- 1. ----------><br><---------- 2. ----------><br>T W/G Tm <---- 3 ----> W/Gm |
| 1986 | 4. 5.<br>Tm <---- 6.----> W/Gm |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

The Wilcox Client Data Scale was originally recorded in inverse order with the lowest number representing normal function and the highest number representing dependency. To maintain consistency, this idiosyncratic format was continued in the follow-up data.

Subject attrition was relatively severe due to the problems discussed earlier. The methodological problems that arose and the statistical management of these problems are discussed where appropriate. Note at this point, however, that attrition left the number of subjects in individual cells on some statistical tests either very low or missing. In general, where this occurred, the data were collapsed to eliminate empty cells.

Where individual t-tests are reported, the more conservative separate variable estimate procedure was used. (Notice that with this procedure, the degrees of freedom may have decimal values). The level of $p<.05$ was adopted because of the large numbers of comparisons in this study.

## Comparison of the Four Population Samples in 1983

The 1983 data for the four groups of T, W/G, Tm and W/Gm are described according to sex, intellectual level, age, length of stay in an institution, aspects of the adaptive behaviour scores and psychological function scores, ratings on nine subscales of ability, expressive speech, understanding of language, behaviour, extraordinary pathology, reported cause of mental retardation, reported health problems, number and type of medications, number of treatments, number of procedures, and actual and projected service levels as recorded on the Wilcox Client Data Scale. These descriptors

include the variables most frequently cited in the preceding literature review.

Comparisons are made between the T and Tm groups and between the W/G and W/Gm groups to examine the extent of homogeneity between the matched groups and their respective populations. Further comparisons are made between Tm and W/Gm to explore the success of the matching variables and the degree of homogeneity in these two groups on variables other than those used for matching.

## Analysis of Matching Variables for the 1983 Data

In this section, analysis of the variables used specifically to match subjects is presented. The variables include level of retardation, age, length of stay in an institution, adaptive behaviour score, and psychological function score and sex. These variables were considered simultaneously and were not ordered by significance.

### *Sex* (1983)

Sex was used in the matching of Tm and W/Gm only as a tie-breaker where all the other variables were equal because of the limited direct effect of sex reported in the literature. The breakdown into males and females in percentage by group is shown in Figure 1 and the distributions are shown in Table 3. Sex differences were not found between T and Tm

[$X^2(1, N = 308) = .03531$, $p = .8509$], W/G and W/Gm [$X^2(1, N = 937) = 1.3639$, $p = .2429$] or **Tm and W/Gm [$X^2(1, N = 93) = .09064$, $p = .76$].**

**Table 3**
**Frequency of Distribution of Sex by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Sex | T | W/G | Tm | W/Gm |
| Female | 88 | 371 | 37 | 35 |
| Male | 127 | 473 | 56 | 58 |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

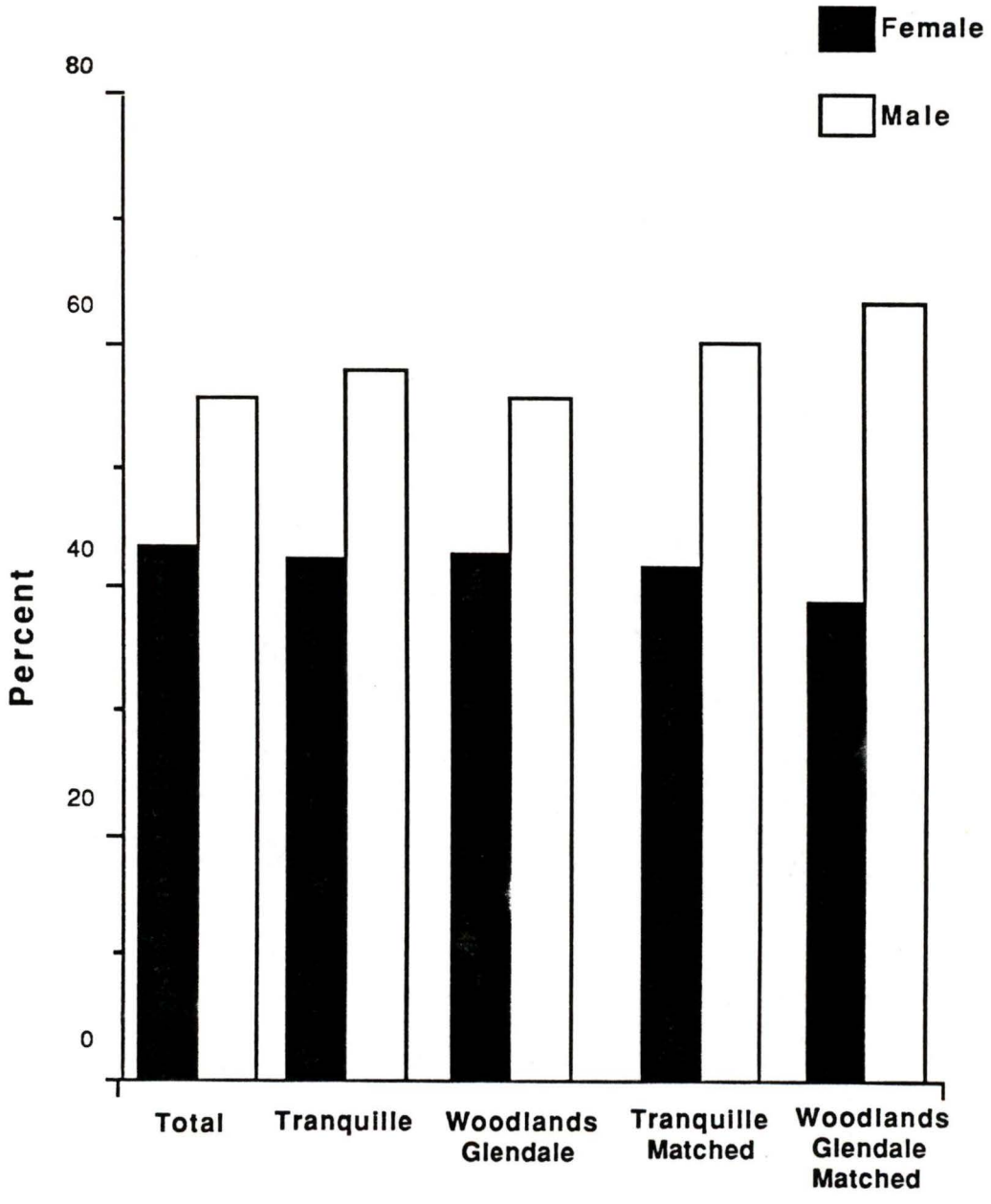


**Figure 1.** **Sex by Group**

*Level of Retardation (1983)*

Only individuals classified as moderately, severely or profoundly retarded were selected for this study. Examination of Figure 2 and Table 4 shows that Tm had twice as many moderately retarded subjects in 1983 as W/Gm and half as many more in the severely retarded category, while W/Gm 1983 had twice as many profoundly retarded subjects. No significant difference was found between T and Tm [$X^2(2, N = 308) = .89659$, $p = .6387$], or W/G and W/Gm [$X^2(2, N = 937) = 2.36277$, $p = .3069$] were comparable. **Comparison of Tm with W/Gm showed a significant difference [$X^2(2, N = 186) = 10.03291$, $p = .0066$].** This difference showed that the Tm subjects were of higher levels of intelligence overall and that the W/Gm subjects were reported as more profoundly than moderately retarded.

That there was a difference was unfortunate but unavoidable because better matches were not available. This discrepancy will be discussed further below.

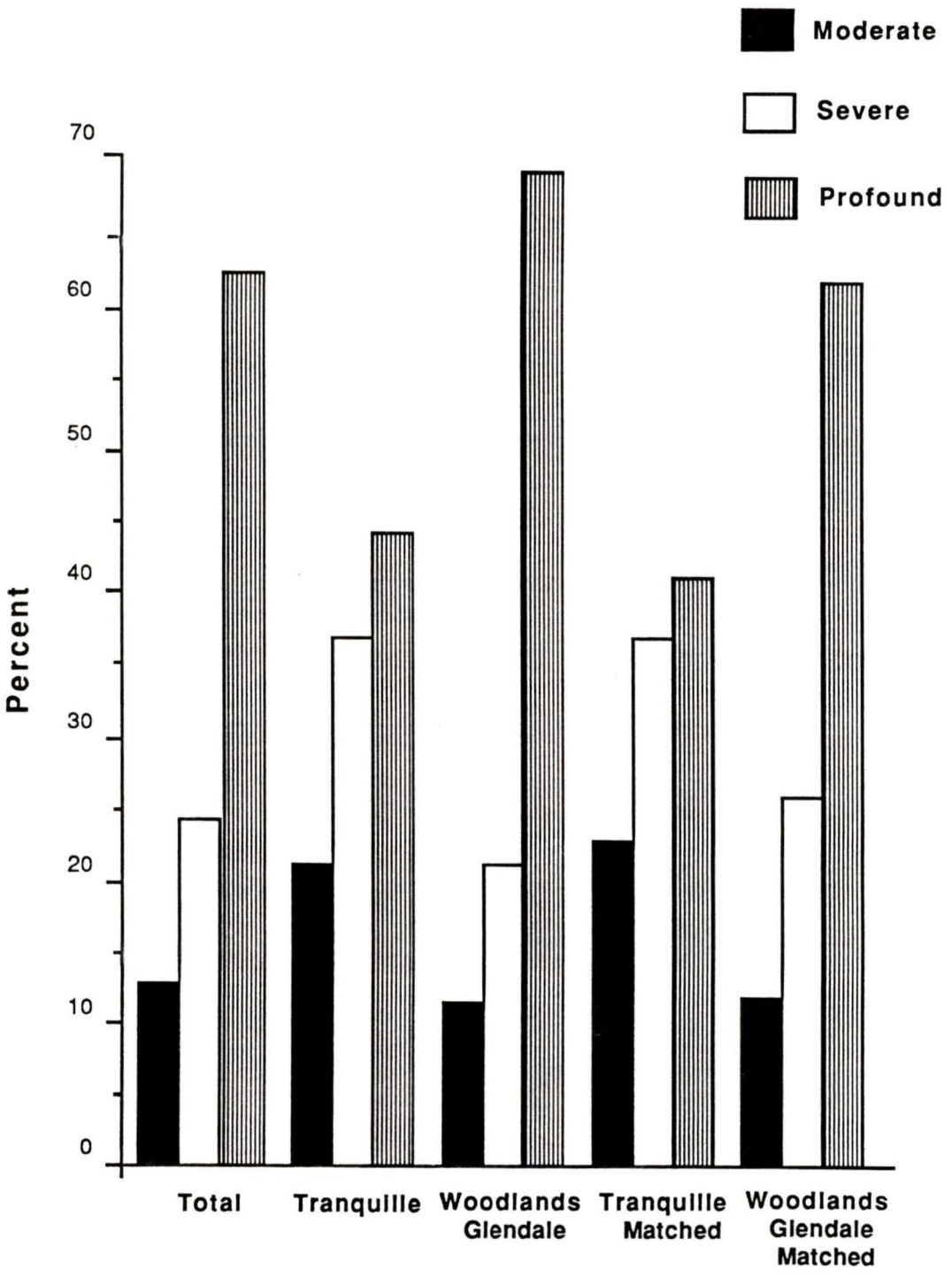


**Figure 2.** **Level of Retardation by Group**

**Table 4**
**Frequency of Intelligence Levels by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Range | T | W/G | Tm | W/Gm |
| moderate | 42 | 87 | 22 | 11 |
| severe | 77 | 167 | 34 | 24 |
| profound | 96 | 590 | 37 | 58 |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

*Age (1983)*

Age was condensed into cohorts of 10 years (see Table 5 and Figure 3). The mean ages of Tm and T [$t(306) = .24$, $p = .808$], in W/Gm and W/G [$t(935) = 1.72$, $p = .085$], **and in Tm and W/Gm [$t(184) = .14$, $p = .885$]** were not significantly different.

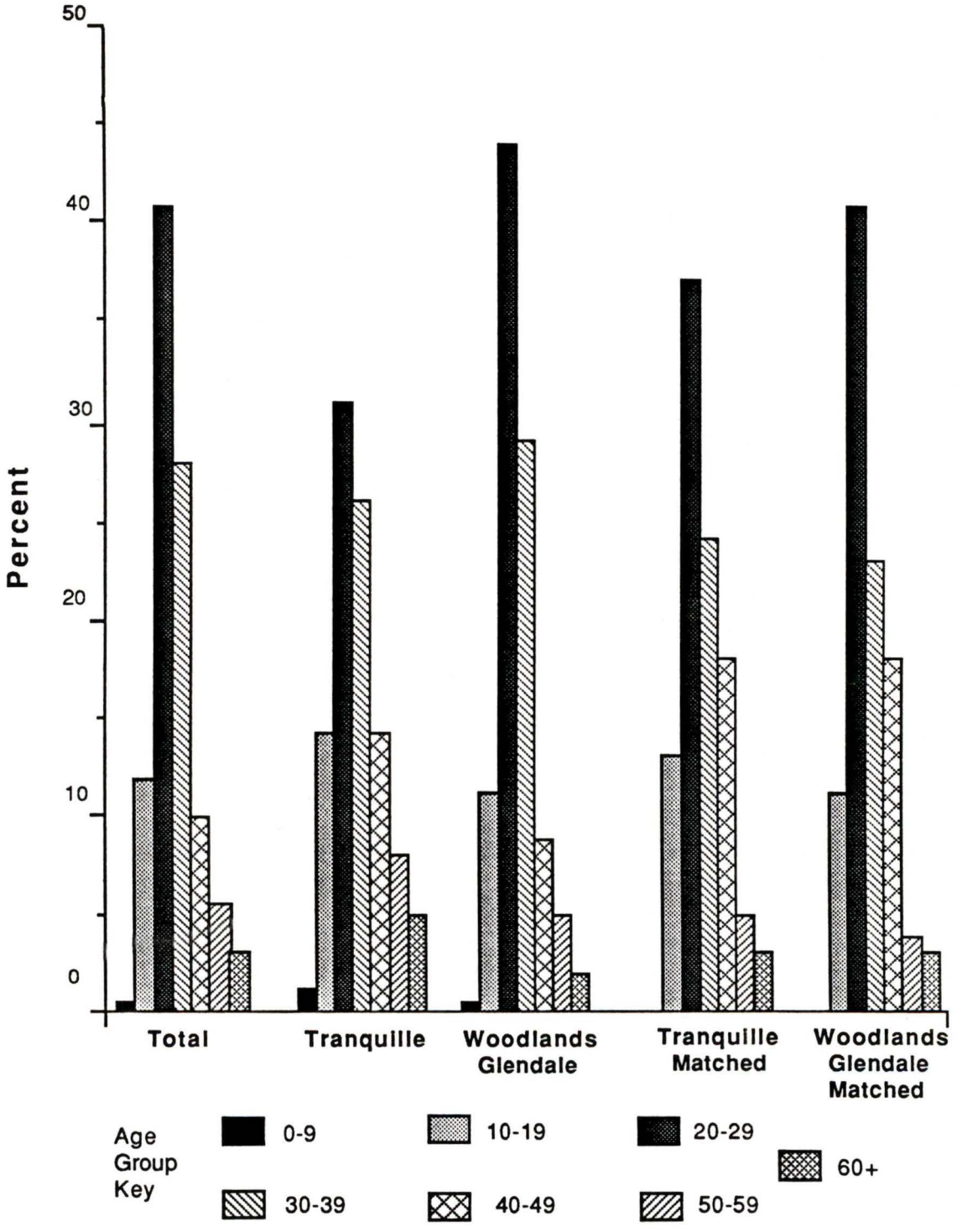


**Figure 3.** **Age in Cohorts by Group**

**Table 5**
**Frequency of Age in 10 Year Ranges by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Age | T | W/G | Tm | W/Gm |
| 0-9 | 2 | 3 | 0 | 0 |
| 10-19 | 32 | 93 | 12 | 10 |
| 20-29 | 65 | 374 | 34 | 38 |
| 30-39 | 57 | 252 | 22 | 21 |
| 40-49 | 26 | 63 | 17 | 17 |
| 50-59 | 20 | 42 | 5 | 4 |
| 60+ | 13 | 17 | 3 | 3 |
| Minimum age | 9 | 7 | 12 | 13 |
| Maximum age | 79 | 77 | 79 | 69 |
| Mean age | 33 | 31 | 33 | 32 |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

*Stay Length (1983)*

The stay length was defined as the length of continuous residence in any institutional facility and is reported here in 5 year increments (see Table 6 and Figure 4). The stay length of some subjects was not known/reported by the caregivers. Descriptively, the distribution for all populations is reasonably comparable. Approximately 25% of the subjects of all the samples had lived in institutions for 10 to 14 years (T-21%, W-22%, Tm-26%, W/Gm-27%). The second

longest stay length varied between 20 and 29 years (W-26%) and 30-39 years (T-21%, Tm-20%, W/Gm-22%). The subjects in the Tm and W/Gm groups had a shorter maximum stay length than the other groups by an average of 13.5 years. The distribution of the stay length was not significantly different between T and Tm [$X^2(8, N = 308) = 6.99, p = .54$] and W/G and W/Gm where the maximum stay length for W/Gm was shorter compared with W/G [$X^2(8, N = 937) = 79.69, p<.001$]. **The pattern of distribution for Tm and W/Gm did not differ significantly [$X^2(6, N = 93) = 4.07272, p = .6668$].** No significant difference was found in comparison of the stay length for T with Tm [$t(306) = 1.7, p = .09$] and W/G with W/Gm [$t(935) = 1.82, p = .068$] **nor in Tm with W/Gm [$t(184) = .55, p = .581$].**

**Table 6**
**Frequency of Stay Length in Years by Sample Group (reported in grouped data)**

| | Group | | | |
|---|---|---|---|---|
| Years | T | W | Tm | W/Gm |
| Unknown | 6 | 65 | 1 | 2 |
| 0-4 | 11 | 36 | 9 | 3 |
| 5-9 | 27 | 54 | 14 | 11 |
| 10-14 | 42 | 179 | 24 | 25 |
| 15-19 | 22 | 159 | 6 | 12 |
| 20-29 | 38 | 226 | 14 | 14 |
| 30-39 | 46 | 109 | 19 | 20 |
| 40-49 | 16 | 9 | 4 | 4 |
| 50+ | 7 | 7 | 2 | 2 |
| Minimum stay | 0 | 0 | 0 | 0 |
| Maximum stay | 67 | 65 | 55 | 50 |
| Mean stay | 21 | 18 | 19 | 20 |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

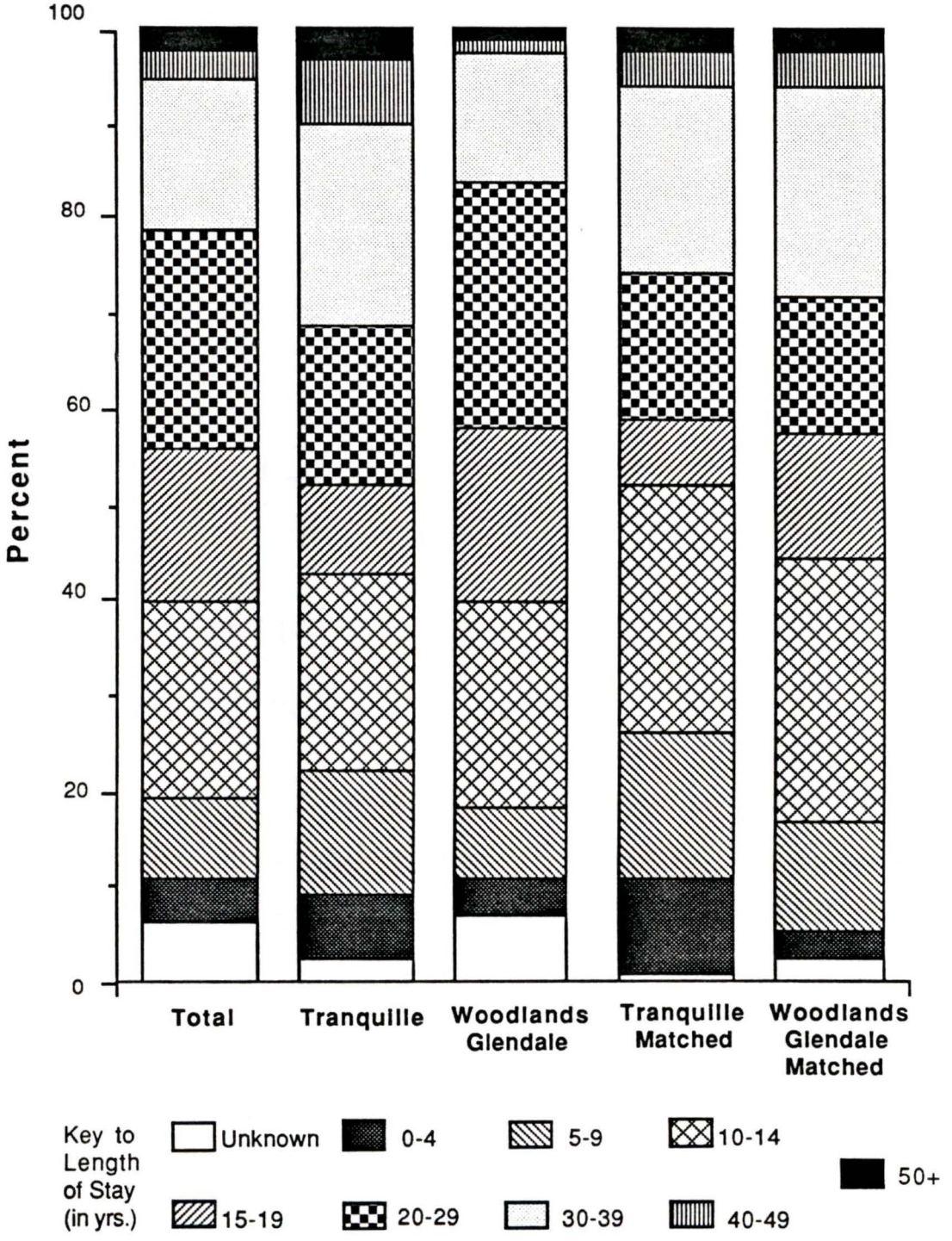


**Figure 4. Length of Stay in Institution for Cohorts by Group**

*Adaptive Behaviour and The Fourteen Component Variables (1983)*

A score of 1 represented the highest degree of independent function as defined individually for each of the variables whereas a score of 5 rated the individual as the most dependent. Ambulation was the ability to travel and ranged from independent gait to the dependent use of a wheelchair. Transfer was defined in terms of ability to move from a bed to chair, toilet or other objective and back again. Bathing, dressing, grooming, eating, control of bowel and bladder, food preparation, housekeeping, and shopping were variables describing personal care and hygiene functions. Vision and hearing had ranges from unimpaired to blind or deaf respectively. Travelling captured the degree of ability and the degree of supervision required to use transportation in a range of independent and dependent alternatives.

*Adaptive Behaviour Score (1983)*

The data from the raw adaptive behaviour scores were used to classify subjects as effective, moderately effective and at-risk (see Table 7 and Figure 5). In comparing the distribution of scores in adaptive behaviour, T was significantly more disabled than Tm [$X^2(2, N = 308) = 22.50512, p<.0001$], W/G was significantly more disabled than W/Gm [$X^2(2, N = 937) = 27.11168, p<.0001$] **whereas a**

**nonsignificant difference was found between Tm and W/Gm [X2(2, 186) = 2.81046, p = .2453].** The Tm and W/Gm groups reported proportionately fewer subjects in the at-risk category.

**Table 7**
**Frequencies and Statistical Levels of Adaptive Behaviour Scores by Sample Group (reported in grouped data)**

| | Group | | | |
|---|---|---|---|---|
| Score | T | W/G | Tm | W/Gm |
| Effective | 80 | 262 | 47 | 36 |
| Moderate | 78 | 323 | 43 | 52 |
| At Risk | 57 | 259 | 3 | 5 |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

Means of the aggregate adaptive behaviour scores are presented at the bottom of Table 8. The subjects in the Tm (M = 35.26) and W/Gm (M = 37.13) groups were significantly more capable in comparison to their counterparts in the (T-Tm) (M = 41.33) [t(259.1) = 5.41, p<.001] and (W/G-W/Gm) (M = 42.51) [t(137.16) = 5.82, p<.001] groups respectively. **No significant difference was found between the Tm (M = 35.26) and W/Gm (M = 37.13) groups [t(184) = 7.0, p = .11].**

**Table 8**
**Median Scores on the Fourteen Daily Living Skill Variables Comprising the Adaptive Behaviour Score Reported by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Variable | T | W/G | Tm | W/Gm |
| Ambulation | 1.0 | 1.0 | 1.0 | 1.0 |
| Transfer | 1.0 | 1.0 | 1.0 | 1.0 |
| Bathing | 4.0 | 4.0 | 4.0 | 4.0 |
| Dressing | 3.0 | 4.0 | 2.0 | 3.0 |
| Grooming | 4.0 | 4.0 | 3.0 | 4.0 |
| Eating | 2.0 | 2.0 | 1.0 | 2.0 |
| Bladder Control | 2.0 | 2.0 | 1.0 | 1.0 |
| Bowel Control | 2.0 | 2.0 | 1.0 | 1.0 |
| Vision | 1.0 | 1.0 | 1.0 | 1.0 |
| Hearing | 1.0 | 1.0 | 1.0 | 1.0 |
| Food Preparation | 5.0 | 5.0 | 5.0 | 5.0 |
| Housekeeping | 5.0 | 5.0 | 5.0 | 5.0 |
| Shopping | 5.0 | 5.0 | 5.0 | 4.0 |
| Travelling | 3.0 | 3.0 | 3.0 | 3.0 |
| **M** A. B. Score | 35.3 | 37.1 | 35.2 | 37.1 |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

*Fourteen Component Variables (1983)*

The median scores of all five groups on each of the 14 variables are shown in Table 8. These scores indicated that the subjects in all five groups were generally independent in ambulation and transfers and unimpaired in vision and hearing, required some supervision with eating, and needed to be

routined in bowel and bladder function. They needed to be accompanied to travel, and required much assistance in dressing, bathing, grooming. Food preparation, housekeeping and shopping were reported as skills which these individuals generally could not accomplish (either because they could not learn the skills or because they had no opportunity to learn them). Some mild variances were noted as seen in Table 8.

Although the medians indicate that the groups were comparable on the 14 variables, the medians do not indicate whether the distributions of scores for the 14 variables (1.e. of 1s, 2s, 3s, etc) were the same across groups. Therefore, these distributions were analyzed using the chi-square distribution test (see Table 9).

**Table 9**
**Chi-Square Values and Significance Levels on the Fourteen Daily Living Skills Variables Comprising the Adaptive Behaviour Score for Between Group Comparisons**

| | Group Comparisons | | |
|---|---|---|---|
| Variable | Tvs.Tm N=308 | W/Gvs.W/Gm N=937 | Tmvs.W/Gm N=186 |
| Ambulation | 19.1*** | 31.9*** | 1.4 |
| Transfer | 22.7*** | 30.3*** | .9 |
| Bathing | 4.9 | 11.7* | 4.0 |
| Dressing | 9.2 | 25.8*** | 22.8*** |
| Grooming | 5 | 9.7* | 21.1*** |
| Eating | 19.6*** | 16.8** | 11.2** |
| Bladder Control | 27.3*** | 22.1*** | 5.3 |
| Bowel Control | 23.9*** | 18.5** | 10.6* |
| Vision | 6.3* | 4.3 | 1.3 |
| Hearing | 5.4 | .6 | .9 |
| Food Preparation | 2.5 | 12.8* | 4.3 |
| Housekeeping | 10.8* | 38.2*** | 24.9*** |
| Shopping | 3.3 | 16.8*** | 4.7 |
| Travelling | 14.0*** | 19.9*** | 1.2 |

Note: All statistics are rounded to 1 decimal place. * = $p<.05$. ** = $p<.01$. *** = $p<.001$. T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

The distribution of scores in bathing, dressing, grooming, hearing, food preparation, and shopping activities showed Tm to be comparable to T. However, the pattern of distribution showed that Tm was more functionally capable than T on the remaining variables. Only in vision and hearing did W/Gm and W/Gm appear to have representative distribution

patterns. The distributions of all the other variables showed W/Gm was more capable than W/G.

**In 1983, the subjects in Tm and W/Gm were reported to have a significantly different distribution pattern in the activities of dressing, grooming, eating, bowel control, and housekeeping in which Tm subjects rated more frequently in the higher functional levels than the subjects in W/Gm.**

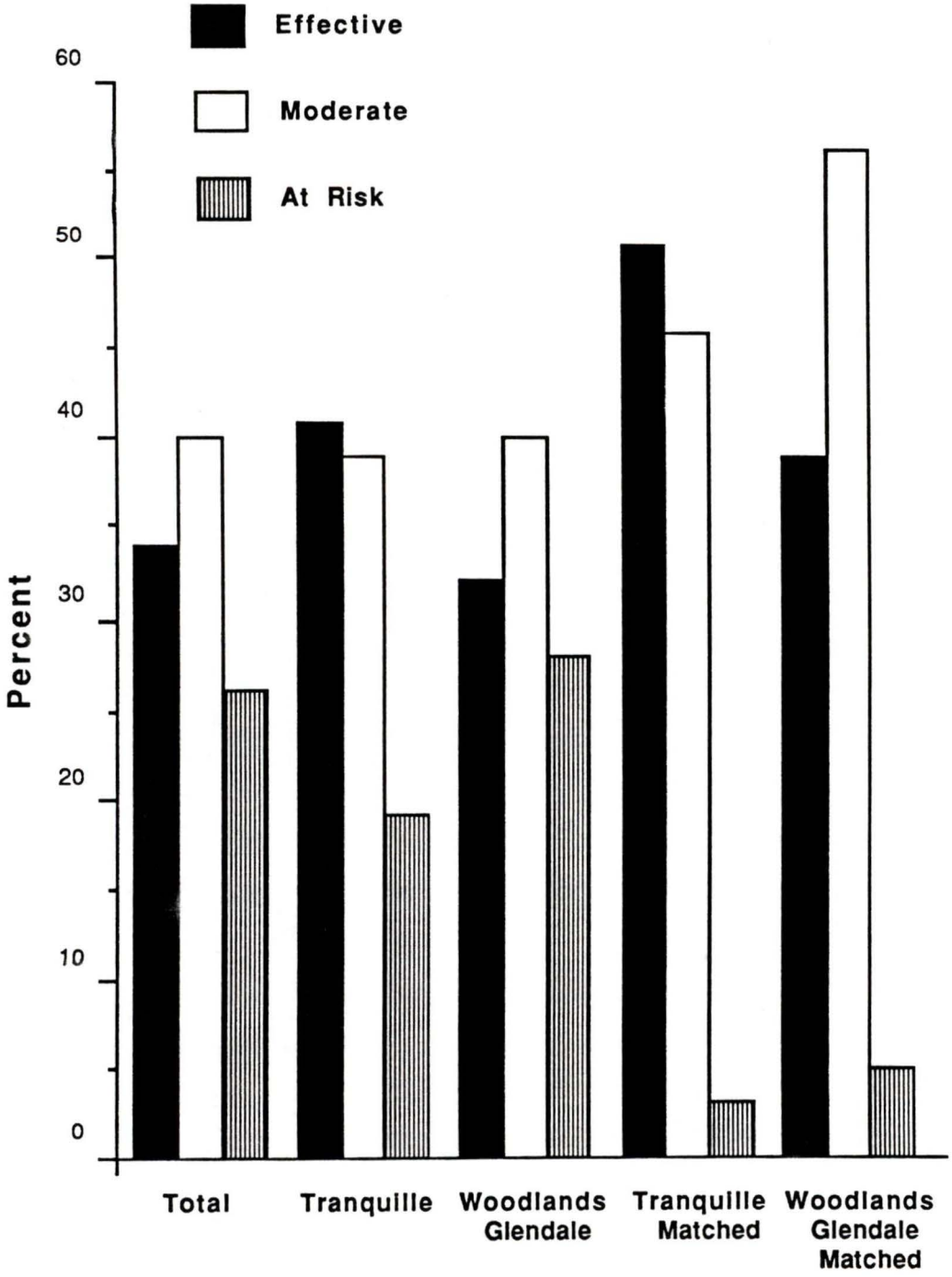


**Figure 5.** **Adaptive Behaviour Level by Group**

*Psychological Function Score and Six Component Variables (1983)*

A score of 1 represented the most capable level of function whereas a rating of 5 represented the most dependent. The variable called speech recorded the individual's ability to express spoken language, whereas understanding represented their ability to understand spoken language. General comprehension was defined as the degree of ability to interpret common non-language properties associated with rapport between people such as gestures, facial expressions and "body-language". Self-direction was defined as the degree of initiative the individual demonstrated overall. Emotional stability represented the nature of the mood of the individual over time. The behaviour variable reported the typical pattern of an individual's usual disposition.

*Psychological Function Score (1983)*

The psychological function scores are reported in grouped categories from the raw data on four separate levels which include good, fair, poor and at-risk. Close to 50% of the subjects in all groups were rated as functioning in the poor category, while approximately 75% scored fair or lower. The data reported in Figure 6 and Table 10 show similar distribution patterns in the 4 categories across all groups though proportionately more subjects in T rated in the at-risk

category than in W/G. In comparing the pattern of ability on the aggregate psychological function scores, T was significantly different from Tm [$X^2(3, N = 308) = 11.77628$, $p = .0082$], but W/G and W/Gm [$X^2(3, N = 937) = .08944$, $p = .7649$] were comparable. **No significant difference was found between Tm and W/Gm on the distribution pattern of aggregate data [$X^2(3, 186) = .53989$, $p = .910$].**

**Table 10**
**Frequency of Psychological Function Scores by Sample Group (reported in grouped data)**

| | Group | | | |
|---|---|---|---|---|
| Score | T | W/G | Tm | W/Gm |
| Good | 1 | 62 | 6 | 5 |
| Fair | 49 | 212 | 19 | 23 |
| Poor | 91 | 416 | 43 | 41 |
| At Risk | 74 | 154 | 25 | 24 |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

The aggregate psychological function scores are reported in Table 11. Subjects in Tm ($M = 21.21$) were functioning at a higher level than subjects in T ($M = 22.34$) [$t(306) = 2.06$, $p = .04$]. Individuals in W/G ($M = 20.398$) and W/Gm ($M = 20.796$) were not significantly different [$t(935) = .76$, $p = .450$] **as**

was also the case between Tm (M = 21.22) and W/Gm (M = 20.796) [t(184) = .355, p = .3047].

**Table 11**
**Median Scores on the Six Variables Comprising the Psychological Function Score Reported by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Variable | T | W/G | Tm | W/Gm |
| Speech | 5.0 | 5.0 | 5.0 | 5.0 |
| Understanding | 3.0 | 3.0 | 2.0 | 3.0 |
| Comprehension | 4.0 | 3.0 | 4.0 | 3.0 |
| Self Direction | 4.0 | 4.0 | 4.0 | 4.0 |
| Emotional Stability | 4.0 | 3.0 | 4.0 | 4.0 |
| Behaviour | 4.0 | 3.0 | 4.0 | 4.0 |
| M P. F. Scores | 22.3 | 20.4 | 21.2 | 20.7 |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

*The Six Component Variables (1983)*

The greatest percentage of subjects in all the groups had no speech or it was not understandable. Their self-direction was low. They understood key words only. Their general comprehension was reported to be limited, while emotional stability was labile and behaviour ranged from requiring constant supervision to actively resistant.

Although the medians indicate that the groups were comparable on the 6 variables, the medians do not indicate whether the distributions of scores for each of the 6 variables were the same across groups. Therefore, those distributions were analyzed using chi-square distribution tests (see Table 12).

**Table 12**
**Chi-Square Values and Significance Levels on the Six Variables Comprising the Psychological Function Score Reported by Between Group Comparisons**

| | Group Comparisons | | |
|---|---|---|---|
| Variable | Tvs.Tm<br>N = 308 | W/Gvs.W/Gm<br>N = 937 | Tmvs.W/Gm<br>N=186 |
| Speech | 20.4*** | 3.6 | 4.4 |
| Understanding | 7.9 | 15.8** | 8.1 |
| Comprehension | 7.5 | 28.0*** | 3.6 |
| Self Direction | 6.9 | 10.7* | 6.5 |
| Emotional Stability | .8 | 7.8 | 3.8 |
| General Behaviour | 3.6 | 13.8* | 5.5 |

Note: All statistics are rounded to one decimal place. * = $p<.05$. ** = $p<.01$. *** = $p<.001$. T = Tranquille subjects; W/G = Woodlands/Glendale subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

The T and the Tm groups were not significantly different except for speech, on which the Tm subjects were more capable than those in T. The subjects in the W/Gm were more capable than the W/G group in the areas of comprehension,

understanding and behaviour. **No significant differences were found between the Tm and W/Gm groups.**

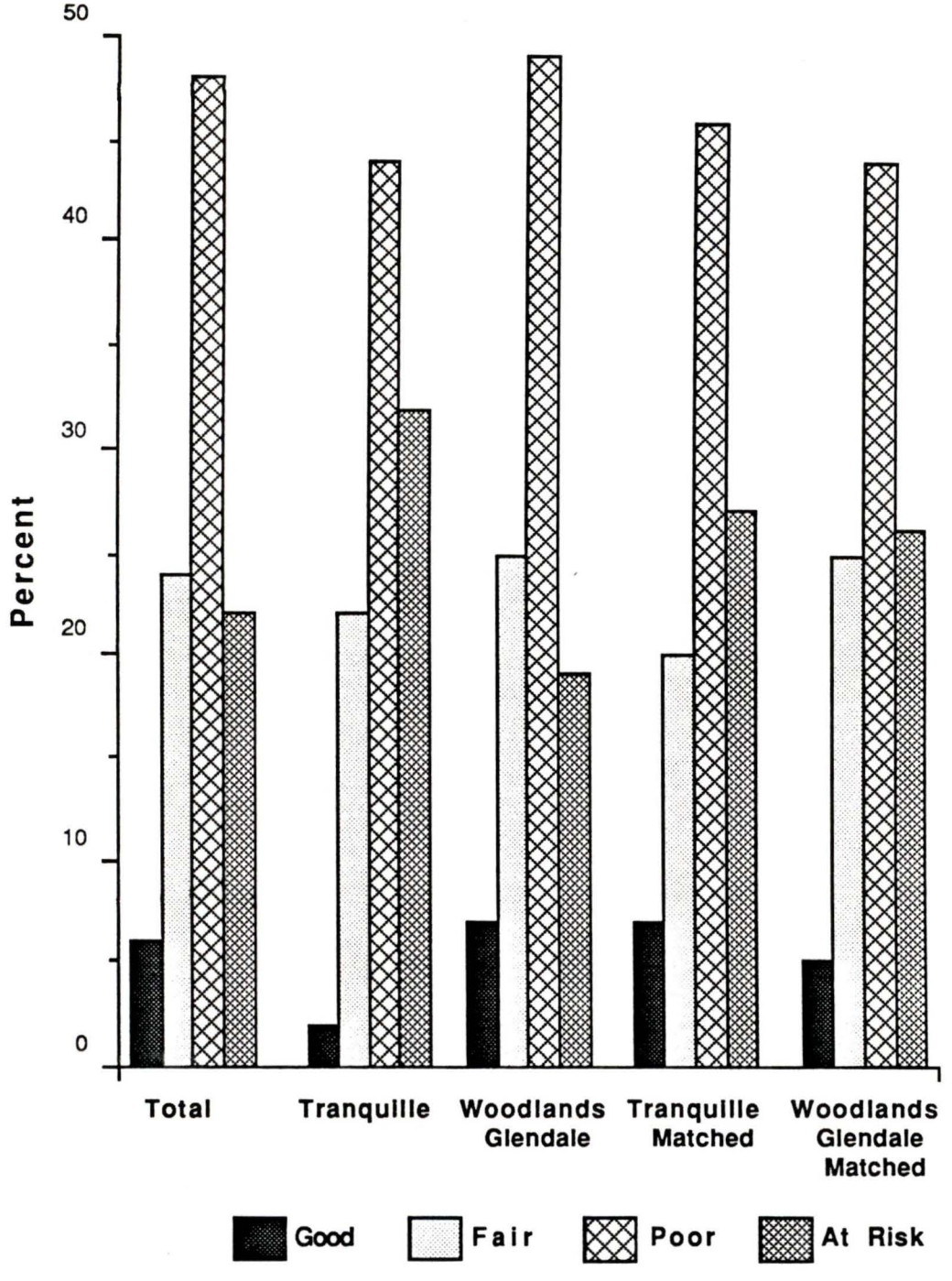


**Figure 6. Level of Psychological Function by Group**

## 1983 Analysis of Variables Other Than Those Used for Matching

This section includes analyses of scores obtained in 1983 on variables not used for matching. They included diagnoses of retardation, diagnoses of health problems, medications, treatments, special procedures, ability scales, extraordinary pathology and actual and projected service levels.

### *Diagnosis of Mental Retardation (1983)*

A single cause of mental retardation was reported. Unspecified diagnosis was the most commonly reported classification of retardation for all groups being 3-4 times more frequent than the next most common, single, diagnosis of Encephalopathy (see Table 13). Downs Syndrome was reported nearly as frequently in all groups as was the category called other specified diagnoses which included a variety of uncommon conditions such as Leigh's disease and Soto's syndrome and which affected approximately 12-13% of each population. The difference between the groups of T and Tm [$X^2(3, N = 308) = .93513$, $p = .8169$] and W/G and W/Gm [$X^2(6, N = 937) = 9.02568$, $p = .1721$] was not significant. **However, the distribution of cause of retardation between the matched subjects in Tm and W/Gm was significantly different [$X^2(4, N = 186) = 10.71339$, $p = .03$].** There were more unspecified causes in Tm with more

unknown, infection, and psychosis causes in W/Gm.

**Table 13**
**Frequency of Reported Cause of Retardation by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Diagnosis | T | W/G | Tm | W/Gm |
| Unknown | 0 | 11 | 0 | 4 |
| Downs Syndrome | 17 | 111 | 10 | 12 |
| Unspecified | 142 | 413 | 61 | 45 |
| Encephalopathy | 30 | 145 | 13 | 12 |
| Other Specific | 25 | 115 | 8 | 11 |
| Trauma | 0 | 2 | 0 | 0 |
| Infection | 1 | 27 | 1 | 4 |
| Psychosis | 0 | 20 | 0 | 5 |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

*Diagnoses of Health Problems (1983)*

Health problems were reported in 35 major diagnostic groupings. Only the 13 most common groups are reported here and included seizures, blindness, general hearing problems, spinal scoliosis, spastic quadriplegia (associated with cerebral palsy), general behaviour problems, violent behaviour to others, self abuse, general skin problems, miscellaneous eye problems, obesity, skeletal deformities other than

scoliosis, and other (see Table 14). Subjects were often reported in more than one diagnostic group. Comparing the proportion of subjects reported as having one or more diagnoses of health problems showed that T was comparable to Tm [$X^2(1, \underline{N} = 308) = .31334$, $\underline{p} = .5756$], W/G was comparable to W/Gm [$X^2(1, \underline{N} = 937) = .08944$, $\underline{p} = .7649$] and that **Tm and W/Gm were not significantly different [$X^2(1, \underline{N} = 186) = 2.37510$, $\underline{p} = .1233$].**

The most commonly reported health problem was seizures occurring in 22% of T, 40% of W/G, 40% of Tm, and 39% of W/Gm. The T group reported general behaviour problems in 8% of its subjects with quadriplegia as a low second at 4%. In W/G subjects, general behaviour problems were reported in 31%, with eye problems and quadriplegia at 16% and 14%. **Tm and W/Gm shared general behaviour problems as their highest category but Tm reported obesity and other health problems as the second highest level while W/Gm showed violent behaviour to others and self aggression as the second most frequent disorder.**

**Table 14**
**Frequency of Reported Health Problems by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Diagnosis | T | W/G | Tm | W/Gm |
| Seizure | 106 | 466 | 37 | 36 |
| Blind | 17 | 74 | 7 | 4 |
| Hearing | 12 | 86 | 6 | 9 |
| Scoliosis | 32 | 116 | 2 | 8 |
| Quadriplegia | 45 | 163 | 5 | 6 |
| General Behaviour | 64 | 339 | 35 | 48 |
| Violent | 7 | 124 | 5 | 24 |
| Self Abusive | 9 | 120 | 8 | 22 |
| Skin Problems | 25 | 121 | 10 | 18 |
| Miscellaneous Eye | 10 | 175 | 4 | 23 |
| Obesity | 27 | 80 | 12 | 12 |
| Skeletal | 8 | 66 | 4 | 9 |
| Other | 22 | 105 | 12 | 15 |
| Total Health Problems | 384 | 2035 | 132 | 366 |
| **N** Without Problems | 15 | 19 | 6 | 1 |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

*Total Number of Drugs and Selected Special Medications (1983)*

The types of medications were recorded in 18 categories. The 10 highest are reported here and included antipsychotic, tranquilizer, anticonvulsant, antibiotic, pain, skin, vitamin, fecal softeners, other, and none or no medications (see Table 15). Subjects may have been reported in more than one

medication group. Antipsychotic medication was the most common type in all groups except for T where it was secondary to anticonvulsant drugs. Anticonvulsants were the second most common one in W/G, and Tm, but W/Gm indicated antidepressants as the second rank. Antidepressants were generally the third most frequent medication in the other groups.

**Table 15**
**Frequency of Medication Type by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Type | T | W/G | Tm | W/Gm |
| Antipsychotic | 79 | 382 | 50 | 58 |
| Tranquilizers | 76 | 339 | 42 | 35 |
| Anticonvulsant | 98 | 402 | 35 | 23 |
| Antibiotic | 12 | 81 | 1 | 7 |
| Pain | 16 | 80 | 0 | 5 |
| Skin | 22 | 214 | 13 | 30 |
| Vitamins | 32 | 100 | 16 | 8 |
| Fecal Softeners | 48 | 316 | 18 | 24 |
| Other | 217 | 110 | 8 | 10 |
| None | 22 | 49 | 9 | 8 |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

Some drug types were identified individually in the Tm and W/Gm populations so they could be examined separately (see

Table 16). The total number of types of medications was recorded and broken down into prescription, controlled or nonprescription medication. The types of drugs used for control of behavioural problems were also isolated and included antipsychotic, tranquilizer, and antiseizure medication. Antiseizure medications were included in this category because of their capacity to influence mood and muscle tone while affecting seizure activity. The mean scores only are presented.

**Table 16**
**Mean Scores of Special Categories of Drugs and T Values and Significance Levels of Special Categories of Drugs in the Tm and W/Gm Groups**

| | Group | | |
|---|---|---|---|
| Type | Tm | W/Gm | Tmvs.W/Gm |
| Total Drugs | 3.0 | 3.7 | 2.2 |
| Prescription | 2.4 | 2.5 | .5 |
| Control | .0 | .1 | 1.7 |
| Nonprescription | .6 | 1.1 | 2.2 |
| Antipsychotic | .6 | .8 | 2.4* |
| Tranquilizers | .6 | .5 | .9 |
| Antiseizure | .7 | .5 | .8 |

Note: Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

*Total Number of Drugs (1983)*

**W/Gm took significantly more total drugs than Tm [t(181) = 2.597, p = .010].**

*Selected Other Special Medications (1983)*

**W/Gm took significantly more antipsychotic medication as compared with Tm [t(186) = 2.386, p = .018]. The number of tranquilizers taken did not differ significantly between Tm and W/Gm [t(186) = .9049, p = .367]. There was no significant difference in the number of antiseizure drugs taken by Tm compared with W/Gm [t(186) = .76026, p = .448]. Tm subjects took the same number of prescription drugs as W/Gm [t(186) = .514, p = .608]. Tm subjects took the same number of controlled drugs as W/Gm [t(186) = 1.6887, p = .093]. Tm took less nonprescription medication than W/Gm [T(186) = 2.597, p.294].**

*Treatments (1983)*

Treatments were defined as the type of care not requiring the qualifications of a nurse (usually being given by a nursing aide). Of the 12 classifications recorded, the 5 largest are reported here. Some subjects were reported to be receiving more than one treatment. Included are the putting on and taking off equipment such as braces; skin care; behaviour training program; other; and none or no treatments required

(see Table 17). The largest percentage of all populations required no treatments and skin care was the second ranked treatment.

Comparing the proportion of subjects reported to be receiving one or more treatments showed that T was not significantly different from Tm [$X^2(1, N = 308) = 1.83468$, $p = .1756$], and that W/G was comparable to W/Gm [$X^2(1, N = 937) = .03728$, $p = .8469$]. **W/Gm received significantly more treatments than Tm [$X^2(1, N = 186) = 18.08811$, $p<.0001$].**

**Table 17**
**Frequency of Type of Treatments by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Treatments | T | W/G | Tm | W/Gm |
| Equipment | 18 | 183 | 5 | 15 |
| Skin | 37 | 358 | 9 | 36 |
| Behaviour Program | 35 | 97 | 8 | 14 |
| Other | 3 | 94 | 1 | 6 |
| None | 186 | 309 | 62 | 32 |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

*Special Procedures (1983)*

Procedures were defined as the specialized care which required qualified nursing personnel. The categories described catheter care; tracheostomal care; monitoring of oxygen; renal dialysis; and other. Of the 7 classifications recorded, only the 5 largest groups are reported (see Table 18). The greater number of subjects in all groups required no special procedures. Subjects in T required significantly more procedures than those in W/G [$X^2(2, 1245) = 22.6$, $p<.001$]. The other comparisons showed no significant difference between the T and Tm groups [$X^2(2, 309) = 1.2$, $p = .5385$], the W/G and W/Gm groups [$X^2(2, 937) = 3.34919$, $p = .1874$], and **between the Tm and W/Gm groups [$X^2(2, 186) = 3.04972$, $p .2177$].**

**Table 18**
**Frequency of Special Procedures by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Procedures | T | W/G | Tm | W/Gm |
| Catheter | 1 | 8 | 0 | 1 |
| Tracheostomy | 0 | 12 | 0 | 0 |
| Oxygen | 0 | 10 | 0 | 0 |
| Renal Dialysis | 0 | 0 | 1 | 0 |
| Other | 2 | 57 | 0 | 3 |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

*Ability Scales (1983)*

The nine ability scale scores were derived from combined scores on 2 or more of the 14 variables comprising the adaptive behaviour score and the 6 variables comprising the aggregate psychological function score. The data are presented in Tables 19 and 20 and the detailed results follow.

**Table 19**
**Mean Scores on Nine Scales of Ability by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Scale | T | W/G | Tm | W/Gm |
| Mobility | 4.3 | 4.8 | 2.0 | 2.0 |
| Selfcare | 15.9 | 17.2 | 14.2 | 15.8 |
| Toilet | 4.9 | 5.5 | 3.5 | 3.9 |
| Sensory | 3.1 | 2.8 | 2.5 | 2.7 |
| Communication | 10.1 | 9.8 | 8.5 | 9.2 |
| Awareness | 7.9 | 7.0 | 7.4 | 7.0 |
| (Un)disturbed | 7.2 | 6.3 | 7.4 | 7.1 |
| Living | 22.2 | 20.7 | 20.7 | 19.2 |
| (In)depend. | 56.0 | 54.8 | 50.8 | 51.1 |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

**Table 20**
**T Values and Significance Level on the Nine Scales of Ability by Between Group Comparisons**

| Scale | Group | | |
|---|---|---|---|
| | Tvs.Tm N=308 | W/Gvs.W/Gm N=937 | Tmvs.W/Gm N=186 |
| Mobility | 5.6*** | 9.3*** | .2 |
| Selfcare | 3.6*** | 3.4*** | 1.4 |
| Toilet | 4.5*** | 5.4*** | .5 |
| Sensory | 3.2** | 1.2 | 1.0 |
| Communication | 3.2** | 1.5 | .6 |
| Awareness | 2.5* | .1 | 2.6* |
| (Un)disturbed | 1.0 | 3.1** | 1.6 |
| Living | 3.6*** | 3.8*** | 4.6*** |
| (In)dependence | 4.0*** | 2.9** | 1.9 |

Note: All statistics are rounded to one decimal place. * = $p<.05$. ** = $p<.01$. 888 = $p<.001$. T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

Mobility Scale (1983) - All groups were reported to be generally independent on the mobility scale though Tm group had slightly higher numbers of dependent people (see Figure 7). The subjects in T were significantly less independently mobile than Tm subjects. Similarly, the W/Gm subjects were more mobile than those in W/G. **There was no significant difference in mobility between Tm and W/Gm.**

**Selfcare Scale (1983)** - The T subjects were significantly less capable in selfcare than Tm and the W/G subjects were less capable than W/Gm. **No significant difference was found between the Tm subjects and those in W/Gm.**

**Toilet Scale (1983)** - The T group were significantly less able in toileting skills than Tm. The W/G subjects were less able than W/Gm. **No significant difference was found between Tm and W/Gm.**

**Sensory Scale (1983)** - The subjects in T had significantly less able sensory skills than Tm. No significant difference was noted between the W/G group and W/Gm **nor was there a significant difference between Tm and W/Gm.**

**Communication Scale (1983)** - T subjects were significantly less capable in communication than Tm. No significant difference was found between W/G and W/Gm **nor was there a significant difference between Tm and W/Gm.**

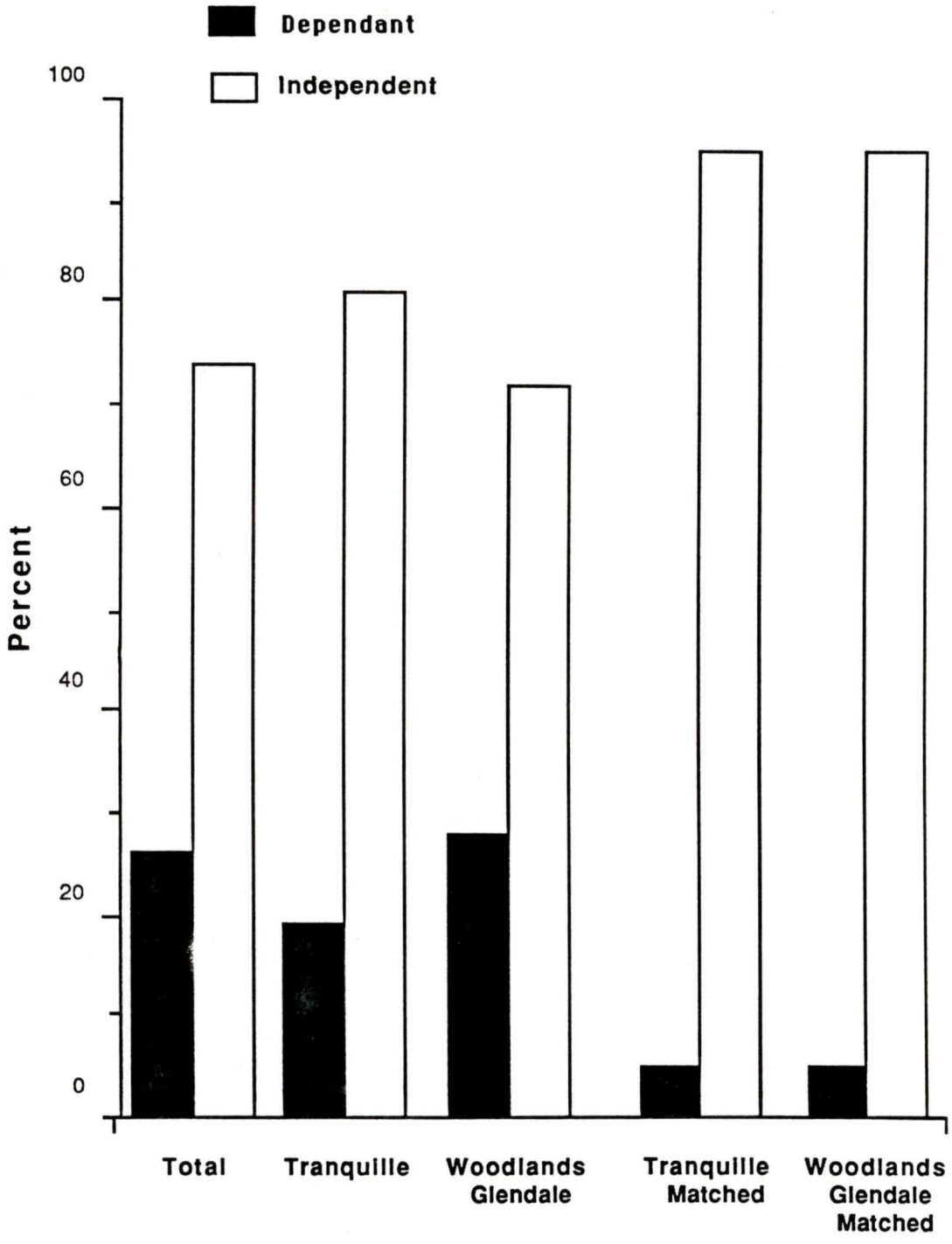


Figure 7. Level of Mobility by Group

**Awareness Scale (1983)** - The T subjects were significantly less aware of their environment than Tm. No significant difference was found between W/G and W/Gm. **W/Gm subjects were found to be significantly more aware than Tm.**

**(Un)disturbed Scale (1983)** - There was no significant difference between T and Tm. The W/G population was significantly less disturbed than W/Gm. **No significant difference was found between Tm and W/Gm.**

**Living Scale (1983)** - Tm were significantly more independent than T. W/Gm subjects were significantly more capable than W/G and **W/Gm was found to be significantly more skilled than Tm.**

**(In)dependence Scale (1983)** - Tm was found to be significantly more independent than T as W/Gm was more independent than W/G. **No significant difference in independence skills was found between Tm and W/Gm.**

Selected ability scales were compared with the adaptive behaviour and psychological function scores respectively depending on the origin of the items used in the composition of each subscale (see Table 21). For all groups, there was a high correlation between the adaptive behaviour score and the selfcare scale, moderate with the toileting scale and the living scale and low with the sensory scale. The adaptive

behaviour scale correlated inversely with the mobility scale.

The psychological function score correlated moderately with the communication and (un)disturbed scales and highly with the awareness scale. No correlation was made with the (in)dependence scale because of the interdependency between ability scales in relation to items used in the adaptive behaviour score and also in the psychological function score.

**Table 21**
**Correlation Values on Comparison of Scores on 5 Ability Scales with the Adaptive Behaviour Score and on 3 Ability Scales with the Pscyhological Function Score**

| | Group | | |
|---|---|---|---|
| Scale | Tm | W/Gm | Allm |
| With A.B.Score | | | |
| Mobility | -.5142 | -.4125 | -.4584 |
| Selfcare | .8915 | .8441 | .8661 |
| Toilet | .7274 | .7346 | .7322 |
| Sensory | .0974 | .2298 | .1741 |
| Living | .7619 | .6613 | .6613 |
| With P.F.Score | | | |
| Communication | .7672 | .7020 | .7287 |
| Awareness | .8455 | .8395 | .8416 |
| (Un)disturbed | .6217 | .7884 | .7083 |

Note: Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale; Allm = all matched subjects.

*Extraordinary Pathology (1983)*

Extraordinary pathology was determined by selecting those individuals who had a reported medical problem in any one of the categories of violence toward others, self-abuse causing physical harm, "digging" faeces, or sexual abuse plus a score of 3, 4 or 5 on either emotional stability or behaviour (see Table 22). Low frequencies were reported in all sample groups with 6% in T, 20% in W/G, 11% in Tm and 30% in W/Gm. Because of the low incidence rate, interpretation of significance testing was not feasible but it is apparent that **Tm had less than W/Gm** without adjustment for differences in intellectual levels.

**Table 22**
**Frequency of Incidence of Extraordinary Pathology by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| | T | W/G | Tm | W/Gm |
| f | 19 | 187 | 10 | 28 |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

*Actual Service Levels (1983)*

In 1983, the actual level of service received by the subjects in the institution at that time was recorded in exact time (see Table 23). Because the range of exact time was recorded, only the mean in hours per year are reported in each case. The variables included physiotherapy, psychiatrist services, the care of other medical specialists, physician care, psychologist care, vocational training, nursing care and the care of a nursing aide.

T and Tm reported no significant difference in the total level of care [$t$(225.67) = .26, $p$ = .791] and W/G and W/Gm received comparable amounts of care [$t$(185.86) = .44, $p$ = .661]. **Tm did not receive significantly more care than did W/Gm [$t$(163.32) = 1.11, $p$ = .267].**

**Table 23**
**Mean Scores of Hours of Actual Service in 1983 by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Level | T | W/G | Tm | W/Gm |
| Physician | 11.9 | 3.8 | 7.1 | 4.7 |
| Nurse | 562.5 | 507.8 | 261.4 | 334.3 |
| Psychologist | 4.6 | 1.7 | 2.7 | 2.4 |
| Physiotherapy | 5.4 | .7 | 2.4 | .9 |
| Vocational | .0 | 3.1 | .0 | 1.1 |
| Psychiatrist | .0 | .3 | .0 | .1 |
| Other Special | .0 | .0 | .0 | .0 |
| Aide | 8160.1 | 8228.5 | 8474.6 | 8401.7 |
| Sum Score | 8744.6 | 8746.0 | 8748.2 | 8745.2 |

Note: All statistics are rounded to one decimal place. T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

The *t* values and significance levels for comparisons of levels of different types of care are presented in Table 24 and the detailed results follow.

**Table 24**
**T Values and Significance Levels for Actual Service Hours in 1983 by Between Group Comparisons**

| Scale | Group Comparisons | | |
|---|---|---|---|
| | Tvs.Tm N=308 | W/Gvs.W/Gm N=937 | Tmvs.W/Gm N=186 |
| Doctor | 303.3* | 1.4 | 2.3* |
| Nurse | 4.6*** | 4.0*** | 1.7 |
| Psychology | 1.4 | .8 | .3 |
| Physiotherapy | 1.5 | .2 | 1.1 |
| Vocational | .0 | 1.5 | 1.0 |
| Psychiatric | .7 | 1.1 | 1.3 |
| Other Special | 1.4 | .1 | 1.3 |
| Aide | 4.4*** | 4.0*** | 1.7 |
| Sum Score | .2 | .2 | 1.0 |

Note: All statistics are rounded to one decimal place. * = $p<.05$. ** = $p<.01$. 888 = $p<.001$. T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

**Care by a Physician (1983)** - The T group received significantly more physician's care than the Tm group. No difference was found between W/Gm and W/G. **The subjects in Tm83 received significantly greater care by a physician than did W/Gm83.**

**Qualified Nursing Care (1983)** - T received significantly more nursing care than Tm and W/G more than W/Gm. **The**

**difference found between Tm83 (M = 261.3665) and W/Gm83 (M = 334.3449) was not significant.**

**Care by Aide Staff (1983)** - T received significantly more aide care than Tm and W/G more than W/Gm. **No significant difference was found between Tm and W/Gm.**

**Physiotherapy Services (1983)** - No significant difference in the amount of physiotherapy was reported in any of the comparisons between T and Tm; W/G and W/Gm; **Tm and W/Gm.**

**Psychology Services (1983)** - No significant difference in the amount of psychological services between **Tm and W/Gm**; W/G and W/Gm or T and Tm.

**Psychiatric Services (1983)** - No significant difference in psychiatric services was found in comparisons of T with Tm, W/G with W/Gm, and **Tm with W/Gm.**

**Vocational Services (1983)** - No significant difference vocational services was found between T and Tm, W/G and W/Gm, or between **Tm and W/Gm.**

**Service by Other Medical Specialists (1983)** - The amount of time received by subjects in any of the groups of service by other medical specialists was very low. No significant difference was noted in any comparisons: T with Tm; W/G with W/Gm; **Tm with W/Gm.**

**Sum Score (1983)** - No significant difference was found between T and Tm or between W/G and W/Gm. **There was no significant difference between Tm and W/Gm on the total hours of care received in 1983.**

*Projected Service Levels (1983)*

The caregiver was asked to project the amount of care the individual would require if discharged to the community in 1983 (see Table 25). The median of five levels is reported in each case where 1 is the level of care needed only if injured and 5 is an intensive level of care required. The labels represent health counselling by a public health nurse, supervision of diet, podiatry, optical services, supervised exercise program, physiotherapy, vocational training, audiology care, dentist care, speech therapy treatments, special treatments by a nurse in public health, hospital admission, orthotic care, physician visits, psychologist treatment, or school.

In comparing the total level of care projected to be necessary, T was found to be comparable to Tm [$t(151.74) = .17$, $p = .867$], and W/G comparable to W/Gm [$t(116.71) = 2.04$, $p = .043$]. **Tm was projected to need significantly more care overall in 1983 than W/Gm [$t(184) = 4.69$, $p<.001$].**

**Table 25**
**Median Scores of Reported Projected Service Levels and Mean of Sum Score in 1983 by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Level | T | W/G | Tm | W/Gm |
| Doctor | 4 | 2 | 4 | 2 |
| Nursing | 3 | 2 | 3 | 2 |
| Psychologist | 1 | 1 | 1 | 2 |
| Physiotherapy | 1 | 1 | 1 | 1 |
| Vocational | 5 | 5 | 5 | 5 |
| Diet Care | 1 | 1 | 1 | 1 |
| Podiatry | 1 | 1 | 1 | 1 |
| Optical | 1 | 1 | 1 | 1 |
| Exercise | 5 | 5 | 5 | 5 |
| Audiology | 1 | 1 | 1 | 1 |
| Dentist | 2 | 2 | 2 | 2 |
| Speech Therapy | 1 | 1 | 1 | 1 |
| Treatments | 1 | 2 | 1 | 1 |
| Hospital Admissions | 1 | 1 | 1 | 1 |
| Orthotics | 1 | 1 | 1 | 1 |
| School | 1 | 1 | 1 | 1 |
| Sum Score Mean | 33.5 | 31.7 | 32.9 | 30.5 |

Note: T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

The chi-square distribution values and significance levels for comparisons of different types of care are presented in Table 26 and the detailed description follows.

**Table 26**
**$X^2$ Values and Significance Levels for Projected Service Levels and T-value for Sum Score in 1983 by Between Group Comparisons**

| | Group Comparisons | | |
|---|---|---|---|
| Scale | Tvs.Tm N=308 | W/Gvs.W/Gm N=937 | Tmvs.W/Gm N=186 |
| Doctor | 10.8* | 10.9* | 61.4*** |
| Nursing | 4.9 | 14.6** | 19.5*** |
| Psychology | 8.5* | 10.7* | 24.9*** |
| Physiotherapy | 11.5** | 17.0*** | 7.9* |
| Vocational | 1.4 | 1.8 | 1.2 |
| Diet | 5.1 | 13.7*** | 12.1** |
| Podiatry | 7.7 | 2.6 | 6.2* |
| Optical | .5 | .5 | .0 |
| Exercise | 9.9* | 7.8* | 5.0 |
| Audiology | .9 | .1 | .4 |
| Dentistry | .9 | 4.3 | 3.2 |
| Speech | 5.4 | 3.8 | 12.4** |
| Treatments | 3.3 | 2.9 | 13.5** |
| Hospitalization | .5 | 5.8* | 1.1 |
| Orthotics | 6.66** | .2 | .2 |
| School | .1 | .1 | 1.0 |
| Sum Score | .83 | 1.7 | .0*** |

Note: All statistics are rounded to one decimal place. * = $p<.05$. ** = $p<.01$. *** = $p<.001$. T = Tranquille subjects minus Tranquille matched subjects; W/G = Woodlands/Glendale subjects minus Woodlands/Glendale matched subjects; Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects.

**Doctor's Visits (1983)** - T needed significantly more care by a physician than Tm; W/G needed more than W/Gm; **and Tm was projected to need more than W/Gm.**

**Nursing (1983)** - This variable represents the amount of care by a public nursing staff. No significant difference was reported in a comparison of T and Tm. Significantly higher projected levels of service were found in comparison of the distribution pattern in W/G compared with W/Gm, and **Tm was also projected to need significantly higher levels of care in the community than W/Gm.**

**Psychological Services (1983)** - Tm was projected to need more psychological service than T; W/Gm needed more than W/G; **and W/Gm needed more than Tm.**

**Physiotherapy (1983)** - Significance was found in all three comparisons: T needed more than Tm, W/G needed more than W/Gm, and **Tm was projected to need significantly more physiotherapy than W/Gm.**

**Vocational Programmes(1983)** - No significant difference in the need for vocational programming was found between T and Tm, W/G and W/Gm, **and no significant difference between Tm and W/Gm.**

**Diet Care (1983)** - Defined as care by a dietitician, no significant difference was noted in the T and Tm groups. A significantly higher need for diet care was projected for in W/G than W/Gm **and Tm was projected to need more diet care compared with W/Gm.**

**Podiatry(1983)** - No significant difference was noted in comparing T with Tm or W/G with W/Gm. T needed significantly more podiatry care than W/G and **Tm was projected to need more podiatry than W/Gm.**

**Optical Care (1983)** - No significance in need of optical care was noted in the differences found between T and Tm, W/G and W/Gm, **nor was there a significant difference between Tm and W/Gm.**

**Exercise Programme (1983)** - Exercise was defined as a formal, regular, guided programme usually under the recommendation of a physiotherapist. The Tm group needed significantly more exercise than T and W/Gm needed more than W/G. **No significant difference was found between Tm and W/Gm.**

**Audiology (1983)** - No significant difference in need of audiological services was found between T and Tm, W/G and W/Gm, and **no significant difference was found between Tm and W/Gm.**

**Dentistry (1983)** - No significant difference in need of dentistry was noted between T and Tm, W/G and W/Gm, **and no significant difference was found between Tm and W/Gm.**

**Speech Therapy (1983)** - No significant difference was found in comparing T with Tm or W/G with W/Gm. **Tm was projected to need significantly more speech therapy than W/Gm.**

**Treatment/Procedure(s) (1983)** - No significant difference was found in comparing T with Tm and W/G with W/Gm. **W/Gm was projected to need significantly more treatments/procedures than Tm.**

**Hospitalization (1983)** - W/G needed significantly more projected service than W/Gm. No significant difference was noted in a comparison of the subjects in T and Tm, and **no significant difference was found between Tm and W/Gm.**

**Orthotic/Prosthetic Work (1983)** - T needed significantly more orthotic/prosthetic service than Tm. No significant difference was found in comparing W/G W/Gm **nor was there a significant difference between Tm with W/Gm.**

**School (1983)** - No significance was found in the comparisons between T with Tm, W/G with W/Gm. **Projected need for Tm was not different compared with W/Gm.**

**Sum Scores (1983)** - Comparison of T with Tm and W/G with W/Gm did not show a significant difference in the total projected need. **Tm was projected in 1983 to need significantly more service if moved to the community compared with W/Gm.**

## Summary of Findings in 1983 for Tranquille and Woodlands/Glendale Matched Subjects

### 1. Representativeness of Tm Compared to T (1983)

The matched group selected from the Tranquille subjects who were moved to the community appeared to be generally representative of subjects in the original Tranquille population on the six matching variables of sex, intellectual level, age, length of stay, adaptive behaviour score and psychological function score the Tranquille matched subjects were not significantly different from the Tranquille population on the six variables.

The Tranquille matched subjects received essentially the same amount of actual service as the Tranquille population in four of the seven categories (physiotherapy, psychology, psychiatry, and vocational training) and received less care by physician, aide, and nurse. The Tranquille matched subjects were projected to need mostly the same amount of service as the Tranquille population though the matched group was projected to need greater care in psychology and exercise while the whole population required more care by a doctor, physiotherapist and orthotist/prosthetist.

2. Representativeness of W/Gm Compared with W/G (1983)

The matched subjects selected from the Woodlands/Glendale institutional population generally appeared to be representative of the Woodlands/Glendale population on four of the six matching variables. However, the Woodlands/Glendale matched subjects differed significantly from the Woodlands/Glendale population on age and stay length both of which were greater in the Woodlands/Glendale population than in the matched sample.

The Woodlands/Glendale matched subjects received no more than the Woodlands/Glendale population in care by aide, nurse, or psychiatrist, but significantly more in care by doctor, physiotherapist, and vocational training, and significantly less in care by psychologist. Comparable amounts of service were projected for both the Woodlands/Glendale matched group and the Woodlands/Glendale population on nine types of care. However, the original population was seen as needing more in care by a doctor, nurse, physiotherapist, dietician, and hospital while the matched group needed more care by a psychologist, and exercise programme.

3. The Effectiveness of the Matching Procedure (1983)

The procedure of matching subjects from Tranquille and Woodlands/Glendale found no significant difference on five of the six matching variables. However, a significant difference was noted on the matching variable of level of intellectual function showing the Tranquille matched subjects were less severely retarded overall. This difference will be elaborated in the discussion section.

4. Comparison of Tm and W/Gm on Other Variables (1983)

The matched subjects in Tranquille and Woodlands/Glendale were found to be more alike than they were different overall. Variances on some specific variables did present a mixed picture of deviation with Tranquille reported as more capable, receiving more care or requiring less intervention medically on some items and Woodlands/Glendale on other components. Generally, however, the comparisons suggested that the two groups were similarly disabled, and received comparable levels of care in the institution but were projected to need more care in total, if placed in a community setting.

No significant difference was noted in the average number of prescription, controlled, tranquilizers, or antiseizure medications taken by subjects in either sample of Tranquille matched or Woodlands/Glendale matched subjects. However, the

Woodlands/Glendale matched subjects took more drugs overall and more antipsychotic and nonprescription drugs.

The distributions of incidence of etiology of mental retardation were significantly different. More Tranquille matched subjects were reported in the unspecified category while more Woodlands/Glendale matched subjects presented in the unknown, infection and psychosis categories. More Tranquille matched subjects were reported to have health problems of obesity and the "other" category. The Woodlands/Glendale matched subjects were more violent and self-aggressive. The two matched groups did not differ significantly on the incidence of reported diagnoses in general. Extraordinary pathology was reported three times more frequently in the Woodlands/Glendale matched group as in the Tranquille matched group.

No significant difference was found between Tranquille matched and Woodlands/Glendale matched subjects on the mobility, selfcare, toilet, sensory, communication, (un)disturbed, or (in)dependence scales. The Woodlands/Glendale matched subjects were rated as significantly more able in awareness and living skills.

Subjects in the Woodlands/Glendale matched sample were reported to have received a higher frequency of treatments

though no significant difference was found in the number of procedures each received.

There was no significant difference in the total amount of care each received in 1983. They received similar levels of care by a nurse, aide, physiotherapist, psychologist, psychiatrist, vocational training and other health specialists differing only in the amount of care by a physician on which the Tranquille matched group was projected to need significantly more care than the Woodlands/Glendale matched subjects. The Tranquille matched subjects were projected in 1983 to need more care by doctor, nurse, physiotherapy, dietary, podiatry, and speech therapy if moved to a community setting whereas Woodlands/Glendale matched subjects were projected to need more care by a psychologist and in treatments and procedures.

**Comparison of the Matched Subjects in Tranquille and Woodlands/Glendale in 1986 and Between 1983 and 1986**

Differences in scores between 1983 and 1986 reflected change in the ability of the subjects which may have been due either to actual or perceived gains or losses in skill. Actual change was assumed to result from some modification of the individual's ability. Perceived change was assumed to be a result of change in caregiver or change in one caregiver's perception over time. It was impossible to determine whether reported differences reflected actual or perceived change. Either type of change may have influenced the outcome of the reporting of the level of the individuals' abilities over time. (Actually, many of the former staff of Tranquille, finding themselves unemployed by reason of the closure of Tranquille, were employed as the new staff in community facilities thus possibly supporting constancy in the perception of ability and even constancy in any possible bias in that perception). The details regarding training, attitudes, costs, effectiveness of the caregivers in relationship to the community based residents will be presented in a future paper by the author.

*Reported Cause of Mental Retardation*

The incidence of reported cause of mental retardation of the Tm and W/Gm groups is reported in Table 27. There was no significant difference between the two matched groups Tm and W/Gm in 1986 [$X^2(6, 186) = 11.23670$, $p = .0813$]. Comparison of the two groups over time showed that the distribution of each group had changed significantly over time [Tm $X^2(30, N = 93) = 111.43964$, $p<.0001$] and [W/Gm $X^2(20, N = 93) = 57.84434$, $p<.0001$]. Noticeably, there was report of more trauma cases in 1986 and more unspecified diagnoses.

**Table 27**
**Incidence of Reported Cause of Mental Retardation by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Diagnosis | Tm83 | Tm86 | W/Gm83 | W/Gm86 |
| Unknown | 0 | 0 | 4 | 1 |
| Downs | 10 | 11 | 12 | 11 |
| Unspecified | 61 | 61 | 45 | 62 |
| Encephalopathy | 13 | 2 | 12 | 6 |
| Other Specific | 8 | 9 | 11 | 6 |
| Trauma | 0 | 4 | 0 | 1 |
| Infection | 1 | 6 | 4 | 0 |
| Psychosis | 0 | 0 | 5 | 0 |

Note: Tm83 = Tranquille matched subjects in 1983; W/Gm83 = Woodlands/Glendale matched subjects in 1983; Tm 86 = Tranquille matched subjects in 1986; W/Gm86 = Woodlands/Glendale matched subjects in 1986.

*Reported Health Problems*

The reported health problems in 1986 are presented in Table 28. The proportion of subjects between Tm and W/Gm reported to have one or more health problems in 1986 was not significant [$X^2(1, 186) = .000$, $p = 1.0$]. A significant difference was found between Tm and W/Gm in 1983. Each group was compared over time on McNemar's test of correlated proportions. Tm ($M = 4.1$) showed a significant change to having more people reported as having no health problems while W/Gm ($M = .5$) reported no significant change.

**Table 28**
**Incidence of Reported Health Problems in 1983 and 1986 by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Diagnosis | Tm83 | Tm86 | W/Gm83 | W/Gm86 |
| Seizure | 37 | 44 | 36 | 39 |
| Blind | 7 | 10 | 4 | 6 |
| Hearing | 6 | 5 | 9 | 1 |
| Scoliosis | 2 | 6 | 8 | 0 |
| Quadriplegia | 5 | 5 | 6 | 4 |
| General Behaviour | 35 | 38 | 48 | 35 |
| Violent | 5 | 31 | 24 | 30 |
| Self Abusive | 8 | 27 | 22 | 23 |
| Digging/Smearing | 0 | 7 | 6 | 15 |
| Skin Problems | 10 | 28 | 18 | 20 |
| Urinary Problems | 3 | 21 | 5 | 7 |
| Miscellaneous Eye | 4 | 7 | 23 | 23 |
| Diarrhea | 1 | 6 | 0 | 10 |
| Obesity | 12 | 1 | 12 | 0 |
| Skeletal | 4 | 10 | 9 | 9 |
| Other | 12 | 21 | 15 | 36 |
| Total Health Problems | 151 | 267 | 245 | 258 |
| **N** Without Problems | 15 | 0 | 19 | 1 |

Note: Tm83 = Tranquille matched subjects in 1983; W/Gm83 = Woodlands/Glendale matched subjects in 1983; Tm86 = Tranquille matched subjects in 1986; W/Gm86 = Woodlands/Glendale matched subjects in 1986.

*Adaptive Behaviour Score and the Fourteen Component Variables*

The aggregate adaptive behaviour score and the fourteen component variables were compared by analysis of variance (anova) to determine if there was a significant difference

between Tm and W/Gm in 1986 after the 1983 scores and levels of retardation were partialled out. Where there was no significance and the level of retardation was not found to have a significant effect on the anova, the groups were examined by regression analysis to determine if, excluding group membership, there was an overall change on all subjects. The data are presented in Table 29 and in the following specific detail the mean of the difference scores are reported.

*Adaptive Behaviour Score*

No significant difference was noted between the matched groups in 1983. In 1986, the distribution of the adaptive behaviour scores did not vary significantly [$X^2(2, 184) = 1.77492$, $p = .4117$]. No significant difference was found in 1983 between Tm and W/Gm and neither Tm ($M = 4.82$) nor W/Gm ($M = 3.82$) made significant gains over time [$F(3, 184) = 2.337841$, $p = .1280$].

**Table 29**
**Mean Scores of Adaptive Behaviour Score and Medians of Fourteen Component Variables in 1983 and 1986 by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Variable | Tm83 | Tm86 | W/Gm83 | W/Gm86 |
| Ambulation | 1.0 | 1.0 | 1.0 | 1.0 |
| Transfer | 1.0 | 1.0 | 1.0 | 1.0 |
| Bathing | 4.0 | 3.0 | 4.0 | 4.0 |
| Dressing | 2.0 | 2.0 | 3.0 | 3.0 |
| Grooming | 3.0 | 3.0 | 4.0 | 3.0 |
| Eating | 1.0 | 1.0 | 2.0 | 2.0 |
| Bladder | 1.0 | 1.0 | 1.0 | 1.0 |
| Bowel | 1.0 | 1.0 | 1.0 | 1.0 |
| Vision | 1.0 | 1.0 | 1.0 | 1.0 |
| Hearing | 1.0 | 1.0 | 1.0 | 1.0 |
| Food Preparat'n | 5.0 | 3.0 | 5.0 | 4.0 |
| Housekeeping | 5.0 | 3.0 | 5.0 | 3.0 |
| Shopping | 5.0 | 3.0 | 4.0 | 3.0 |
| Travel | 3.0 | 3.0 | 3.0 | 3.0 |
| M A. B. Score | 35.2 | 30.3 | 37.1 | 33.3 |

Note: All statistics are rounded to one decimal place. Tm83 = Tranquille matched subjects in 1983; W/Gm83 = Woodlands/Glendale matched subjects in 1983; Tm86 = Tranquille matched subjects in 1986; W/Gm86 = Woodlands/Glendale matched subjects in 1986.

*Fourteen Component Variables*

**Ambulation** - No significant gains were made by either Tm ($M$ = -.13) and W/Gm ($M$ = .00) over time [$F(1, 186)$ = 3.5009609, $p$ = .0594] from 1983 when there was no significant difference between Tm and W/Gm.

**Transfer** - In 1983 the two groups were not significantly different and no significant change was found between Tm ($M$ = -.13) and W/Gm ($M$ = .00) over time [$F(1, 186) = 3.114225$, $p$ = 0792].

**Bathing** - No significant difference was found between the groups in 1983. A significant and comparable improvement over time was noted in 1986 for all subjects in Tm ($M$ = -.13) and W/Gm ($M$ = .00) in 1983 regardless of group membership [$F(1, 186) = 4.674244$, $p$ = .0329].

**Dressing** - A significantly different pattern of scores was found in 1983 in which the Tm subjects were reported to be significantly more capable that those in W/Gm. In 1986, there was no significant difference between the Tm ($M$ = .40) and W/Gm ($M$ = .34) groups [$F(1, 186) = .008$, $p$ = .931] though both groups were found to have made significant and equal gains over time [$F(1, 186) = 3.932289$, $p$ = .0488].

**Grooming** - In 1983, Tm was found to be significantly more able than W/Gm on grooming skills. No significant difference was found in 1986 between Tm ($M$ = .28) and W/Gm ($M$ = .18) [$F(1, 186) = .092$, $p$ = .762]. Each group showed significant and comparable gains over time [$F(1, 186) = 4.932841$, $p$ = .0276].

**Eating** - Though a significant difference was reported in 1983, no significant change was noted in either group of Tm ($M$ = .01) or W/Gm ($M$ = .24) in 1986 [$F(1, 186) = 3.418$, $p$ = .223].

**Bladder** - No significant difference in distribution pattern was found between the groups in 1983 and there was no significant change over time between Tm ($M$ = .01) and W/Gm ($M$ = .24) [$F(1, 186) = .006724$, $p$ = 9365].

**Bowel** - Tm subjects were significantly more capable in 1983. In 1986, no significant difference [$F(1, 186) = 1.493$, $p$ = .223] or change [$F(1, 186) = 1.493$, $p$ = .223] was noted between Tm ($M$ = .0) and W/Gm ($M$ = -.2).

**Vision** - There was no significant difference in 1983. It was expected that no change would be reported in ability in vision or hearing as a result of developmental gain over time. A difference is considered to be representative of a change in perception rather than to reflect a true gain in ability. Tm ($M$ = .23) was reported to have significantly more ability than W/Gm ($M$ = .00) in 1986 [$F(1, 186) = 4.374$, $p$ = .038].

**Hearing** - There was no significant difference in 1983. No significant changes were reported in 1986 [$F(1, 186) = .20976$, $p$ = .6475] between Tm ($M$ = -.25) and W/Gm ($M$ = -.04).

**Food Preparation** - No significant difference was found in 1983. In 1986, Tm ($M$ = 1.3) lost significantly more skills in food preparation than W/Gm ($M$ = .37) [$F(1, 185) = 32.118$, $p<.001$].

**Housekeeping Skills** - No significant difference was noted in 1983. No significant change was reported in 1986 [$F(1, 186) = 8.678916$, $p = .0036$] between Tm ($M$ = .71) and W/Gm ($M$ = .73).

**Shopping** - There was no significant difference in 1983. Analysis in 1986 found that Tm ($M$ = 1.3) had gained significantly more skill in shopping than had W/Gm ($M$ = .37) [$F(1, 185) = 32.118$, $p<.001$].

**Travel** - No significant difference was noted in 1983. In 1986, Tm ($M$ = 1.3) had gained significantly more in their travel ability as compared with W/Gm ($M$ = .37) [$F(1, 185) = 32.118$, $p<.001$].

*Psychological Function Score and the Six Component Variables*

The aggregate psychological function score and the six component variables were compared by anova to determine if there was a significant difference between Tm and W/Gm in 1986 after group membership and the difference in intellectual levels in 1983 had been partialled out. These data are reported in Table 30. Where the difference was not significant

and the intellectual levels were not found to have affected the score significantly, the groups were further examined by regression analysis to determine if, excluding group membership, there had been a change in all subjects. Specific detail is reported with the mean of the difference scores.

*Psychological Function Score*

No significant difference in the aggregate psychological function score was found between Tm and W/Gm in 1983 but a significant difference was found in 1986 in which W/Gm (M of difference = 2.88) gained less than Tm (M of difference = 4.29) [$F(1, 186) = 4.385$, $p = .038$].

**Table 30**
**Mean Scores of Psychological Function Score and Medians of Six Component Variables in 1983 and 1986 by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Variable | Tm83 | Tm86 | W/Gm83 | W/Gm86 |
| M P. F. Score | 21.1 | 16.8 | 20.7 | 17.8 |
| Speech | 5.0 | 4.0 | 5.0 | 5.0 |
| Understanding | 2.0 | 2.0 | 3.0 | 5.0 |
| Comprehension | 4.0 | 2.0 | 3.0 | 3.0 |
| Self-Direction | 4.0 | 3.0 | 4.0 | 3.0 |
| Emot'n Stability | 4.0 | 3.0 | 4.0 | 3.0 |
| Behaviour | 4.0 | 3.0 | 4.0 | 3.0 |

**Note:** All statistics are rounded to one decimal place. Tm83 = Tranquille matched subject in 1983; W/Gm83 = Woodlands/Glendale matched subjects in 1983; Tm86 = Tranquille matched subject in 1986; W/Gm86 = Woodlands/Glendale matched subjects in 1986.

**Speech** - No significant difference was noted in speech ability in 1983. There were no significant change over time [$F(1, 186) = .478864$, $p = .490$] between Tm ($M = .06$) and W/Gm ($M = .03$).

**Understanding of Spoken Language** - The two groups were not significantly different in 1983. No significant change was reported in 1986 [$F(1, 186) = .106929$, $p = .7441$] between Tm ($M = .71$) and W/Gm ($M = .73$).

**Comprehension** - The two groups were not significantly different in 1983. No significant change was found over time. The subjects in each group of Tm ($M$ = .71) and W/Gm ($M$ = .73) had made gains comparably [$F(1, 186) = 7.284601$, $p = .0076$].

**Self-direction** - In 1983, the groups were not significantly different. Subjects in both Tm ($M$ = .91) and W/Gm ($M$ = .61) gained comparably and significantly over time [$F(1, 186) = 11.519236$, $p = .0008$].

**Emotional Stability** - The Tm and W/Gm groups did not differ significantly in 1983. There continued to be no significant change over time in 1986 [$F(1, 186) = 3.1329$, $p = .0784$] for either Tm ($M$ = .88) or W/Gm ($M$ = .58).

**Behaviour Control** - No significant difference was found in 1983 and no significant change in 1986 [$F(1, 186) = 3.538161$, $p = .0616$] between Tm ($M$ = .55) and W/Gm ($M$ = .32).

*Nine Ability Scales*

The nine ability scales were compared by anova to determine if there was a significant difference in 1986 after the group membership and the difference in intellectual levels in 1983 had been partialled out. These data are reported in Table 31. Where there was no significant difference in 1986

and the effect of intellectual levels was not found to have been significant, the groups were examined by regression analysis to determine if, excluding group membership, there was a significant overall change. Specific detail reported the mean of the difference scores.

**Table 31**
**Mean Scores on the Nine Ability Scales in 1983 and 1986 by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Variable | Tm83 | Tm86 | W/Gm83 | W/Gm86 |
| Mobility | 2.0 | 2.7 | 2.0 | 2.5 |
| Selfcare | 14.2 | 12.6 | 15.8 | 14.6 |
| Toilet | 3.5 | 3.3 | 3.9 | 3.5 |
| Sensory | 2.5 | 3.0 | 2.7 | 2.7 |
| Communication | 8.5 | 10.6 | 9.2 | 10.5 |
| Awareness | 7.4 | 5.2 | 7.0 | 5.9 |
| (Un)disturbed | 7.4 | 6.0 | 7.1 | 5.9 |
| Living | 20.7 | 16.2 | 19.2 | 18.2 |
| (In)dependent | 50.8 | 49.2 | 51.1 | 50.9 |

Note: All statistics are rounded to one decimal place. Tm83 = Tranquille matched subjects in 1983; W/Gm83 = Woodlands/Glendale matched subjects in 1983; Tm86 = Tranquille matched subjects in 1986; W/Gm86 = Woodlands/Glendale matched subjects in 1986.

**Mobility Scale** - There was no significant difference in 1983. No significant change occurred over time between Tm ($M$ = -.01) and W/Gm ($M$ = -.01) [$F(1, 186) = .0027$, $p = .9583$].

**Selfcare Scale** - No significant difference was found between the two groups in 1983. There was also no significant change over time [$F(1, 186) = 3.247204$, $p = .0732$] between Tm ($M = 1.75$) and W/Gm ($M = 1.38$).

**Toilet Scale** - The two groups were not significantly different in 1983. In 1986, Tm ($M = 4.44$) had gained significantly more in toileting skills as compared with W/Gm ($M = .98$) [$F(1, 186) = 49.640$, $p<.001$].

**Sensory Scale** - No significant difference was found in 1983. In 1986, both groups were reported to have lost skills. W/Gm ($M = -.04$) gained significantly less skills than Tm ($M = -.49$) [$F(1, 186) = 7.999$, $p = .005$].

**Communication Scale** - No significant difference was found in 1983. No significant change was noted in 1986 [$F(1, 186) = 2.8866$, $p = .0911$] between Tm ($M = .01$) and W/Gm ($M = .01$).

**Awareness Scale** - W/Gm was significantly more aware of their environment in 1983. In 1986, Tm ($M = 4.44$) were reported to have gained significantly more awareness of their environment than did W/Gm ($M = .98$) [$F(1, 186) = 49.640$, $p<.001$].

**(Un)disturbed Scale** - There was no significant difference in the ability of the two groups in 1983. Both Tm ($M$ = 1.44) and W/Gm ($M$ = .90) made comparable and significant gains over time [$F(1, 186) = 4.08848$, $p = .0444$].

**Living Skills** - W/Gm was found to be significantly more able in 1983. The 1986 analysis showed that Tm ($M$ = 4.44) gained significantly more in skills contributing to general living than did W/Gm ($M$ = .98) [$F(1, 186) = 49.640$, $p<.001$].

**Independence Scale** - No significant difference was found between the groups in 1983. Both Tm ($M$ = -.01) and W/Gm ($M$ = -.01) lost significant and equal skill over time [$F(1, 186) = 12.166144$, $p = .0006$].

No correlation was made with the (in)dependence scale (see Table32). The adaptive behaviour score correlated highly with selfcare and living and moderately with toileting. The psychological function score correlated highly with the awareness scale and moderately with those of communication and (un)disturbed.

**Table 32**
**Correlation Values of Comparison of Scores on 5 Ability Scales with the Adaptive Behaviour Score and on 3 Ability Scales with the Psychological Function Score**

| | Group | | |
|---|---|---|---|
| Scale | Tm | W/Gm | Allm |
| With A.B.Score | | | |
| Mobility | -.5309 | -.5660 | -.5393 |
| Selfcare | .9091 | .8676 | .8920 |
| Toilet | .6708 | .7876 | .7250 |
| Sensory | .1850 | .2243 | .1774 |
| Living | .8822 | .8624 | .8695 |
| With P.F.Score | | | |
| Communication | .6446 | .6221 | .6294 |
| Awareness | .7586 | .8566 | .8141 |
| (Un)disturbed | .6458 | .5852 | .6130 |

Note: Tm = Tranquille matched subjects; W/Gm = Woodlands/Glendale matched subjects; Allm = all matched subjects.

*Total Number of Medications and Specific Types of Drugs*

Detail about the total number of drugs and the more detailed breakdown of medications are presented in Table 32. Selected types of medications affecting behaviour were explored to examine the quality and degree of change in medications within Tm and W/Gm from 1983 to 1986 and between Tm and W/Gm in 1986. They were compared by anova to determine if there was a significant difference in 1986 after the group

membership and the difference in intellectual levels in 1983 had been partialled out. Where there was no significant difference in 1986 and intellectual levels were not found to have been significant, the groups were examined by regression analysis to determine if, excluding group membership, there was a significant overall change in all subjects

*Total Number of Drugs*

There was no significant difference in the total number of drugs taken by the two groups in 1983. No significant differences were found within the Tm ($M$ = .34) and W/Gm ($M$ = .45) over the three years [$F(1, 186) = .0001681$, $p = .9575$] (see Table 33).

**Table 33**
**Mean Scores for Medication and Specified Types of Medications in 1983 and 1986 by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Variable | Tm83 | Tm86 | W/Gm83 | W/Gm86 |
| Total Drugs | 3.0 | 3.3 | 3.7 | 4.0 |
| Prescription | 2.4 | 2.4 | 2.5 | 2.6 |
| Control | .0 | .0 | 0.1 | .1 |
| Nonprescription | .6 | .5 | 1.1 | 1.3 |
| Antipsychotic | .6 | .6 | .8 | .7 |
| Tranquilizers | .6 | .4 | .5 | .4 |
| Antiseizure | .7 | .6 | .5 | .6 |

Note: All statistics are rounded to one decimal place. Tm83 = Tranquille matched subjects in 1983; W/Gm83 = Woodlands/Glendale matched subjects in 1983; Tm86 = Tranquille matched subjects in 1986; W/Gm86 = Woodlands/Glendale matched subjects in 1986.

**Prescription Drugs** - There was no significant difference between groups in the number of prescription drugs taken by the matched groups in 1983. Neither Tm (*M* = .08) nor W/Gm (*M* = .28) significantly changed the number of prescription drugs between 1983 and 1986 [*F*(4, 183) = .033856. *p* = .8542].

**Controlled Drugs** - No difference was noted between the groups in 1983. No significant change was noted in either Tm (*M* = .01) or W/Gm (*M* = -.02) in 1986 [*F*(4, 183) = .90006, *p* = .3437].

**Nonprescription Drugs** - Tm took less nonprescription drugs than W/Gm in 1983. There was no significant difference in 1986 between Tm (*M* = .24) and W/Gm (*M* = .18) [*F*(4, 183) = .124, *p* = .725] and no significant change over time [*F*(4, 183) = 1.444, *p* = .9699].

**Antipsychotic Drugs** - W/Gm took significantly more antipsychotic drugs in 1983 than Tm. Though both Tm (*M* = -.03) and W/Gm (*M* = -.15) had reduced over time the number of antipsychotic drugs taken, there was no significant difference in 1986 [*F*(4, 183) = 1.366, *p* = .244] and no significant changes over the three years [*F*(4, 183) = .351649, *p* = .5539].

**Tranquilizer Drugs** - No significant difference was noted in 1983. No significant change in either Tm ($M$ = -.18) or W/Gm ($M$ = -.03) occurred over time [$F(4, 183) = .234256$, $p = .6290$].

**Antiseizure Drugs** - Tm and W/Gm did not differ significantly in 1983. No significant change was reported over time [$F(4, 183) = 2.027776$, $p = .1561$] between Tm ($M$ = .09) and W/Gm ($M$ = .10).

*Treatments*

A comparison of the incidence of treatments was made between Tm and W/Gm in 1986 (see Table 34). The treatments reported to be required in 1986 included putting on and taking off equipment/braces, care of the skin and/or scalp, eye care, enemas, behaviour programme, foot care and other. Though the categories of eye care, enemas and foot care were reported more frequently in 1986 than in 1983, the distribution of the types of treatment were not significantly different in 1986 between Tm and W/Gm [$X^2(1, 186) = .34665$, $p = .5560$]. Comparing each group over time on McNemar's test of correlated proportions showed that the types of treatments Tm subjects received changed significantly ($M$ = 5.9) in 1986 while W/Gm ($M$ = 2.7) did not.

**Table 34**
**Incidence of Treatments in 1983 and 1986 by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Treatment | Tm83 | Tm86 | W/Gm83 | W/Gm86 |
| Equipment | 5 | 22 | 15 | 15 |
| Skin Care | 9 | 25 | 36 | 32 |
| Behaviour Programme | 8 | 2 | 14 | 1 |
| Eye Care | 2 | 1 | 4 | 5 |
| Enemas | 1 | 4 | 2 | 10 |
| Foot Care | 15 | 7 | 3 | 2 |
| Other | 1 | 12 | 6 | 11 |

Note: Tm83 = Tranquille matched subjects in 1983; W/Gm83 = Woodlands/Glendale matched subjects in 1983; Tm86 = Tranquille matched subjects in 1986; W/Gm86 = Woodlands/Glendale matched subjects in 1986.

*Procedures*

In 1986, there was no significant difference in the distribution of procedures requiring the skills of a qualified nurse between the subjects in the Tm and the W/Gm groups [$X^2(3, 186) = 6.20225$, $p = .1022$].

*Extraordinary Pathology*

Comparisons were made of the incidence of reporting of extraordinary pathology to determine if the concept suggested by deinstitutionalization philosophy, that the extent to which pathology will be reported would decrease more in the

community based group than in those remaining in the institution, would be validated. The frequencies of extraordinary pathology for Tm and W/Gm are reported in Table 35.

**Table 35**
**Frequency of Extraordinary Pathology in 1983 and 1986 by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| | Tm83 | Tm86 | W/Gm83 | W/Gm86 |
| f | 10 | 35 | 28 | 34 |

Note: Tm83 = Tranquille matched subjects in 1983; W/Gm83 = Woodlands/Glendale matched subjects in 1983; Tm86 = Tranquille matched subjects in 1986; W/Gm86 = Woodlands/Glendale matched subjects in 1986.

The incidence of extraordinary pathology was not large enough to reliably interpret statistically. It was not possible to determine any significant change in the incidence of behavioural diagnoses (including general behaviour problems, self-abuse, and violence to others) between the Tm and W/Gm from 1983 to 1986 or to determine if there was a significant difference in 1986 between Tm and W/Gm. However, the pattern of reported change was the same with both groups showing a greater incidence of all types of behavioural disorders in 1986.

*Levels of Service Care*

The levels of service actually being received are called "actual" and the levels of service considered to be necessary if/when placed in the community or because actual service was considered inadequate are called "projected". The projected care was recorded in levels where 1 represented no care required (other than that of the average citizen) and 5 represented an intense level of care required (one or more times a week). Actual care received was measured in hours and translate into equivalent levels to be compatible with the projected levels of care reported. It was perceived by the assessors that caregivers often hesitated to quantify actual and perceived levels of care reportedly because of the fluctuating need for care. As a result, many empty cells are reported.

Comparisons were made of the actual and projected levels of care within the same year and over time to determine if there was a difference in the amount of actual or projected service between the two groups at one time or across time, or between the actual and projected levels for a group at one time or across time. Specific detail reported the mean of the difference scores while the tables report the means of the sample group.

*Comparison of the Actual Levels of Direct Care in 1983 with Projected Levels of Direct Care in 1983 for Tm and for W/Gm*

In 1983, the actual service levels received by individuals in institutions only included care by nurse, aide, physiotherapist, psychologist, physician, vocational trainer and psychiatrist. No psychiatric service was reported in any subsequent recording of projected or actual services. Because of this and the low incidence rate of actual time reported for psychiatric care in 1983, this variable is disregarded. The amount of care by the aide staff in the institutions has been replaced in the community by comparable amount of time by individuals with comparable training who function as the staff in the home. Therefore, comparisons using the reported data on actual services received in 1983 can only be made in reference to the care of physician, nurse, psychologist, physiotherapist, and vocational staff. The data are reported in Table 36.

**Table 36**
**Mean Scores of Actual and Projected Levels of Service in 1983 by Sample Group**

| | Comparison | | | |
|---|---|---|---|---|
| Service | TmA | TmP | W/GmA | W/GmP |
| Physician | 3.7 | 3.3 | 3.3 | 2.2 |
| Nursing | 4.8 | 3.1 | 4.9 | 2.3 |
| Psychologist | 1.6 | 1.4 | 1.6 | 1.4 |
| Physiotherapy | 1.2 | 2.0 | 1.1 | 1.5 |
| Vocational | 1.0 | 3.6 | 1.0 | 3.7 |
| Sum Scores | 12.3 | 13.4 | 12.0 | 11.1 |

Note: All statistics are rounded to one decimal place. TmA = Actual level of care for Tranquille matched subjects in 1983; W/GmA = Actual level of care for Woodlands/Glendale matched subjects in 1983; TmP = Projected level of care for Tranquille matched subjects in 1983; W/GmP = Projected level of care for Woodlands/Glendale matched subjects in 1983.

**Physician** - Both groups received more actual care in 1983 than they were projected to need if moved to a community setting. The difference in Tm ($M$ = .39) was significantly less than in W/Gm ($M$ = 1.11) [$F(1, 186) = 7.683$, $p$ = .006].

**Nursing** - Both groups received more actual nursing care in 1983 than they were projected to need. The difference in the relationship was significantly less for Tm ($M$ = 1.70) compared with W/Gm ($M$ = 2.59) [$F(1, 186) = 18.776$, $p<.001$].

**Psychologist** - There was no significant difference between the groups Tm ($M$ = .24) and W/Gm ($M$ = .17) in the relationship between the actual and projected levels of care in 1983 [$F(1, 186) = .052$, $p = .820$].

**Physiotherapy** - Both groups were reported to receive less physiotherapy than was projected to be necessary if moved to a community setting. Tm ($M$ = -.80) was reported to have the greater difference compared with W/Gm ($M$ = -.33) [$F(1, 186) = 6.870$, $p = .010$].

**Vocational** - Neither Tm ($M$ = -.2.63) nor W/Gm ($M$ = -.266) were found to have a significant difference in the relationship of the actual care or projected need for vocational service [$F(1, 186) = .036$ $p = .850$].

**Sum Scores** - Analysis of sum scores showed that the relationship of actual health care to projected need for service was significantly lower for Tm ($M$ = -1.11) than it was for W/Gm ($M$ = .88) [$F(1, 186) = 14.878$, $p<.001$].

*Comparison of the Hours of Actual Care in 1983 With the Actual Care in 1986 for Tm and for W/Gm*

Detail for the actual hours of care in 1983 compared with the actual hours of care in 1986 are presented in Table 37.

**Table 37**
**Mean Scores of Actual Hours of Care per Year in 1983 and 1986 by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Service | Tm83 | Tm86 | W/Gm83 | W/Gm86 |
| Physician | 7.1 | 2.1 | 4.7 | 3.0 |
| Nursing | 261.3 | .0 | 334.3 | .8 |
| Psychologist | 2.7 | 9.8 | 2.4 | 1.8 |
| Physiotherapy | 2.4 | 2.3 | .9 | 4.2 |
| Vocational | .0 | 18.3 | 1.1 | .0 |
| Sum Score | 273.7 | 33.9 | 343.4 | 9.1 |

Note: All statistics are rounded to one decimal place. Tm83 = Actual level of care for Tranquille matched subjects in 1983; W/Gm83 = Actual level of care for Woodlands/Glendale matched subjects in 1983; Tm86 = Actual level of care for Tranquille matched subjects in 1986; W/Gm86 = Actual level of care for Woodlands/Glendale matched subjects in 1986.

**Physician** - The amount of actual care in 1983 was greater in relationship to the actual care in 1986 for both groups. Tm ($M$ = 5.174) had significantly more actual care in 1983 by a physician than was actually received in 1986 as compared with W/Gm ($M$ = 1.67) [$F(3, 184) = 8.114$, $p = .009$].

**Nursing** - There was no significant difference in the relationship of actual nursing care over time from 1983 to 1986 between the two groups of Tm ($M$ = 262.5) and W/Gm ($M$ = 334.33) [$F(3, 184) = 3.102$, $p = .080$].

**Psychology** - There was no significant difference in the amount of care by a psychologist in 1983. Tm ($M$ = -7.08) had significantly more less in 1983 in relationship to the hours of care in 1986 as compared with W/Gm ($M$ = .54) [$F(1, 186)$ = .570, $p$ = .451].

**Physiotherapy** - No significant difference was found in the relationship of the amount of actual hours of physiotherapy service in 1983 to 1986 between Tm ($M$ = .11) and W/Gm ($M$ = -3.38) between 1983 and 1986 [$F(2, 185)$ = .735, $p$ = .393] such that the two groups showed no significant change over time.

**Vocational** - No significant difference was noted between the two groups Tm ($M$ = -18.28) and W/Gm ($M$ = 1.11) in the relationship of actual hours of therapy received in 1983 and 1986 [$F(1, 186)$ = 2.886, $p$ = .091].

**Sum Scores** - Analysis of the sum scores of the total services actually received in 1983 relative to the services projected in 1983 to be necessary to successful placement in the community between the two groups showed that both groups received more total actual care in 1983 than was projected to be necessary. Tm ($M$ = 241.86) had significantly less of a difference compared with W/Gm ($M$ = 334.28) [$F(3, 184)$ = 4.484, $p$ = .036].

*Comparison of Actual Levels of Direct Care in 1986 With Projected Levels of Direct Care in 1986 for Tm for W/Gm*

Details of the actual and projected levels of care in 1986 are presented in Table 38.

**Table 38**
**Means for Actual and Projected Levels of Care in 1986 by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Service | TmA | TmP | W/GmA | W/GmP |
| Physician | 2.7 | 2.5 | 2.8 | 2.7 |
| Nursing | 1.5 | 1.6 | 1.0 | 1.0 |
| Psychology | 1.5 | 1.9 | 2.3 | 2.4 |
| Physiotherapy | 1.4 | 1.8 | 1.3 | 1.4 |
| Vocational | 1.2 | 1.6 | 1.0 | 1.2 |
| Diet Care | 1.3 | 1.5 | 1.6 | 1.5 |
| Podiatry | 1.5 | 1.5 | 1.4 | 1.3 |
| Optical | 1.6 | 1.6 | 1.2 | 1.2 |
| Exercise | 4.1 | 5.1 | 4.2 | 5.0 |
| Audiology | 1.3 | 1.3 | 1.1 | 1.1 |
| Dental | 1.9 | 2.0 | 2.0 | 2.0 |
| Speech | 1.4 | 3.2 | 1.1 | 1.8 |
| Treatment | 1.8 | 1.6 | 1.8 | 1.8 |
| Hospitalization | 1.2 | 1.1 | 1.2 | 1.0 |
| Orthotic | 1.3 | 1.4 | 1.3 | 1.2 |
| School | 4.5 | 5.0 | 4.3 | 5.0 |
| Sum Score | 26.9 | 29.1 | 25.7 | 24.9 |

Note: All statistics are rounded to one decimal place. TmA = Actual level of care for Tranquille matched subjects in 1983; W/GmA = Actual level of care for Woodlands/Glendale matched subjects in 1983; TmP = Projected level of care for Tranquille matched subjects in 1986; W/GmP = Projected level of care for Woodlands/Glendale matched subjects in 1986.

**Physician** - The actual in 1986 was greater than the projected in 1986 for both groups though no significant difference was found between the two groups of Tm ($M$ = .16) and W/Gm ($M$ = .06) in the relationship of the actual and projected use of a physician's service in 1986 [$F(3, 184]$ = 2.189, $p$ = .141].

**Nursing** - The actual nursing care in 1986 was less than the need projected in 1986. No significant difference was found between Tm ($M$ = -.07) and W/Gm ($M$ = -.02) in comparing the relationship of actual to projected nursing service levels in 1986 [$F(20, 167)$ = .060, $p$ = .806].

**Psychology** - The difference between actual 1986 and projected 1986 was negative in both cases. There was no significant difference between groups Tm ($M$ = -.41) and W/Gm ($M$ = -.17) in the relationship of actual to projected psychological care in 1986 [$F(30, 157)$ = .2.457, $p$ = .119].

**Physiotherapy** - No significant difference was noted between the matched groups Tm ($M$ = -.47) and W/Gm ($M$ = -.15) in the relationship of actual to projected physiotherapy needs [$F(15, 172)$ = 3.007, $p$ = .085].

**Vocational** - Tm ($M$ = -33) and W/Gm ($M$ = -.23) did not differ significantly in the relationship of actual to projected vocational requirements [$F(17, 170)$ = .277, $p$ = .599].

**Diet** - W/Gm ($M$ = .11) had significantly more actual care in 1986 than was projected to be needed in 1986 as compared with Tm ($M$ = -.12) [$F(5, 181) = 9.541$, $p = .002$].

**Podiatry** - The difference in relationship of actual to projected podiatry needs was not significantly different between Tm ($M$ = -.02) and W/Gm ($M$ = .03) in 1986 [$F(4, 183) = .822$, $p = .366$].

**Optical** - Tm ($M$ = -.07) did not differ significantly from W/Gm ($M$ = .01) in the relationship of actual to projected optical care in 1986 [$F(3, 184) = 1.235$, $p = .268$].

**Exercise** - No significant difference was found between the two groups Tm ($M$ = -1.00) and W/Gm ($M$ = -.72) in the relationship of actual to projected exercise needs in 1986 [$F(9, 178) = 2.120$, $p = .147$].

**Audiology** - No significant difference was noted in the relationship of projected and actual audiology care in Tm ($M$ = -.01) and W/Gm ($M$ = .01) [$F(6, 181) = .371$, $p = .543$].

**Dental** - No significant difference was reported in the relationship of actual and projected dental care in Tm ($M$ = -.05) and ($M$ = .00) W/Gm [$F(7, 180) = .647$, $p = .422$].

**Speech** - Both groups received less actual speech therapy in 1986 than was projected to be needed. W/Gm ($M$ = -.71) had a significantly smaller discrepancy than did Tm ($M$ = .-186) [$F(35, 152) = 16.831$, $p<.001$].

**Treatments/Procedures** - No significant difference was found between Tm ($M$ = .16) and W/Gm ($M$ = .02) in the relationship of projected to actual treatment and procedure requirements [$F(10, 177) = 2.356$, $p = .127$].

**Hospitalization** - There was no significant difference in the relationship of actual to projected use of hospitalization between Tm ($M$ = .11) and W/Gm ($M$ = .19) [$F(1, 186) = .942$, $p = .333$].

**Orthotic/Prosthetic** - A significant difference was found between the groups in the relationship of actual to projected orthotic and prosthetic service needs in 1986. Tm ($M$ = -.17) had less actual care in 1986 than was projected while W/Gm ($M$ = .02) had more [$F(1, 186) = 5.765$, $p = .017$].

**School** - The difference between the Tm ($M$ = -.47) and W/Gm ($M$ = -.67) groups was not significant in the relationship of actual and projected schooling requirements [$F(164, 23) = .121$, $p = .732$] though both groups received less actual schooling than was projected to be necessary.

**Sum Scores** - A significant difference was found. Tm ($M$ = -2.18) had higher levels of care in 1986 projected as necessary to community living in relationship to the actual care received in 1986 while W/Gm ($M$ = .75) had more actual care than was projected [$F(1, 186) = 22.258$, $p<.001$].

*Comparison of Projected Levels of Direct Care in 1983 With Projected Levels of Direct in 1986 for Tm and for W/Gm*

Comparison was made of the service levels projected to be necessary for success in a community setting in 1986 with the level projected in 1983 (see Table 39).

**Table 39**
**Mean Scores for Projected Levels of Service in 1983 and 1986 by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Service | Tm83 | Tm86 | W/Gm83 | W/Gm86 |
| Physician | 3.3 | 2.5 | 2.2 | 2.7 |
| Nursing | 3.1 | 1.6 | 2.2 | 1.0 |
| Psychology | 1.4 | 1.9 | 1.4 | 2.4 |
| Physiotherapy | 2.0 | 1.8 | 1.5 | 1.4 |
| Vocational | 3.7 | 1.6 | 3.6 | 1.2 |
| Dietary Care | 1.5 | 1.5 | 1.4 | 1.5 |
| Podiatry | 1.7 | 1.5 | 1.5 | 1.3 |
| Optical | 1.1 | 1.6 | 1.1 | 1.2 |
| Exercise | 4.2 | 5.1 | 3.8 | 5.0 |
| Audiology | 1.1 | 1.3 | 1.1 | 1.1 |
| Dental | 2.0 | 2.0 | 2.0 | 2.0 |
| Speech | 2.4 | 3.2 | 1.5 | 1.8 |
| Orthotics | 1.2 | 1.4 | 2.0 | 1.8 |
| Treatments | 1.4 | 1.6 | 1.0 | 1.0 |
| Hospitalization | 1.0 | 1.0 | 1.1 | 1.2 |
| School | 1.0 | 5.0 | .8 | 5.0 |
| Sum Score | 13.4 | 29.1 | 11.1 | 24.9 |

**Note**: All statistics are rounded to one decimal place. Tm83 = Projected level of care for Tranquille matched subjects in 1983; W/Gm83 = Projected level of care for Woodlands/Glendale matched subjects in 1983; Tm86 = Projected level of care for Tranquille matched subjects in 1986; W/Gm86 = Projected level of care for Woodlands/Glendale matched subjects in 1986.

**Physician** - The projected need in 1983 was less than the 1986 projection in W/Gm ($M$ = -.51) and was significantly different from Tm ($M$ = .76) where the projected need in 1983 was greater than that in 1986 [$F(3, 184) = 44.356$, $p<.001$].

**Nursing** - There was no significance in the difference between Tm ($M$ = 1.52) and W/Gm ($M$ = 1.21) in the relationship of the projected levels of care by nursing personnel over the three years [$F(20, 167) = 3.472$, $p = .064$].

**Psychology** - No significant difference was found between the Tm ($M$ = -.54) and W/Gm ($M$ = -1.05) groups in the relationship of projected need for psychological services over time [$F(30, 157) = 1.773$, $p = .185$].

**Physiotherapy** - Tm ($M$ = .14) and W/Gm ($M$ = .10) did not differ significantly in the relationship of projected need for physiotherapy over time [$F(15, 172) = .085$, $p = .772$].

**Vocational** - The difference between Tm ($M$ = 2.13) and W/Gm ($M$ = 2.40) was not significant in the relationship of projected needs for vocational services [$F(17, 170) = .742$, $p = .390$].

**Dietary** - No significance difference was found between Tm ($M$ = .10) and W/Gm ($M$ = -.12) in the relationship of the projected need for dietary care [$F(5, 182) = 1.261$, $p = .263$].

**Podiatry** - There was no significant difference between Tm ($M$ = .20) and W/Gm ($M$ = .14) in the relationship of projected need for podiatry care [$F(4, 183) = .051$, $p = .821$].

**Optical** - Tm ($M$ = -.5) had a significantly lower projected need for optical care in 1983 than was projected in 1986 as compared with W/Gm ($M$ = -.04) [$F(1, 18694) = 17.783$, $p<.001$].

**Exercise** - There was no significant difference between Tm ($M$ = -.85) and W/Gm ($M$ = -1.19) in the relationship of projected exercise need over time [$F(9, 178) = 2.379$, $p = .125$].

**Audiology** - Tm ($M$ = -.24) had a significantly lower projected need for audiological care in 1983 than was projected for 1986 as compared with W/Gm ($M$ = -.02) in the relationship of projected need [$F(6, 181) = 12.087$, $p = .001$].

**Dental** - There was no significant difference in the relationship of projected need for dentistry between Tm ($M$ = -.02) and W/Gm ($M$ = .00) [$F(7, 180) = .008$. $p = .928$].

**Speech** - The difference between Tm ($M$ = -.83) and W/Gm ($M$ = -.33) was not significant in the relationship of projected requirement for speech therapy [$F(35, 152) = 1.325$, $p = .251$].

**Orthotic/Prosthetic** - There was no significant difference between Tm ($M$ = -.22) and W/Gm ($M$ = -.11) in the relationship of projected need for orthotics and prosthetic services [$F(16, 171) = .097$, $p = .756$].

**Treatments/Procedures** - No significant difference was found between Tm ($M$ = -.20) and W/Gm ($M$ = .28) in the relationship of projected levels of care [$F(10, 177) = 3.545$, $p = .061$] .

**Hospitalization** - No significant difference was found between the Tm ($M$ = .00) and W/Gm ($M$ = .01) groups in the relationship of projected need for treatments and procedures [$F(18. 169) = .059$, $p = .808$].

**School** - There was no significant difference noted between Tm ($M$ = -4.12) and W/Gm ($M$ = -4.17) in the relationship of projected schooling needs [$F(164, 23) = .135$, $p = .718$].

**Sum Scores** - Tm ($M$ = 2.45) was reported to have no greater need projected in 1986 in relationship to that which was reported in 1983 as compared with W/Gm ($M$ = 3.01) [$F(1, 186) = .009$, $p = .926$].

*Comparison of Projected Levels of Direct Care in 1986 With Tm Versus W/Gm*

A comparison was made between the levels of projected need of care of Tm and W/Gm to compare the level care considered to be necessary to these individuals (see Table 40).

**Table 40**
**T Values and Significance Levels and Mean Scores for Comparison of Levels of Service Projected in 1986 by Between Group Comparison and Group**

| | Group Comparison | Group | |
|---|---|---|---|
| Service | Tm86Pvs.W/Gm86P N = 186 | Tm | W/Gm |
| Physician | 1.0 | 2.5 | 2.7 |
| Nursing | 4.2*** | 1.6 | 1.0 |
| Psychology | 2.6* | 1.9 | 2.4 |
| Physiotherapy | 2.0 | 1.8 | 1.4 |
| Vocational | 1.8 | 1.6 | 1.2 |
| Dietcare | .2 | 1.5 | 1.5 |
| Podiatry | 1.6 | 1.5 | 1.3 |
| Optical | 5.5*** | 1.6 | 1.3 |
| Exercise | .6 | 5.1 | 5.0 |
| Audiology | 3.6*** | 1.3 | 1.1 |
| Dental | .5 | 2.0 | 2.0 |
| Speech | 5.1*** | 3.2 | 1.0 |
| Treatment | .5 | 1.6 | 1.8 |
| Hospitalization | .6 | 1.0 | 1.0 |
| Orthotics | 1.5 | 1.4 | 1.2 |
| School | .0 | 5.0 | 5.0 |
| Sum Score | 4.3*** | 29.1 | 24.9 |

**Note**: All statistics are rounded to one decimal place. * = $p<.05$. ** = $p<.01$. *** = $p<.001$. Tm86P = Projected level of care for Tranquille matched subjects in 1986; W/Gm86P = Projected level of care for Woodlands/Glendale matched subjects in 1986.

There was no significant difference found between the matched groups in the projected levels of care by doctor, vocational service, dietary care, podiatry service, exercise, dental care, treatment/procedures, hospitalization, orthotics/prosthetics, and school.

A significant difference was found between Tm and W/Gm in the projected service levels of nursing, psychology, physiotherapy, optical, audiology, and speech therapy. In each case Tm was projected to have a greater need for the respective treatment than did W/Gm.

**Sum Score** - Tm showed a significantly higher projected need for service as compared with W/Gm [$F(1, 186) = 18.155$, $p<.001$].

*Comparison of Projected Levels in 1983 with the Actual Levels of Care in 1986 for Tm and for W/Gm*

A comparison was made of the difference in the levels of care projected in 1983 to be necessary to the function of the individuals within each of the matched groups. A further comparison was made of the significance of the difference between the Tm and the W/Gm groups (see Table 41).

**Table 41**
**Mean Scores for Projected and Actual Levels of Care in 1983 and 1986 by Sample Group**

| | Group | | | |
|---|---|---|---|---|
| Service | Tm3P | Tm6A | W/Gm3P | W/Gm6A |
| Physician | 3.3 | 2.7 | 2.2 | 2.8 |
| Nursing | 3.1 | 1.5 | 2.3 | 1.0 |
| Physiotherapy | 2.0 | 1.3 | 1.5 | 1.2 |
| Vocational | 3.6 | 1.2 | 3.7 | 1.0 |
| Psychological | 1.4 | 1.5 | 1.4 | 2.0 |
| Dietary | 1.6 | 1.3 | 1.4 | 1.6 |
| Podiatry | 1.7 | 1.5 | 1.5 | 1.4 |
| Optical | 1.2 | 1.6 | 1.1 | 1.2 |
| Exercise | 4.2 | 4.1 | 3.9 | 4.0 |
| Audiological | 1.1 | 1.3 | 1.1 | 1.1 |
| Dental | 1.9 | 1.9 | 2.0 | 2.0 |
| Speech | 2.4 | 1.4 | 1.5 | 1.1 |
| Treatment | 1.5 | 1.8 | 2.1 | 1.7 |
| Hospitalization | 1.1 | 1.1 | 1.0 | 1.2 |
| Orthotics | 1.2 | 1.2 | 1.1 | 1.2 |
| School | .4 | 1.6 | .2 | 1.2 |
| Sum Score | 31.5 | 26.9 | 27.9 | 25.7 |

Note: All statistics are rounded to one decimal place. Tm3P = Projected level of care for Tranquille matched subjects in 1983; W/Gm3P = Projected level of care for Woodlands/Glendale matched subjects in 1983; Tm6A = Actual level of care for Tranquille matched subjects in 1986; W/Gm6A = Actual level of care for Woodlands/Glendale matched subjects in 1986.

**Physician** - The actual in 1986 was greater than the projected in 1983 in W/Gm ($M$ = -.57) and was significantly different compared to Tm ($M$ = .59) in which the actual service in 1986 was less than the projected in 1983 [$F(1, 186)$ = 37.050, $p<.001$].

**Nursing** - Both groups received less actual care in nursing in 1986 than had been projected in 1983 to be necessary. The difference in W/Gm ($M$ = 1.27) was significantly smaller than in Tm ($M$ = 1.68) [$F(1, 186) = 5.398$, $p = .021$].

**Psychological** - No significant difference was found between Tm ($M$ = -12) and W/Gm ($M$ = -.57) in this relationship in the need for psychological services [$F(1, 186) = 1.744$, $p = .188$].

**Physiotherapy** - A significant difference was found in the relationship of actual 1986 to projected 1983 in physiotherapy services between the groups with Tm ($M$ = .65) receiving relatively less actual care in 1986 than W/Gm ($M$ = .24) [$F(1, 186) = 4.252$, $p = .041$].

**Vocational** - No significant difference was found in the relationship of vocational care received in 1986 and projected in 1983 between Tm ($M$ = 2.43) and W/Gm ($M$ = 2.69) [$F(1, 186) = 1.043$, $p.308$].

**Dietary** - A significant difference was found between Tm ($M$ = .28) and W/Gm ($M$ = -.20) in which Tm received a greater amount of actual care in 1986 in relationship to the amount projected in 1983 than did W/Gm [$F(1, 186) = 5.999$, $p = .015$].

**Podiatry** - No significant difference was found in the actual 1986-projected 1983 relationship in podiatry between Tm ($M$ = .23) and W/Gm ($M$ = .11) [$F(1, 186) = .489$, $p = .485$].

**Optical** - Both groups received less actual care in 1986 than was projected in 1983 to be necessary. Tm ($M$ = -.43) received significantly less as compared with W/Gm ($M$ = -.05) [$F(1, 186) = 14.930$, $p<.001$].

**Exercise** - No significant difference was noted in the relationship of 1986 and 1983 actual and projected levels of service between Tm ($M$ = .19) and W/Gm ($M$ = -.13) groups [$F(1, 186) = 2.359$, $p = .126$].

**Audiological** - Both groups received less actual service in 1986 than had been projected in 1983 to be needed. Tm ($M$ = -.23) received significantly less than did W/Gm ($M$ = -.03) [$F(1, 186) = 6.974$, $p = .009$].

**Dental** - No significant difference was found in the relationship of dental actual 1986 and projected 1983 between Tm ($M$ = .02) and W/Gm ($M$ = .01) [$F(1, 186) = .233$, $p = .630$].

**Speech** - The difference in the need for service projected in 1983 compared to the actual amount of care in 1986 was significantly less in W/Gm ($M$ = .41) than in Tm ($M$ = 1.00) [$F(1, 186) = 7.483$, $p = .007$].

**Treatment/Procedures** - Tm ($M$ = -.26) received a significantly greater amount of actual care in 1986 than had been projected in 1983 to be necessary as compared with W/Gm ($M$ = .34) [$F(1, 186) = 5.936$, $p = .016$].

**Hospitalization** - No significant difference was found between Tm ($M$ = -.09) and W/Gm ($M$ = -.16) in the comparison in this relationship [$F(1, 186) = .585$, $p = .445$].

**Orthotics/Prosthetics** - There was no significant difference between Tm ($M$ = -.04) and W/Gm ($M$ = -.11) in this comparison over time [$F(1, 186) = 1.045$, $p = .308$].

**School** - No significant difference was noted between the Tm ($M$ = -1.27) and W/Gm ($M$ = -.98) groups on the comparison of school needs over time [$F(1, 186) = 1.335$, $p = .249$].

**Sum Scores** - A significant difference was found in this relationship. Tm ($M$ = 4.63) had significantly greater projected needs for service in 1983 than did W/Gm ($M$ = 2.26) [$F(1, 186) = 5.748$, $p = .018$].

## Summary of Findings in 1986 for Tranquille and Woodlands/Glendale Matched Subjects

A summary of the findings in 1986 and over time between 1983 and 1986 is presented in Table 42.

**Table 42**
**Summary of Findings in 1983 and 1986 for Matched Subjects in Tranquille and Woodlands/Glendale by Between Group Comparisons**

| | Group Comparison | |
|---|---|---|
| Variable | Tm83vs.WGm83 N = 93 | Tm86vs.WGm86 N = 93 |
| Dx. of Retard | no | no |
| Dx. of Health | ?no | no |
| A. B. Score | no | no |
| P. F. Score | no | +* |
| Abilities | ?no | ?no |
| Total Drugs | no | no |
| Treatments | no | ?no |
| Procedures | no | no |
| Actual | no | ?no |
| Projected | no | ?no |

Note: +* = positive significant difference. no = no significant difference. ?no = mixed picture generally not significant. Tm83 = Tranquille matched subjects in 1983; W/Gm83 = Woodlands/Glendale matched subjects in 1983; Tm86 = Tranquille matched subjects in 1986; W/Gm86 = Woodlands/Glendale matched subjects in 1986.

*Reported Cause of Mental Retardation*

There was no significant change in the reported cause of mental retardation or in the levels of retardation in the two groups.

*Adaptive Behaviour and Psychological Function Scores*

Significant gains were made by both groups in adaptive behaviour scores and psychological function scores over time and both generally showed gains in the component scores which made up these two scales. Tranquille gained significantly more on vision, food preparation and shopping. No significant difference was noted between the two groups on the aggregate adaptive behaviour score. Tranquille was shown to have made significantly greater gains on the aggregate psychological function scores.

*Nine Ability Scales*

Significant and equivalent differences over time were noted for both groups in four of the nine ability scales. On the toilet, awareness and living scales, the data showed that Tranquille made significantly greater gains. On the sensory scale Woodlands/Glendale matched subjects were found to have lost less than Tranquille.

No comparison was made of the independence scale with either the adaptive behaviour or psychological function score.

The adaptive behaviour score correlated highly with both the selfcare and living scales and moderately with toileting. The psychological function score correlated highly with the awareness scale and moderately with each of communication and (un)disturbed.

*Medications*

Comparisons of aspects of the drug data showed no significant differences in 1986 in the total number of drugs taken, prescription, controlled or non-prescription drugs, the number of tranquilizers, antipsychotic medication or antiseizure medication between the two groups.

*Treatment and Procedures*

The number of procedures were not significantly different and the frequencies reported in treatments and in health problems were not descriptively greatly different between the two groups.

*Services*

**Actual 1983 Relative to Projected 1983** - In comparing the difference between the actual hours of care received in 1983 and the projected hours in 1983, Woodlands/Glendale subjects received significantly more actual physician and nursing care than was projected as necessary while Tranquille received more actual physiotherapy care than had been projected. There was

no significant difference on the other two types of service. Analysis of the sum score found that Tranquille had a greater projected need relative to the actual care in 1983 than Woodlands/Glendale.

**Actual 1983 Relative to Actual 1986** - Tranquille matched subjects were found to receive, on one type of service, significantly less actual care in 1986 than actual in 1983 compared to Woodlands/Glendale. On the other four types of service, there was no significant difference. The sum score of actual care in 1983 compared to the actual in 1986 showed that W/Gm received more total actual care relative to the projected need than did Tm.

**Actual 1986 Relative to Projected 1986** - Woodlands/Glendale matched subjects were reported on dietary and school services to receive more actual care in 1986 than was projected in 1983 to be necessary for a community setting as compared with Tranquille. Both groups received less actual care in speech in 1986 than was projected to be necessary. On the other thirteen types of service, there was no significant difference. The sum score showed that Woodlands/Glendale actually received significantly more care than was projected to be necessary in 1986.

**Projected 1983 Relative to Projected 1986** - The projected need for physician care was greater in 1986 than in 1983 for

Woodlands/Glendale but was significantly greater in 1983 than in 1986 for Tranquille. In podiatry and audiology, both groups were found to have a greater need in 1986 than in 1983 and in each case Tranquille was found to have the greater need. On the other twelve types of service, there was no difference. The sum score showed no significant difference between the two groups.

**Projected 1986** - There was no significant difference in comparing the two groups on twelve of the service types. Tranquille was projected in 1986 to need higher levels of care than Woodlands/Glendale in nursing, psychology, physiotherapy, optical, audiology, and treatments/procedures service as well as on the sum score.

**Projected 1983 Relative to Actual 1986** - Compared with Tranquille, Woodlands/Glendale received more actual care in 1986 than was projected in 1983 to be necessary on physician, dietary, and hospitalization service. Both groups received less actual care in 1986 than was projected to be necessary in 1983 on nursing, physiotherapy, optical, audiology, and speech services. There was no significant difference on the other eight types of service. Analysis of the sum score showed that Tranquille had a significantly higher projected need for service in 1983 relative to the actual care in 1986 than did Woodlands/Glendale.

# X. Discussion

## Presentation of Outcome of Predictions

1. The matched subjects group in both the Tranquille and Woodlands/Glendale samples were not significaicantly different on the matched variables. However they were more able than their respective parent populations on many other variables (see Table 42). The subjects not selected for community placement from Tranquille and the unmatched subjects from Woodlands/Glendale were more severely disabled generally.

2. There were significant and statistically equivalent changes over time in both the adaptive behaviour and psychological function scores in both matched groups. There was no significant difference between the matched groups on aggregate adaptive behaviour score in 1986. Tranquille matched subjects showed significantly greater gains on the aggregate psychological function score.

3. The community based Tranquille subjects took no fewer drugs than the institutionalized Woodlands/Glendale subjects in 1986 and the total number of drugs had not

significantly changed over time. A like pattern was found in analyzing the number of prescription, nonprescription, control, antipsychotic, tranquilizer and antiseizure medications.

4. The amount of health services provided did not significantly increase over time for either group. The caregivers generally reported a greater projected need for health services than the amount of care being received both in 1983 and 1986 by either group. The Tranquille subjects in the community received significantly less health care services than the Woodlands/Glendale subjects remaining in the institution. Both groups were projected to need comparable amounts of care both in 1983 and in 1986.

5. The incidence of extraordinary pathology was not analyzed statistically because of the low rate of reported incidence.

## The Representativeness of the Samples of this Study

The sample groups were compared to their respective populations on the six matching variables (sex, level of retardation, age, length of stay, adaptive behaviour score and psychological function score) and forty other variables. It is apparent from Tables 3 through 15, and 17

through 25, and 44 that the Tm and W/Gm were generally more able than their respective parent populations.

**Table 43**
**Representativeness of Sample Groups in Comparison with Their Respective Populations**

| Variable | Tm versus T | W/Gm versus W/G |
|---|---|---|
| Sex | no significance | no significance |
| Retard. Level | no significance | no significance |
| Retard. Cause | no significance | no significance |
| Age | no significance | no significance |
| Length of Stay | no significance | no significance |
| A.B.Score | Tm more able | W/Gm more able |
| 14 Components | no significance | W/Gm more able (10) |
| P. F. Score | Tm more able | no significance |
| 6 Components | Tm more able on 4 | W/Gm more able (3) |
| Health Problems | no significance | no significance |
| Medications | no significance | W/Gm took less |
| Treatments | no significance | no significance |
| Procedures | Tm more able | no significance |
| Mobility | Tm more able | W/Gm more able |
| Selfcare | Tm more able | W/Gm more able |
| Toiletting | Tm more able | W/Gm more able |
| Sensory | Tm more able | no significance |
| Communications | Tm more able | no significance |
| Awareness | Tm more able | no significance |
| (Un)disturbed | no significance | W/Gm less disturbed |
| Living | Tm more able | W/Gm more able |
| (In)dependence | Tm more able | W/Gm more able |

**Note:** Tm = Tranquille matched subjects. W/Gm = Woodlands/Glendale matched subjects.

The availability of Tranquille subjects in the community for reassessment determined the choice of

The availability of Tranquille subjects in the community for reassessment determined the choice of subjects for the present study. In examining comparative data on the reported personal and functional information on the matched subjects in Tranquille and the parent population, it is noticeable that the subjects chosen from the community group are more capable than the parent population on almost every variable. This suggests that selection for transfer to the community, out of the original Tranquille institutional population, may have been influenced by factors expected to impact success in the community or have been based on an expectation that these individuals would have a greater chance for success.

Comparing the matched subjects with the entire institutional population in 1983 showed that 88% of the matched subjects were ambulatory as compared with 55% of the whole population; 84% could do an independent transfer related with 52% in all; 51% of matched subjects were independent in eating compared with 35%; 52% had bladder control contrasted with 34%; and 57% of the matched sample had bowel control related to 36% of the original population. Independence in eating, bowel and bladder control, mobility and transfers has practical implications for staffing ratios, programme content and care costs. Individuals with greater ability in these personal care elements would require less supervision and less

sophisticated programming. The original population of Tranquille was significantly less severely retarded than that of Woodlands or Glendale. It is possible that this was a contributing factor that led to Tranquille being targeted as the initial facility for deinstitutionalization.

Some aspect of preselection may also have been operative in the selection of community based candidates for the study, as staff of the regional and district levels of the Ministry of Social Services and Housing reportedly limited access to individuals considered to be less personally or functionally capable or less successful in the transition to community living.

It is reasonable that preferential selection of subjects of higher intellectual and personal function than the parent population would have produced a skew in the data. If this were the case, it would support a number of observations.

The severely and profoundly retarded individuals selected for this study did not generally demonstrate more significant gains in the community environment than the subjects remaining in the institution. The subjects in the community appeared to be the most capable of a population of profoundly and severely retarded individuals. More seriously severely and profoundly retarded individuals than those selected for this study and placed in the community

presently live in the residential facilities of Woodlands and Glendale. They appear to be at risk of being less able to use the opportunity for placement in the community than the 93 matched moderately, severely and profoundly retarded subjects in this study by reason of further and more serious physical and functional disability. Since the more severely retarded subjects in the matched sample in the Woodlands/Glendale group showed as nearly comparable gains in both the adaptive behaviour and psychological function scores in spite of lower intellectual function levels, it may be that, institutional care of the moderately, severely and profoundly retarded individuals in this study may actually afford the even more seriously retarded and physically disabled individuals remaining in the institutions a better care environment than would the community.

## Adaptive Behaviour and Psychological Function Scores

### Adaptive Behaviour and the Fourteen Component Variables

No significant differences were noted between the two matched groups in 1983 on the aggregate adaptive behaviour score. No significant gains were made by either group over time.

Significant and equivalent gains over time were noted in three of the fourteen reported skills (bathing,

dressing, grooming) for both the former Tranquille subjects and the Woodlands/Glendale subjects. These are all personal care skills. It is possible that these skills simply improve over time by repetition and patterned learning.

No significant gains were made by either group in ambulation, transfers, eating, bladder control, bowel control, hearing, or housekeeping. It was interesting to note that these "natural", bodily functions did not improve with repetition over time. Bowel and bladder function and maladaptive eating (the soiling of food) may not have improved because they are frequently related to behavioural reactions (all categories of which increased in both groups over time). Housekeeping would seem to have been more likely to have improved because of its similarity to the repetitive tasks of personal care. Hearing was not expected to have improved nor necessarily to have deteriorated significantly. The lack of improvement in ambulation or transfers may have been more closely related to the behavioural reactions than to physical deterioration as those physical conditions (such as skeletal problems) which might have affected these skills did not change greatly over time.

Former Tranquille subjects improved significantly more than Woodlands/Glendale on shopping and travel skills. This may have been due to greater opportunity in the community

to participate in such activities. Yet, they lost more skill in food preparation than did the Woodlands/Glendale subjects though seemingly there would have been greater opportunity to develop this skill in the community setting.

Reported gains from the community placement experience were essentially limited to the areas of shopping and travelling in the adaptive behaviour skill.

Psychological Ability

No significant difference was noted in 1983 between the Tranquille and Woodlands/Glendale matched subjects on the psychological function score. Neither group made any significant change in speech ability, understanding spoken language, emotional stability, or behavioural control over all subjects between 1983 and 1986. Both groups made significant and parallel gains over time in comprehension and self-direction.

It appears that though there was no significant difference between the groups on any of the six component variables and though the difference in the significant changes over time in comprehension and self-direction was found to be not significant, the total of small changes in the six components resulted in a significant difference in 1986. Tranquille subjects were found to have made significantly greater gains on the aggregate psychological

function score than had those individuals remaining in Woodlands/Glendale.

**Drug Usage**

The excessive use of drugs for the presumed control of pathological behaviour is a criticism of institutions made by proponents of community placement. Although strongly held by its advocates, this allegation has not been extensively addressed by data in the literature. No norms are reported for the amount of medication taken by or given to the mentally retarded in the community, to the retarded of higher levels of ability or to the population of intellectually capable but behaviourally disordered subjects deinstitutionalized from mental hospitals.

Medications used by the subjects in this study were reported in eighteen categories. Anticonvulsant drugs were the second most commonly reported (seizures were the most common health problem). In Tranquille 53%, and in Woodlands/Glendale 62% of the matched subjects, were reported to take antipsychotic and 45% and 38% respectively took antidepressant medication in 1983.

No significant difference was noted between the groups in the total number of medications, the number of prescription ,controlled, nonprescription, tranquilizer or antiseizure drugs in 1986. Both groups had significantly

and comparably reduced the number of antipsychotic drugs over time. These results did not corroborate the position of deinstitutionalization philosophy that institutions use more medications to control behaviour than do community facilities. In fact, the data show that drug use both in the institution and community facility had not significantly changed over time and was not significantly less in the community sample. It is of interest that the number of medications remained relatively constant though the reported level of behavioural and disturbed behaviour decreased while the incidence of extraordinary pathology increased.

**Levels of Health Services**

The deinstitutionalization philosophy is founded in part in an assumption that the individual's behavioural characteristics are, at least in part, an outcome of the interaction with his/her environment. If this is true, then the number and type of community support services received will be influential in fostering the individual's potential for growth and development.

In 1983, the Tranquille matched subjects were shown to have received somewhat higher levels of service than Woodlands/Glendale subjects. No reason was determined for this though it is possible it may have reflected a greater

expectation of potential for achievement rather than a real measure of the projected essential level of care.

In 1986, the Woodlands/Glendale subjects in the institutions received somewhat more care than did the Tranquille subjects in the community. It is possible that the level of health services provided in the institution was higher than in the community because of the availability of salaried staff in the institutions.

The levels of health service were not examined to try and determine a standard of essential levels of care for simple health (indeed there does not seem to be such a standard). Rather, the relationship of the projected and actual levels of care were analyzed in order to answer three questions.

1. Did the community group receive the care in the community which it was projected they would need to be successful?

2. Were the community group receiving equivalent levels of services as those remaining in the institution?

3. How did the levels of service being received by each relate to the gains made by these subjects over time?

The Tranquille subjects transferred to the community received less actual care in the community in 1986 than had

been projected in 1983 to be necessary for beneficial gains from community living. It is possible that the level of service projected in 1983 to be necessary to successful community placement represents a subjectively inflated estimate of the amount of service necessary. The reality of the impending closure of Tranquille in 1983 may have influenced the opinion of the caregivers as to the necessary future service. This observation would seem to be not supported by the fact that Tranquille was found to have a higher projected need again in 1986 in relation to actual level of care received in 1986.

The community group received more overall care and more psychological care and vocational training in 1986 than did the group remaining in the institution.

The lack of receiving some essential services in the institution compared to the community did relate positively to the lack of significant gains in the aggregate psychological function score but to essentially no other variables. Considering the fact that the Woodlands/Glendale residents actually lost more service from 1983 to 1986 than did the Tranquille people, it is interesting that the Woodlands/Glendale subjects made generally as many gains over time as did the community based individuals. Both groups were receiving at least as much care as they were projected to need for community success.

Of the projected service requirements considered to be important, the most frequently projected to be necessary to a greater degree than was being received were speech therapy, optical care, physiotherapy, diet care, psychology and vocational training. The services of nursing and physician care were generally more extensively available in the institution than were projected to be necessary. It is possible that the "institution" has been organised on a health model and service such as nursing and physician care are readily available because of the "sick" and "healing" concepts implied in a hospital structure. The availability of services such as psychology, vocational training and optical care which have traditionally not been offered to any great extent in the hospital were not so readily available but were seen as more necessary for success in the community.

**Extraordinary Pathology**

The change in the reported incidence of extraordinary pathology from 1983 to 1986 was minimal for both groups. It is reasonable that the incidence of extraordinary behavioural pathology overall was under reported at both times as it was observed by the assessors that the caregivers felt a great sense of loyalty and protection for their charges in both the community and the institution. However, it is possible that the slightly greater increase

in the reported frequency of extraordinary pathology in Tranquille was due to the new circumstances in which the clients lived. There may have been less tolerance of this type of pathology in the community setting.

Behaviour appeared to be the most difficult category of health problems for caregivers to report objectively. This may be due to the non-concrete nature of the problem or because of an implied accountability (or lack of) by the caregiver for the control or need of control of behaviour. Perhaps a finer, more sensitive tool is needed to assess/ determine the frequency of extraordinary pathology to circumnavigate the risk of subjective report.

Simply recounting the data on the incidence of this type of pathology is not adequately representative of its importance. The need to protect these subjects from the infection and illness potential from behaviour such as digging the intestinal tract, smearing faeces, and hyperaphagia and to protect staff and others from violence by these subjects represents a commanding proportion of staff time and resources. It is unfortunate that these data were not collected/reported in greater detail so as to afford deeper interpretation.

## Other Considerations

### Intellectual Ability

According to McCarver and Craig (1974), intelligence has been examined as a variable in most studies of community transition. They reported that the findings are generally inconsistent and that the relationship between levels of retardation and successful community placement lacks concrete support. Windle (cited in McCarver and Craig, 1974) relates the confounding in intellectual ability to a lack of control of other related variables.

In the present study, significantly more of the matched subjects in Tranquille were found to be in the moderately retarded level than those in Woodlands/Glendale. Although significant differences might have been expected on the numerous variables discussed reporting that Tranquille subjects showed greater gains in the community because of greater intellectual ability, such a pattern was not generally demonstrated. The results may apply more to the severely and profoundly retarded handicapped rather than to the moderately retarded. However, this cannot be firmly stated as comparisons of the results betweeen the moderate and the severe-profound groups have not been done at this time.

The discrepancy of higher levels of intelligence in the Tranquille matched subjects as compared with those in Woodlands/Glendale was accepted as unavoidable because of the complex care used to identify the optimal available match. Using the six matching variables, three potential matched subjects were identified for each of the community based former Tranquille subjects who were confirmed as eligible for the study. Wherever possible, the first choice was used as the match. However, subject loss transpired in the Woodlands sampling at this juncture as well. The Ministry of Social Services and Housing required that the staff social workers obtain permission for all potential subjects before approving them for the study, whereas the Ministry of Health allowed blanket approval for access to all subjects within Glendale on the basis of the detail to confidentiality and the fact that this study was an extension of the 1983 work. Subject loss in Woodlands because of refusal by parent or social worker forced matching procedures to be less than ideal.

Sex

The Tranquille (41% female, 59 % male) and Woodlands/Glendale (43% female, 57% male) populations held proportionately more males than females in line with Scheerenberger's (1981) report that the deinstitutionalized population in the United States is 56% male and 44% female.

Consistent with Richardson, Koller and Katz (1986), the Tranquille matched subjects of the community-based group in this study consisted of more males (60%) than females (40%). The matched subjects in Woodlands/Glendale included approximately two thirds male (62%) to one third female (38%).

These data are contrast with detail reported by McCarver and Craig (1974). They reference numerous studies that suggest possible relationships of sex with selection variables. In their study, more males than females were admitted because of preadmission problems, more females than males tended to be released, and females tended to have a higher failure rate and therefore to be more highly recidivistic. It is possible that the several commonly reported causes of mental retardation individually affect the male population more frequently than females resulting in a higher rate of retardation in males. There is a higher mortality rate and morbidity rate in male births than in female births in general. However, in light of the higher ratio of males to females both in the institution and in the community, it would seem that selection preference had been active in both the admission of patients to the institutions in British Columbia and the movement of subjects from the institution prior to the study and in the selection of subjects for the move to the community.

Length of Stay

The length of institutionalization has an inconsistent and confounded relationship with success in the community in the literature reported by McCarver and Craig (1974) though the rate of recidivistic returns to institutional placements related positively to ultimate community failure. They comment that institutionalized individuals are a special group by the very reason of their having been selected for institutionalization. This preselection bias is not likely to have influenced the comparisons of the matched groups of Tranquille and Woodlands/Glendale because length of stay was used as a matching variable.

Age

Though some researchers predicted that other factors such as age and personality had greater predictive value than intelligence, McCarver and Craig (1974) concluded that most investigators reported no relationship between age and success. Because of its relationship to other important variables such as physical health, age at release has been studied extensively. It is a common selection factor for discharge and for predicting success. Studies like that of Locker, Rao and Weddell (1984) showed an older, longer institutionalized group to succeed better than younger clients. Perhaps, as the clients approach geriatric age, they become more alike their normal peers by reason of the

decline of the peers therefore the expectations are diminished and more achievable.

The Tranquille and Woodlands/Glendale group comparisons were not affected by an age effect since they were matched on age plus or minus five years. No significance can be attributed to younger or elder age differences as the data were not analysed for possible age effects within these matched groups.

The transition of subjects from Tranquille to the community in British Columbia took approximately one year from the time of the announcement of the intent to depopulate. The effect of the short timelines of this process may be reflected in the lack of greater gains by the Tranquille matched subjects than those made by the Woodlands/Glendale matched subjects in adaptive behaviour and psychological function. Reportedly, neither a plan of training for many of the residents at Tranquille nor education of staff and the facility in preparation for transition over time were carried out with this group as a result of the decision to move these people out of Tranquille which was announced in 1982 and effected in 1983.

Causes of Mental Retardation

It was assumed that the causes of mental retardation would not change over time as the medical history would be constant. However, the causes of mental reatardation were reported to have changed in 1986 in both the community and the institution. This change most likely reflects change over time in either the caregivers' unsubstantiated opinion of the causes or the fact that the medical history information is becoming less available to the caregiver. Or it may be considered less necessary by the caregiver.

Causes of Health Problems

For similarly reasons as stated in causes of mental retardation, it was assumed that the causes of health problems would not change over time. However, a difference was noted between the two groups as the Tranquille matched group was reported to which to have had more with no health problems in 1986 as compared with 1983 in the perception of the caregivers. This change also likely reflects change over time in either the caregivers' opinion of the causes or the fact that the medical history information is less available, or considered less necessary by the caregiver.

## XI. Conclusion

In spite of limited information regarding the predictability of success rates of retarded individuals with physical impairments in community placements, it is reasonable to suggest that careful selection was made in 1983 on the basis of a variety of factors as to which individuals would be good candidates for transition. However, the result of deinstitutionalization in this study of moderately, severely and profoundly retarded individuals has no clear outcome. The study underscores the many disparities presented by McCarver and Craig (1974) and the findings would suggest that the same confounding of results is operant.

In this study, the empirical data show that the Tranquille subjects now in the community made gains in many areas, but that similar gains were made by the matched Woodlands/Glendale population which remained in the institution. Only in the aggregate psychological function score did Tranquille subjects show greater gains.

Determination of whether the deinstitutionalization of the subjects in this study is or is not a success may be influenced by one's own perspective. That the Tranquille matched group and the Woodlands/Glendale matched group did

not differ on most variables may be considered a positive finding in itself as the Tranquille subjects did not deteriorate by the move to the community. In other words, they were as well off in the community as the other subjects were remaining in the institution. On the other hand, the philosophy of proponents of deinstitutionalization has been premised on a belief that individuals in institutions are actively at risk of greater deterioration than are comparable individuals in the community. This was not substantiated in this study. There was some indication that there was a slight improvement in the community group in comparison with the institutional group but it should be remembered that this is based on caregiver report and must be interpreted with care.

The decision of whether the reported outcomes of this study are to be defined as success or nonsuccess, appears to come down to the cyclic argument around defining and measuring the quality of life. This has been a major issue in advocacy of deinstitutionalization. This study did not attempt to define or measure the quality of life. As a result, no final resolution has been possible as to the comparative success or failure of the results of this community move.

## XII. Future Research

This study underscores the need for more and better research into the special learning abilities and needs of the severely and profoundly retarded. This work offers a unique opportunity for a longitudinal study with prerelocation data and repeated post-location data with appropriate comparison groups. It would be worthwhile repeating this examination over time. It is possible, however, that access for further study would be denied as a request for further subjects has already been refused.

The basic experimental design of this study was justified and appropriate. However, the sheer magnitude of the work made it almost impossible to foresee some of the problems arising in the interpretation of the material. The subjective nature of research in mental retardation demands more strict and objective a priori outcome projection. Better preplanning would result and may have resulted in a more unequivocal conclusion.

Though assessment by personal contact has been usually used in comparable research as compared with written contact, it would be interesting and perhaps enlightening to explore the nature, quality and subject matter of the questions which must be asked to increase confidence in the

validity of the information obtained. It was apparent that even with the support of ministerial appointees for this study, caregivers, care societies and ministry staff were sometimes reluctant to commit information about these individuals - at times succeeding (overtly and covertly) in preventing access to an individual and certainly producing a skew in the data. This difficulty has cost this study much - personally, fiscally, and professionally.

Further analysis of this data is needed to unravel the confounding which persist in determining which variables contribute to prediction and which to outcome. It will be interesting and necessary to do stepwise multiple regression analyses to analyze the complexities inherent in the data.

As suggested earlier in the study, a descriptive model must be developed which is capable of representing the multiple dimensions of the severely and profoundly retarded retarded population. An experimental model of this nature was developed in the process of this study. More work is needed to clarify the terminology and trial its structure.

Three major analyses were carried out in association with this study. The first examined the education, training and characteristics of the caregivers, their value system and the reason for this employment, their perception of their relationship with the retarded individual and their

opinion of the degree of success or failure of the transition. It also assessed data on family interest, characteristics of the locale, geographical location, the nature of design of the facility, the number and background of other residents. This work will be presented in a future paper by the author.

The second analysis was a comparison of the caliber of the Wilcox Client Data Scale as a functional assessment tool for profoundly and severely retarded individuals. Subjects were evaluated simultaneously on the Wilcox Client Data Scale and on the Daily Living Skills Domain of the Vineland Adaptive Behaviour Scale. The objective is to establish the concurrent validity of the Wilcox Client Data Scale by correlation analysis.

A Canadian study comparable to the one done by Scheerenberger (1981) would have been invaluable to establish a data base of the nature of the mentally retarded population in Canada and obtaining accurate detail on this population to extend and consolidate the diverse reports of individual hospitals, and special care facilities for the mentally retarded which vary from province to province.

Research is imperative to guard against the backlash of a new decade of ideology for mental retardation and to "avoid the disasters of the past" (pg.35, Talbot (1988). To

date the results of research in profound and severe retardation are outstanding only for their inconclusiveness. What is best for these people is a profoundly complex issue. No unilateral solution will suffice. That is the challenge for the future.

## WILCOX CLIENT DATA SCALE

Family Name _____ Usual Given Name and Initials _____

Ward/Non-Ward _____ Persons Legally Responsible _____

Marital Status: Single _____ Married _____ Widowed _____
Divorced _____ Separated _____ Other _____

IQ Range: Border Line: 95 - 70 Mild: 70 - 50 Moderate: 49 - 35
Severe: 34 - 20 Profound: < 20

Sex: M F Birthdate: _____ ___ ___ Medical Plan No.:_____
(YYYY/MM/DD)

How long has client been under care in this facility? _____

Physician: _____ Dentist: _____

Medical Background:

_____

_____

_____

Medications:

_____

_____

_____

Treatments:

_____

_____

_____

Special Procedures: Catheter Care _____

Bladder Irrigation _____ Tube Feeding _____

Tracheostomy _____ Oxygen Therapy _____

Renal Dialysis _____ Other _____

Allergies:_____

Wears Glasses _____ Uses Hearing Aid ___

Current Diet: Regular _____ Therapeutic _____

## 1. AMBULATION

| 1 Independent | 2 Uses walker/ cane | 3 Uses crutches | 4 Independent use of Wheelchair | 5 Dependent use of Wheelchair |
|---|---|---|---|---|

## 2. TRANSFER (Bed/chair/toilet)

| 1 Independent | 2 Supervision | 3 Intermittent assistance | 4 Significant assistance | 5 Continuous assistance |
|---|---|---|---|---|

## 3. BATHING

| 1 Independent | 2 Independent with mechanical aids | 3 Minor assistance | 4 Continued assistance | 5 Resists |
|---|---|---|---|---|

## 4. DRESSING

| 1 Independent | 2 Supervision daily partial help | 3 Periodic or | 4 Dependent | 5 Resists |
|---|---|---|---|---|

## 5. GROOMING/HYGIENE

| 1 Independent supervision | 2 Needs some items | 3 Assist with assistance | 4 Total | 5 Resists |
|---|---|---|---|---|

## 6. EATING

| 1 Independent | 2 Independent with special provision for disability | 3 Intermittent help | 4 Must be fed | 5 Resists |
|---|---|---|---|---|

## 7. BLADDER CONTROL

| 1 Continent | 2 Routine toileting or reminder | 3 Incontinence due to identifiable factors | 4 Incontinent less than once once per day | 5 Incontinent more than once once per day |
|---|---|---|---|---|

## 8. BOWEL CONTROL

| 1 Continent | 2 Routine toileting or reminder | 3 Incontinence due to identifiable factors | 4 Incontinent less than once once per day | 5 Incontinent more than once once per day |
|---|---|---|---|---|

## 9. VISION

| 1 Unimpaired | 2 Adequate for personal safety | 3 Distinguishes only light or dark | 4 Blind, safe in familiar location | 5 Blind requires assistance |
|---|---|---|---|---|

## 10. HEARING

| 1 Unimpaired | 2 Mild impairment | 3 Moderate impairment adequate for safety | 4 Impaired inadequate for safety | 5 Deaf |
|---|---|---|---|---|

## 11. SPEECH

| 1 Unimpaired | 2 Simple, intelligible | 3 Simple, partially intelligible | 4 Isolated words | 5 No speech, not understandable |
|---|---|---|---|---|

## 12. UNDERSTANDING

| 1 Unimpaired | 2 Simple phrases only | 3 Key words only | 4 Unknown | 5 Not responsive |
|---|---|---|---|---|

13. IF CLIENT CANNOT SPEAK, INDICATE MEANS OF EFFECTIVENESS

| 1 Effective | 3 Moderately effective | 5 Not effective |
|---|---|---|

14. MEANS

| Bliss | Sign | Other |
|---|---|---|

15. DENTAL

| 1 Unimpaired | 2 Partial denture | 3 Upper or lower | 4 Dentures only | 5 No dentures, no teeth |
|---|---|---|---|---|

Mental Health (Client's Behaviour - Most Days)

Good---------- Needs Care

16. COMPREHENSION

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

17. SELF DIRECTION

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

18. EMOTIONAL STABILITY

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

19. BEHAVIOUR DISORDER

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

---

20. FOOD PREPARATION

| 1 Inadequate | 2 Adequate if ingredients supplied | 3 Makes/buys meals - diet inadequate | 4 No opportunity/ does not participate | 5 Physically or mentally unable |
|---|---|---|---|---|

21. HOUSEKEEPING

| 1 Independent | 3 Perform light tasks | 4 Light tasks/ some assistance | 4 Needs regular help/ supervision | 5 No opportunity does not participate |
|---|---|---|---|---|

22. SHOPPING

| 1 Independent | 2 Small items | 3 Must be accompanied | 4 No opportunity does not participate | 5 Unable |
|---|---|---|---|---|

23. TRAVELLING

| 1 Independent | 2 Private vehicle/ taxi only | 3 Only if accompanied | 4 Unable | 5 Ambulance |
|---|---|---|---|---|

24. TELEPHONE

| 1 Independent | 2 Well known numbers | 3 Answers only | 4 Does not use | 5 Unable |
|---|---|---|---|---|

25. MEDICATIONS AND TREATMENT

| 1 Independent | 2 Reminder or assistance | 3 If medications prepared | 4 Unable | 5 Resists |
|---|---|---|---|---|

HOURS OF CARE PER WEEK

| | Rate | Hours |
|---|---|---|
| Doctor | ___ | ___ |
| Other Medical/Professional | ___ | ___ |
| Nursing | ___ | ___ |
| Aide | ___ | ___ |
| Other | ___ | ___ |

SERVICE INVENTORY
Health Services Required At Present

| | None/ only if injured | 1-4/yr. incident related | 5-10/yr. intermittent | 1-2/mo. regularly | 1 or more/week intensive |
|---|---|---|---|---|---|
| Health Counselling | 1 | 2 | 3 | 4 | 5 |
| Drugs/Therapy | 1 | 2 | 3 | 4 | 5 |
| Diet Care/ Therapy | 1 | 2 | 3 | 4 | 5 |
| Podiatry | 1 | 2 | 3 | 4 | 5 |
| Optical Care | 1 | 2 | 3 | 4 | 5 |
| Physical Exercise | 1 | 2 | 3 | 4 | 5 |
| Physiotherapy | 1 | 2 | 3 | 4 | 5 |
| Occupational Therapy | 1 | 2 | 3 | 4 | 5 |
| Audiology | 1 | 2 | 3 | 4 | 5 |
| Dental Care | 1 | 2 | 3 | 4 | 5 |
| Speech Therapy | 1 | 2 | 3 | 4 | 5 |
| Treatment Procedure | 1 | 2 | 3 | 4 | 5 |
| Hospital Short Term Relief | 1 | 2 | 3 | 4 | 5 |
| Orthotic/ Prosthetic | 1 | 2 | 3 | 4 | 5 |
| Doctor Visit | 1 | 2 | 3 | 4 | 5 |
| Other | 1 | 2 | 3 | 4 | 5 |
| Other | 1 | 2 | 3 | 4 | 5 |

## CARE ENVIRONMENT

Client Name: _____ Care Environment _____

### TYPE OF PLACEMENT

| 1 Natural Family | 2 Foster/ Group Home | 3 Group Home 1-4 res. | 4 Group Home 5 or more | 5 Institution |
|---|---|---|---|---|

### SPONSORSHIP

| 1 Natural Family | 2 MHR Direct | 3 Non-Profit Society | 4 Proprietary | 5 Ministry of Health |
|---|---|---|---|---|

MHR Region # _____ Location: _____
# of Staff (FTE) _____ (City or Town)

### NUMBER OF RESIDENTS

Clients _____ Caregivers _____ Other _____

### DIVERSITY OF RESIDENTIAL BACKGROUND OF CLIENTS

| All Tranquille | Tranquille +W or G | WG only | Mixed | Never in Institution |
|---|---|---|---|---|

### BUILDING DESIGN

| New, Purpose-built | Existing, modified | Existing, no structural changes |
|---|---|---|

### HOUSING UNIT

| Apartment | Townhouse | House | Institution |
|---|---|---|---|

### AVERAGE AGE OF RESIDENTS (CLIENTS)

| Child/ Adolescent 0 - 19 | Young adult 20 - 34 | Middle aged 35 - 54 | Elderly 55+ | Mixed - can't classify |
|---|---|---|---|---|

### AVERAGE LEVEL OF RETARDATION

| Borderline - Moderate | Moderate - Severe | Severe - Profound | Profound | Mixed - can't classify |
|---|---|---|---|---|

### AVERAGE LEVEL OF RETARDATION

| Borderline - Moderate | Moderate - Severe | Severe - Profound | Profound | Mixed - can't classify |
|---|---|---|---|---|

### PHYSICAL ACCESSIBILITY (WHEELCHAIR)

| Fully accessible | Accessible with difficulty | Not accessible no need | Not accessible, physically handicapped residents |
|---|---|---|---|

## CARE GIVER CHARACTERISTICS

Age: ___ Sex: M F Time as Caregiver: _____ years

### PREVIOUS RELATIONSHIP WITH CLIENT

None | Former Institution Staff | Family member

### EDUCATION

Grade 12 | Grade 12 | Some Post-Secondary | University Degree

### RELATED TRAINING

None | Aide course/ specify | Professional training (specify)

---

### ORIGINS OF INTEREST IN MR (all that apply)

Family member | Training | Previous employment | Other (specify) | Not really interested

---

### PRESENT MOTIVATION (all that apply)

Skills | Idealism | Relationship with client | Money | Other | No Reward

---

### Caregiver Satisfaction with Aspects of Care

| | Very Satisfied | Satisfied | Neutral | Unsatisfied | Very Dissatisfied | N/A |
|---|---|---|---|---|---|---|
| Physical Environment | 1 | 2 | 3 | 4 | 5 | |
| Availability of Health Services | 1 | 2 | 3 | 4 | 5 | |
| Availability of Community Services | 1 | 2 | 3 | 4 | 5 | |
| Availability of Training Resources | 1 | 2 | 3 | 4 | 5 | |
| Idea of Deinstitutionalization | 1 | 2 | 3 | 4 | 5 | |
| Implementation of Deinstitutionalization | 1 | 2 | 3 | 4 | 5 | |
| Salary Level | 1 | 2 | 3 | 4 | 5 | 6 |
| Staffing Level | 1 | 2 | 3 | 4 | 5 | 6 |
| Overall Job Satisfaction | 1 | 2 | 3 | 4 | 5 | |

## SERVICE LEVELS

| | # | Frequency Period | Present Duration (x1/4hr = .25) | Service Provider | Location of Service | Service Required |
|---|---|---|---|---|---|---|
| Medication Review | | | | | | |
| Diet Care/ Nutrition | | | | | | |
| Podiatry | | | | | | |
| Optical Care | | | | | | |
| Physical Exercise | | | | | | |
| Physiotherapy | | | | | | |
| Occupational Therapy | | | | | | |
| Audiology | | | | | | |
| Dental Care | | | | | | |
| Speech Therapy | | | | | | |
| Treatment Procedure | | | | | | |
| Health Counselling | | | | | | |
| Hospital Short-Term Relief | | | | | | |
| Orthotic/ Prosthetic | | | | | | |
| Doctor Visit | | | | | | |
| Psychology | | | | | | |
| Respite Care | | | | | | |
| School | | | | | | |
| Employment | | | | | | |
| Achievement Centre | | | | | | |
| Recreation Program | | | | | | |
| Public Transit | | | | | | |
| Handi-Dart | | | | | | |

KEY:

**Frequency - period:** 1 Year 2 Month 3 Week 4 Day

**Service Provider:** 1 Care Staff 2 Government Agency
3 Other Agency 4 Private Practice 5 Other, Specify

**Service Location:** 1 Residence 2 Other

**Service Required:** 1 Only if Injured 2 1-4/yr 3 5-10/yr
4 1-2/mo 5 1 or more/week 6 Daily

## CLIENT BENEFIT

### PERCEIVED BENEFIT TO CLIENT

| A great deal | Some | A Little | None | Negative |
|---|---|---|---|---|

### PERCEIVED RELATIONSHIP WITH CLIENT

| Personal friend advocate | | Parent teacher/ trainer | | Caretaker Other _____ |
|---|---|---|---|---|

### EVER THOUGHT ABOUT ROLE REVERSAL

| Intensely | Often | Sometimes | Never | Inconceivable |
|---|---|---|---|---|

### ESTIMATE OF CLIENT LIFE SATISFACTION

| Very satisfied | Satisfied | Neutral | Dissatisfied | Very dissatisfied |
|---|---|---|---|---|

### FAMILY SUPPORT - DISTANCE

| Within 5 miles | Within 20 miles | Within 100 miles | Over 100 miles | No family |
|---|---|---|---|---|

### FAMILY SUPPORT - CONTACT

| Live with family | Frequent/ weekly or more | Regular/ monthly | Occasional/ 6 x per year | No family or no contact |
|---|---|---|---|---|

APPENDIX B1

Province of
British Columbia

Ministry of
Health

Community Care Services
1515 Blanshard Street
Victoria
British Columbia
V8W 3C8

September 27, 1985

Research Secretariat
100 - 3700 Gilmour Way
Burnaby, British Columbia
V5G 4M1

Dear Sir/Madam:

The purpose of this letter is to provide confirmation that Mrs. Carol Wilcox has authorization to use the Ministry of Health data base for the purpose of gleaning information for her current research project. In addition, it is our intent to offer Mrs. Wilcox advice and direction when needed.

Yours sincerely,

[redacted]

Stan Remple, Ph.D.
Assistant Deputy Minister
Community Care Services

APPENDIX B2

Province of
British Columbia

Ministry of
Human Resources

Executive Director
Parliament Buildings
Victoria
British Columbia
V8W 3A2

September 30, 1985

Research Secretariat,
#100 - 3700 Gilmour Way,
Burnaby, B. C.
V5G 4M1

Dear Sir/Madam:

The purpose of this letter is to provide confirmation that Mrs. Carol Wilcox has authorization to use the Ministry of Human Resources' data base for the purpose of gleaning information for her current research project. In addition, it is our intent to offer Mrs. Wilcox advice and direction when needed.

Yours truly,

[redacted]

S.G. Travers,
Executive Director.

Province of British Columbia
OFFICE OF THE MINISTER

Ministry of Health

Parliament Buildings
Victoria
British Columbia
V8V 1X4

July 1, 1986

Ms. Carol Lynn Wilcox
Department of Physiotherapy
Greater Victoria Hospital Society
63 Gorge Road
Victoria, B.C. V9A 1L2

Dear Ms. Wilcox:

Re: BCHCRF Research Grant Application #107(86-1), Comparison of health and level of functioning before and after community integration of formerly institutionalized moderately, severely and profoundly mentally handicapped persons.

I am pleased to inform you that, on the advice of the Scientific Advisory Committee of the B.C. Health Care Research Foundation, you have been awarded a grant of $52,195 for 12 months, effective July 1, 1986 subject to the attached conditions. Disbursements on all BCHCRF grants will be made on a quarterly basis in advance. A cheque for the first quarter's instalment will be sent to the Financial Officer of your institution, who will be asked to furnish the Foundation with appropriate financial statements as required.

You are requested to submit a progress report on your project and a statement of expenditures to the Research Secretariat of B.C. on the anniversary of the award. In the event that you wish to apply for further funding whether for the same project or a different project, a progress report (not more than 2 pages) and statement of expenditure should be an integral part of an application for funding. The progress report should contain concise information on work accomplished and results/findings during the funding period.

If you receive support from another granting agency for this project you should notify the Foundation through the office of the Research Secretariat of B.C., 100 - 3700 Gilmore Way, Burnaby, B.C. V5G 4M1, telephone 438-2752, so that appropriate adjustments and arrangements can be made for funds to be returned to the B.C. Health Care Research Foundation.

I wish you success in your research project and hope that the results of your studies will lead to benefits for the health care of British Columbians.

Yours sincerely,

[redacted]

J.A. Nielsen
Minister of Health

cc: Greater Victoria Hospital Society

encl: Conditions of Award RG-1

APPENDIX D1

## DRAFT LETTER TO MHR STAFF

With the approval of the Ministries of Health and Human Resources, Ms. Carol Wilcox, Director of Physical Medicine of the Queen Alexandra Hospital is conducting a follow-up study of the level of function and of the Health services being received by former residents of Tranquille. She will be familiar to most ex-residents as she conducted a related study prior to the initiative for deinstitutionalization.

Enclosed you will find an example of the form letter and consent form being sent to clients or guardians. So that you may respond to questions from the clients and guardians contacted, enclosed is an abstract of Ms. Carol Wilcox's proposal.

Participation in the study is <u>strictly voluntary</u> and the ministry is approaching the client or guardian as a neutral third party to guarantee consent is voluntary.

Should you have any questions regarding the study you may contact Ms. Wilcox at (604) 477-1826.

APPENDIX D2

## STUDY ABSTRACT

The purpose of this study is to assess the effects of deinstitutionalization in severely and profoundly retarded populations on their health and ability in personal care and daily living skills. The study population will be selected from the former Tranquille residents placed in the community.

The study is designed to answer the following questions: Have significant changes in the general health status occurred in the community integrated population as compared to residents remaining in institutions? Have significant changes in the ability for personal care and daily living skills taken place. Can information on the quality of life for the former residents be extracted from the data and, if yes, what changes have occurred?

The results of this study will be of potential significance for the development of policy on the transfer of retarded individuals from institutional settings to community placements. The current proposal will make use of a unique opportunity at this time in B.C. to compare the success of integration of a sample of severely or profoundly retarded individuals with similar individuals who continue to reside in institutional facilities and individuals who have lived in the community for some time.

**DRAFT LETTER TO BE GIVEN TO CLIENT OR GUARDIAN**

With the approval of the Ministries of Health and Human Resources, Carol Wilcox, Director of Physical Medicine of the Queen Alexandra Hospital is conducting a follow-up study of the level of function and of the health services being received by former residents of Tranquille placed in the community. She will be familiar to most ex-residents as she conducted a related study prior to the initiative for deinstitutionalization. We are asking that you agree to (participate) (the participation of your ward) in this study. All information will be kept in strict confidence and no data that will allow the identification of any individual will be published. Participation is strictly voluntary. In addition individuals are free to withdraw (be withdrawn) at any time. As the primary caregiver will be the main source of information for this project, your agreement to participate will also constitute agreement for the residential caregiver (the person and/or persons that provide care or assistance to the client in the home) to provide the required information.

If, at any time you have any questions about the project please call your worker.

Residential Caregiver: _____

## DRAFT CONSENT FORM

I, _____ agree to participate (the participation of my ward) in a research project that will study the level of function and the health services being received by ex-residents of the Tranquille Institution placed in the community. This participation will involve the interviewing of my (ward's) primary caregiver and I also agree that he or she can provide information about me.

I understand that the information I provide to the researchers will remain completely confidential. Also, any information provided by the caregiver to the researchers will remain confidential.

I understand that I am (my ward is) free not to participate and that this will not affect my (ward's) ability to receive services from the Ministries of Health and Human Resources. I am also free to withdraw my permission at any time.

Signature:_____ Date:_____

## References

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**A Study of Deinstitutionalization of the Moderately, Severely and Profoundly Retarded Populations of the Three Major Institutions in British Columbia**

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