

Greater Metropolitan Clinical Taskforce

Brain Injury Rehabilitation Directorate

Transitional Living Program Evaluation

Stage Two: A Pilot Project

September 2006



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Executive Summary

The TLP Evaluation has been a two year project that has consisted of two distinct stages. The primary objectives of the project have been to describe current NSW BIRP TLP services and to develop an effective evaluative framework for these programs.

This report describes Stage two of the GMCT Transitional Living Program (TLP) Evaluation undertaken by Kate Hopman, Project Officer for the GMCT Brain Injury Rehabilitation Directorate. Stage two of this evaluation has consisted of the implementation of a pilot outcome measurement project across the eight transitional living programs (TLPs) within the NSW Brain Injury Rehabilitation Program.

Background: The NSW BIRP and TLPs

The NSW BIRP is a state wide network of specialist rehabilitation services for people who have sustained a traumatic brain injury (TBI). The network consists of 11 adult and 2 paediatric programs that offer a different range of services (inpatient, outpatient, transitional living, community based and outreach) to meet the rehabilitation needs of their geographical region and client populations.

TLPs currently operate in eight of the eleven, adult BIRP services within NSW. At the commencement of the TLP Evaluation, limited documentation existed which described these services, the clients who used them, the roles these programs played within the BIRP continuum or the outcomes they achieved. Information of this sort is an imperative precursor to effective program evaluation and thus formed the basis of stage one of the TLP Evaluation.

Stage One

Detailed findings from Stage one of the TLP Evaluation have been discussed within the TLP Evaluation Stage One: Report published in June 2006. This report is available from the GMCT BIRP website:
<http://www.health.nsw.gov.au/birp/birdreports.html>.

Three key findings from Stage one are described briefly below as they underpin the development of the Stage two pilot project.

The first finding was that evaluation of NSW BIRP TLPs could possibly be effectively completed if clinical data was pooled across BIRP TLP services. Data pooling was considered a feasible evaluation option as BIRP TLPs had been found to have similar intervention programs in operation across the network. Prior to data pooling, however, further investigations were recommended to determine whether TLPs were providing services to similar client groups. If TLP clients were not significantly similar then data pooling would be an invalid TLP evaluation strategy.

The second key finding from Stage One of the TLP Evaluation was that although NSW BIRP TLPs were a heterogeneous group of programs, they consistently performed three distinct functions within the NSW brain injury rehabilitation continuum. These three functions were labelled transitional living, community resettlement and community management (descriptions of these functions can be found in Chapter 1). The significance of this finding was that effective evaluation of

BIRP TLPs would require examination of outcomes within each of these three TLP functions, individually.

The final key finding pivotal to the development of this Stage two pilot study, was that the average length of stay for a client participating in a NSW BIRP TLP was short (average 4-7 weeks) compared to the length of stays documented for national and international post acute residential rehabilitation models (3-6 months). The implications of this finding were that evaluative outcome measurement tools would need to be sensitive to change over this short intervention time.

Stage Two

The above findings provided a base from which potential methods for evaluating BIRP TLPs could be examined. The TLP evaluation was thus extended to facilitate the implementation of a pilot project to examine TLP client characteristics and rehabilitation outcomes in more detail.

The pilot study had two primary objectives:

1. To collect detailed client demographic and injury related data and analyse whether TLP clients were similar across NSW TLP services
2. To identify and trial standardised clinical outcome measures within NSW BIRP TLPs.

This report describes the development and findings of this pilot study.

Subjects

The findings of the pilot study are based on a cohort of 128 people with TBI who participated in NSW BIRP transitional living programs in 2005. The cohort consisted of all consecutive admissions to the eight transitional living programs within the NSW BIRP. The eight programs were organised into 4 groups for data analysis. The groups were based on similarities in TLP service delivery models. The four groups were Ryde, Metropolitan programs, Hunter and Regional programs. Descriptions of these program groups can be found in chapter one – Table 1.1.

Methodology

Objective One: Identify TLP Client Characteristics

Demographic and injury related data for each subject was collected by clinicians at each BIRP TLP using a standardised data collection protocol (See Appendix 1). Items within the protocol were based on variables that had been identified within TBI literature as having the potential to influence clinical outcomes. These characteristics included: age, sex, injury severity, time post injury and length of stay (at the TLP). They were then compared across the four program groups.

Objective Two: Measure Clinical Outcomes

The pilot study trialled two standardised clinical outcome measures: the Mayo Portland Adaptability Inventory -4 (Malec, 2005) and the Functional Autonomy Measurement Scale (Herbert, Carrier & Bilodeau, 1998). These measures were selected following an outcomes workshop held with TLP clinicians in August 2004. The outcome measures were administered at admission to and discharge from a TLP.

Results

Objective One: TLP Client Characteristics

No significant differences were found across the four TLP program groups for clients' age, sex, injury severity or length of stay. A statistically significant difference was, however, found in the time between injury and admission to a TLP. This difference was significant for Ryde TLP clients as compared to the other three program groups.

Eighty percent (85%) of subjects admitted to the Ryde TLP were admitted within 9 months of their injury while only 69 %, 53% and 55% were admitted this early to the Metropolitan, Hunter and Regional programs respectively. A closer examination of this cohort of subjects also highlighted a trend towards less severe injuries (ie clients tended to have a length of PTA being between 1-4 weeks rather than greater than 4 weeks).

Objective Two: Clinical Outcomes

The second objective of the pilot study was to trial two standardised clinical outcome measures, the MPAI-4 and the SMAF. The pilot involved assessing the ease of administration and scoring of the measures as well as an analysis of aggregate outcome scores.

Change scores from admission to discharge were examined for both measures, with statistically significant improvement found across both the MPAI-4 and SMAF for most clients. These results indicated that, on average, clients had made significant functional and psychosocial gains over the course of their TLP admission on both measures.

Scores on the MPAI-4 were also analysed across the three BIRP TLP functions of transitional living, community resettlement and community management. Statistically significant changes in functioning and participation were found across both the transitional living and community management groups. Outcomes of the community resettlement group were unable to be assessed using the SMAF or MPAI-4 due to the short length of stay that defined this TLP group.

Examination of the data submitted for the SMAF (at six months following the study commencement) revealed that there were problems with its scoring across the eight NSW TLP programs. The SMAF measure was originally designed for a community dwelling, elderly population. Clinicians within BIRP TLPs identified that the SMAF was difficult to score for those clients who had been transferred directly from inpatient settings as these clients had often not had the opportunity to complete community based IADL tasks since their injury. Consultation with BIRP TLP clinicians was sought following this finding. It was decided that a more standardised approach to administration of the SMAF was required and collection of the SMAF was ceased.

Conclusion

The results of the TLP Evaluation pilot study provide evidence that supports the use of data pooling strategies amongst seven of the eight NSW BIRP TLPs. Direct pooling of data from the Ryde program was not supported as subject data highlighted significant differences for this group in terms of their time between injury and admission to the TLP. Data pooling across the remaining seven programs does however have the potential to facilitate effective evaluation of the efficacy of these programs.

In measuring clinical outcomes, the findings from this pilot study have shown that, on average, clients of NSW TLP services make significant functional and psychosocial gains over the course of their TLP admission and that these gains can be measured

using the MPAI-4 and possibly the SMAF. The MPAI-4 measure was also found to measure change across both the transitional living and the community management functions of the TLP. The use of this measure is therefore supported within a clinical dataset for these programs.

Together the findings from Stage one and Stage two of the TLP Evaluation have contributed to the development of a preliminary evaluative framework for BIRP TLPs. The key elements of this framework are provided as recommendations below.

Recommendations for a NSW BIRP TLP Evaluative Framework

1. The MPAI-4 is collected routinely as part of a state wide clinical data set for NSW BIRP TLPs.
2. The SMAF is piloted for a further six months utilising standardised administration guidelines. It should then be reviewed for suitability for its ongoing use within the NSW BIRP TLP clinical dataset.
3. If the SMAF is incorporated as part of the state wide clinical data set for NSW BIRP TLPs, then validation of the modified SMAF should be completed as part of a Masters student project supported by the Brain Injury Rehabilitation Directorate.
4. An annual TLP outcomes report should be generated by the GMCT and circulated to each BIRP TLP. This report should provide each BIRP TLP with a summary of their clinical outcome data and the mean clinical outcomes from the BIRP TLP network.
5. The GMCT establish a TLP working party that meets on a bi-annual basis to review the TLP outcome data and complete appropriate comparative data analysis. Within this group it is envisaged that service benchmarks and best practises could be discussed and analysed and key factors influencing client outcomes could be identified.
6. Bi-annual review of the standardised clinical outcome measures utilised within the TLP dataset is completed. As part of this review process newly developed outcome measurement tools should be circulated and reviewed by TLP staff. Discussion should then be facilitated about modifying the clinical dataset as deemed appropriate by the TLP working party.
7. Further work is required to develop an effective evaluative strategy for the community resettlement function of BIRP TLP's. It is likely that this function may require analysis at an individual program level as the cost effectiveness of providing intensive services in this manner will be influenced by the geography and population size of each region.
8. To assess the cost effectiveness of TLPs compared to alternative post acute rehabilitation models there is a need for further research. It is recommended that a project officer be employed to investigate alternate service models and to contribute to the ongoing development and review of the TLP evaluative framework.

Chapter 1: Introduction

This report documents the findings of Stage Two of the GMCT Transitional Living Program (TLP) Evaluation. Stage Two of this project has involved the development and implementation of a pilot outcomes study with a focus on trialling standardised clinical outcome measures across the NSW BIRP TLP network.

Chapter one of this report, provides:

- (1) A brief background to the TLP Evaluation
- (2) A summary of the key findings from Stage One of the evaluation and
- (3) An overview of the aims of the pilot study

In 2002 the NSW Department of Health commissioned a review of the NSW Brain Injury Rehabilitation Program (BIRP). A primary recommendation from this review was that the role, cost and effectiveness of BIRP transitional living programs (TLPs) be evaluated.

In alignment with the above recommendation, the NSW BIRP TLP Evaluation was instigated by the GMCT Brain Injury Rehabilitation Directorate (BIRD) in 2004. A project officer was employed and Project Steering Committee formed in May and June of that year. Members of the steering committee included representatives from each of the NSW BIRP services, the GMCT BIRD and the NSW Department of Health.

The TLP Evaluation has been a two stage project which has run over two years. The key aims of each stage of the project are outlined below:

Stage One Aims:

- To describe the current BIRP TLP service models
- To describe the clinical population that utilise NSW BIRP TLPs
- To document the current functions of TLPs within the NSW BIRP
- To identify potential evaluation strategies for NSW TLPs.

Stage Two Aims:

- To compare demographic and injury related data for the client group serviced by NSW BIRP TLPs
- To identify and trial standardised rehabilitation outcome measures in BIRP TLP settings

1.1 The NSW Brain Injury Rehabilitation Program (BIRP)

The NSW BIRP is a state wide network of specialist rehabilitation services for people who have sustained a traumatic brain injury (TBI). The network comprises 13 individual programs: five of which are located in Sydney (3 adult and 2 paediatric) and eight of which are located in regional centres. Each BIRP program offers a different range of rehabilitation services (inpatient, outpatient, transitional living, community based and outreach) according to the needs of their geographical region and client populations.

Transitional living programs (TLPs) currently operate in eight of the eleven, adult BIRP services within NSW. At the commencement of the TLP Evaluation, limited documentation existed which described these services, the clients who used them,

the roles these programs played within the BIRP continuum or the outcomes they achieved. This type of information is essential for program evaluation and thus formed the focus of Stage One of the evaluation project.

1.2 Key Findings from the Stage One Evaluation

Stage one of the TLP evaluation identified that there were a variety of different TLP service delivery models employed within NSW BIRP. These models ranged from programs that were attached to specialist inpatient units and operated seven days a week to programs that were located in the community and closed on weekends. Although no two BIRP TLPs were identical, a baseline of similarities was apparent within some program models. This facilitated program classification into four groups (see Figure 1 below).

Table 1.1

Program Group	Service Delivery Model
New Haven (Ryde)	<ul style="list-style-type: none"> • Program operation- seven days a week • Program location- attached to the Royal Rehabilitation Brain Injury Inpatient Unit • Staffing- inpatient multidisciplinary and nursing teams • Referrals- most inpatients were expected to be admitted to New Haven prior to their discharge
Metropolitan TLPs (Westmead and Liverpool)	<ul style="list-style-type: none"> • Program operation– 5-6 days a week • Program location - community based residences • Staffing- allied health and residential care staff/ living skills educators • Referrals- inpatients continuing to require therapy at a high intensity. On average 70% of clients referred to these services were from their respective attached inpatient services.
Large Regional TLP (Hunter)	<ul style="list-style-type: none"> • Program operation- 5 days a week • Program location- the community • Staffing- allied health and residential care workers • Comprehensive day programs also offered on site • Referrals- approximately 50% from acute inpatient rehabilitation facilities and 50% from community based services.
Regional TLPs (Albury, Bathurst, Goulburn and Tamworth)	<ul style="list-style-type: none"> • Program operation- 5 days a week (some programs had the ability to offer weekend program) • Program location- community based accommodation • Staffing- allied health and residential care workers / living skills educators. • Some of the programs operated on an intermittent basis due to the size of their local population. Clients could also attend the TLP for a number of short blocks of intensive therapy and skill review.

Aside from differing program models, Stage one of the evaluations also identified that BIRP TLPs performed three discrete rehabilitation functions within the NSW BIRP brain injury rehabilitation continuum. Different programs had differing numbers of clients supported within each function. The three functions are described below.

Table 1.2

Function	Function description
Transitional Living	<ul style="list-style-type: none"> • Provision of an intensive rehabilitation program for clients requiring support to transition from the structured hospital setting to their home. • Transitional living programs were, on average, 4-7 weeks in duration and had a rehabilitation focus on increasing independent living skills, increasing community participation and facilitating adjustment to TBI. • Within this function, the TLP acted as a discrete step between inpatient and community based/ non inpatient services.
Community Resettlement	<ul style="list-style-type: none"> • TLP and non inpatient rehabilitation services worked in tandem to support rehabilitation clients • Clients spent only a brief period of time at the TLP (1-2 weeks), where they met BIRP team members and completed initial functional assessments • After completion of assessments an outpatient and home based intervention program was developed as an alternative to a continued residential program • In regional programs clients regularly returned to the TLP for short bursts of intensive intervention and upgrading of their home based program
Community Management	<ul style="list-style-type: none"> • Program provided for clients who have commonly already spent time living in the community • An event or decision has often precipitated the need for a change in the client's living arrangements eg a young adult wanting to move out of the family home. • Completion of living skills assessments and/ intensive living skills training programs.

Further Findings

- TLP services within the NSW BIRP are significantly different to TLP and residential rehabilitation services described in national and international literature. A key difference is a client's short length of stay and the fact that the TLP is an intermediate step prior to community outreach services. In comparison national and international residential rehabilitation programs are often the last step in a person's rehabilitation program. Evaluative frameworks for BIRP TLPs will therefore need to be carefully constructed to insure they are adequate and appropriate for these unique programs.

- NSW TLPs provide intensive rehabilitation services to small client groups. Individually, TLPs have a limited ability to demonstrate program efficacy. Data pooling across programs may however provide a more viable method for program evaluation.
- TLP service models demonstrate high variability across the NSW BIRP. Detailed analysis of client demographic and injury data will need to be completed to determine the similarities and differences of the client groups serviced by each BIRP TLP.
- Each TLP within the BIRP collects clinical outcome data. This outcome data is not currently collected in a standardised format. It may be beneficial to collect standardised clinical outcome data across the BIRP network to facilitate effective evaluation of TLP rehabilitation models.
- There is a reasonable similarity in the types of interventions implemented within BIRP TLPs. These similarities suggest that there may be potential to develop best practise guidelines for NSW BIRP TLP services.

1.3 Stage 2: Pilot Study

The key findings from Stage One of the TLP Evaluation indicated that evaluation of NSW BIRP TLPs may be more effectively completed if clinical data is pooled across BIRP TLP services. Prior to data pooling there was, however, a need to establish whether programs were providing services to similar client groups. If TLP clients are not significantly similar then data pooling will not be a valid TLP evaluation strategy.

A pilot study was therefore developed to look in more detail at the clients of BIRP TLP services and to examine possible methods for collecting standardised clinical outcome data across these services. The pilot study had two primary objectives:

1. To collect detailed client demographic and injury related data and to analyse whether TLP clients were similar across NSW BIRP TLPs
2. To identify and trial standardised rehabilitation outcome measures in BIRP TLP settings

Data collected within the pilot study was analysed by comparing results across the four different service delivery groups (Table 1.1) and the three discrete TLP functions; transitional living, community resettlement and community management (Table 1.2).

The following chapters of this report document the development of this pilot study, its methodology, results and points of discussion. The report concludes with recommendations for the ongoing development of an effective evaluative framework of BIRP TLP services.

Chapter 2: Methodology

This chapter describes the BIRP TLP pilot study. It begins by providing a description of the pilot study sample. It then outlines the development of the data collection protocol and outcome measurement tool selection and concludes with the data analyses undertaken.

2.1 Sample

To address the two objectives of the pilot study all consecutive admissions to NSW BIRP TLPs were recruited over a one year period. The sample therefore was all consecutive admissions from the 1st of January 2005 to the 31st of December 2005. All eight TLP services were involved in collecting data for the pilot study. One program however had to cease data collection after seven months due to staffing issues. Total admissions over this time were 128.

Subjects within this pilot study sample ranged in age from 15-67 with no specific age group representing a significant majority within admissions. Males comprised 76% of the sample, which is reflective of the current gender ratio of TBI incidence across Australia.

Using the duration of PTA as the indicator of injury severity it was found that approximately seventy percent (70%) of the study's subjects were classified as having either a very severe or extremely severe brain injury (PTA length greater than one week). Fifteen percent (15%) of the subjects had other types of non traumatic brain injury.

The mean length of a TLP for subjects within this study was forty four (44) days with a sample range from 2-298 days (Std dev. 44.7). Further data on subject characteristics is documented in Table 3.1 p 16.

2.2 Objective One- TLP Client Characteristics

Data Protocol

In order to address the first project aim a data collection protocol was developed. The findings from Stage One of the evaluation had highlighted a number of client characteristics that were influential in clinical outcome and thus important to review prior to any data pooling. These characteristics included a client's age, sex, initial injury severity as measured by the duration of PTA, time from injury to admission and length of stay. These variables were thus collected as part of the pilot project data collection protocol (see Appendix 1).

2.3 Objective Two

Approaches to Outcome Measurement Selection

A review of TBI literature revealed that a number of different methods have been utilised to measure clinical outcomes in the field of post acute TBI rehabilitation. These methods have included; the collections of descriptive status indices, for example, discharge destinations and employment status (Cope et al 1991; Johnston & Lewis 1991); the implementation of standardised outcome measures (Willer et al.

1999, Powell et al. 2002) and the measurement of individual client goals (Malec, 2001).

For this study it was determined that data would be collected using standardised clinical outcome measures as this method was seen to be the most efficient and reliable method of obtaining outcome data which could be used for program evaluation and comparison (Powell, Wright, Plumb, Atkins, Pantke & Kalmus, 2005).

Standardised Outcome Measures

In recent years, a wide range of standardised clinical outcome measurement tools have been developed to quantify rehabilitation outcomes in the field of TBI. In a report to the Motor Accidents Authority in 2002, Tate and colleagues identified some 110 different measurement scales that they had collected following a comprehensive literature search. The challenge for the TLP evaluation was to sort through this broad range of scales and to determine which measures were appropriate to assess functional and psychosocial outcome within the transitional living environment.

A list of six possible measures was identified through literature review and discussion with researchers in the field. These measures were; the Mayo Portland Adaptability Inventory – version 4 (MPAI-4; Malec, 2005); the Sydney Psychosocial Reintegration Scale (SPRS; Tate et al., 1999), the Community Integration Questionnaire (CIQ; Willer & Corrigan, 1994), the Care and Needs Scale (CANS; Tate, 2003), the Assessment of Living Skills and Resources (ALSAR; Williams et al., 1993), the Craig Handicap and Assessment Reporting Technique (CHART; Whitneck et al., 1985).

One published study was particularly influential in guiding the selection of three of the above clinical outcome measures. This study was completed by Simpson and colleagues in 2004 and trialled a range of standardised outcome measures within a NSW BIRP TLP environment (Liverpool Brain Injury Rehabilitation Unit). This study found that three outcome measures were sensitive in measuring changes in functional and psychosocial status for the study sample. These three scales were the; Sydney Psychosocial Reintegration Scale (SPRS; Tate et al. 1999), the Mayo Portland Adaptability Inventory (MPAI; Malec, 2005) and the Assessment of Living Skills and Resources (ALSAR; Williams et al. 1993).

Three further outcome scales were then added for preliminary review by the TLP Steering Committee. These measures were scales that had been frequently used within published post acute rehabilitation literature and had well established psychometric properties. Copies of the six measures were circulated to all the TLP Steering Committee members. Members were asked to review and pilot the measures with the aim of providing feedback on their utility, to the project officer. This information was summarised and presented to the committee at an outcomes workshop in August 2004 (See Appendix 2- for the summary of feedback).

TLP Outcomes Workshop

The TLP outcomes workshop was held on the 23rd of August 2004. Presenters at the workshop included: Ms Helen Harrington (Program Manager- Bethesda Transitional Living Unit- Victoria), Associate Professor Robyn Tate (Royal Ryde Rehabilitation Studies Unit) and Ms Barbara Strettles (Service Manager- Liverpool Transitional Living Unit).

A large section of the outcomes workshop was focussed on discussing the merits and limitations of the six circulated standardised outcome measurement tools and discussing further measures that could be considered for inclusion within a pilot

study. At the completion of the workshop participants selected the MPAI-4 for inclusion in the study for the following reasons:

- (a) Familiarity: some programs were already using this measure within their outreach programs
- (b) Comprehensiveness: It was perceived to be comprehensive as it covered abilities, adjustment and participation areas
- (c) Demonstrated reliability and validity.

The Mayo Portland Adaptability Inventory

The MPAI-4 is a 35 item scale with three subscales measuring; abilities, adjustment, participation. Each item is rated via a five point rating scale with higher scores indicating greater levels of disability. The MPAI-4 is administered by interview and can be completed by a clinician, client or client's relative.

The psychometric structure of the MPAI has been examined in detail. Recent refinement using Rasch analysis has resulting in a scale with the three subscales detailed above, with Cronbach's α coefficients suggesting good internal consistency (Abilities .80, Adjustment .76, Participation .83 respectively). In terms of validity, the MPAI has shown good concurrent validity with the Disability Rating Scale ($r=0.75$) (www.combi.com).

Measures of Instrumental Activities of Daily Living (IADL)

Participants at the outcomes workshop identified that a large proportion of TLP intervention was targeted at increasing individuals' independent living skills. In particular, community based skills such as "getting around", "participating in community based activities" and "money management". These skills or tasks are frequently referred to as instrumental activities of daily living (IADL's).

Only one of the six measures discussed at the outcomes workshop, focussed on IADL skills. This measure was the ALSAR. Feedback during the workshop identified that the ALSAR scale was currently being modified by the Liverpool Brain Injury Rehabilitation Program to enhance its sensitivity for use with a TBI population. As the measure was only in the early stages of development it was deemed to be unsuitable for trial within this pilot project.

Workshop participants agreed that further examination of IADL scales should occur, with an aim to locate an appropriate standardised measure of these skills for inclusion within the pilot study. This task was delegated to the Project Officer.

A broad range of IADL scales were examined by the Project officer (see Appendix 3). Following this examination the Functional Autonomy Measurement Scale –SMAF (Herbert et al, 1998) was selected for circulation and further consideration by TLP Steering Committee members.

The Functional Autonomy Measurement Scale (SMAF)

The Functional Autonomy Measurement Scale was originally designed for a community dwelling elderly population. It had been recently trialled with post acute rehabilitation populations in Victoria and had been recommended as a potential clinical outcome measurement scale in this field (Smith, Darzins, Steel, Murray, Osborne & Gilsean, 2001).

The SMAF contains 29 items, in which a person's level of disability as well as handicap is rated using a five point rating scale (0, -0.5, -1, -2, -3). Higher disability scores indicate higher levels of independence in functional activities, while the handicap score is based on whether a client has access to resources which can help

them overcome their disability. The measure provides a numbered list of resources and provides the rater opportunity to record up to three resources that the client is currently utilising.

Items within the SMAF are spread over five sub scales; ADL, Mobility, Communication, Mental Functions, and IADL. The IADL scale has 8 individual items which include; housekeeping, meal preparation, shopping, laundry, telephone use, transportation, medication and budgeting.

The SMAF IADL scale was reviewed and endorsed by TLP steering committee members for inclusion in the pilot study for the following reasons:

- the scoring scale appeared to be sensitive and appropriate for a TBI population (ie scoring descriptors included activity limitations resulting from both physical and cognitive impairments)
- the scale had a short administration time (so as not to be onerous on the clinicians who would be participating in the study) and
- the scale had been recently piloted successfully in a post acute rehabilitation study in Victoria (Smith et al, 2001).

After revisions to the scale in 1993, the psychometric properties of the SMAF IADL subscale for test-retest (n=39) over a 2-week period found a mean weighted kappa of 0.69 with an IntraClass Correlation coefficient at 0.95. Interrater reliability between 2 raters found a mean weighted kappa of 0.75, with an IntraClass Correlation of 0.96. In terms of construct validity, the SMAF has been found to correlate highly with the FIM (r=0.94) and the Barthel Index (r=0.92).

2.4 Procedures

The Ethics committees of each Area Health Service were approached prior to commencement of the pilot study and provided with an outline of the study protocol. Each Committee was asked whether ethics clearance would be required for this study:

Key determinants for the need for ethical review were:

- (a) The study did not involve client's having to complete any procedure that was not a part of current standard clinical practise and
- (b) The data released to the GMCT for analysis would be recorded and submitted in a de-identified manner (see data collection form in Appendix 3)

Four Ethics Committees classified the pilot project as quality improvement and deemed that an ethics application was not required. One of these committees, located at Westmead Area Health Service, requested a quality improvement project application be submitted.

Three committees – Hunter New England Area Health Service, Greater Southern Area Health Service and Liverpool Area Health Service requested the submission of ethics applications. Ethical clearance was obtained from each of these services.

Clinicians at each BIRP TLP completed the de-identified demographic data sheet (See Appendix 2) and the MPAI-4 and SMAF measures at admission and discharge for study subjects. Admission measures were completed within the first two weeks of a subject's admission to the TLP.

Those subject's with a length of stay of less than two weeks were not scored on the MPAI-4 or SMAF at discharge as it was felt that this time period was too small to be able to influence functional and participation outcomes. This time period was also not representative of the complete rehabilitation program (i.e. the combined result of residential and home based programs).

2.5 Data Analysis

Objective One- TLP Client Characteristics

To analyse subject characteristics, the TLP sample was divided into the four program groups (described in Chapter 1). The four groups were: Ryde, Metropolitan programs, Hunter and Regional programs. Data numbers were not sufficient to facilitate analysis at an individual program level.

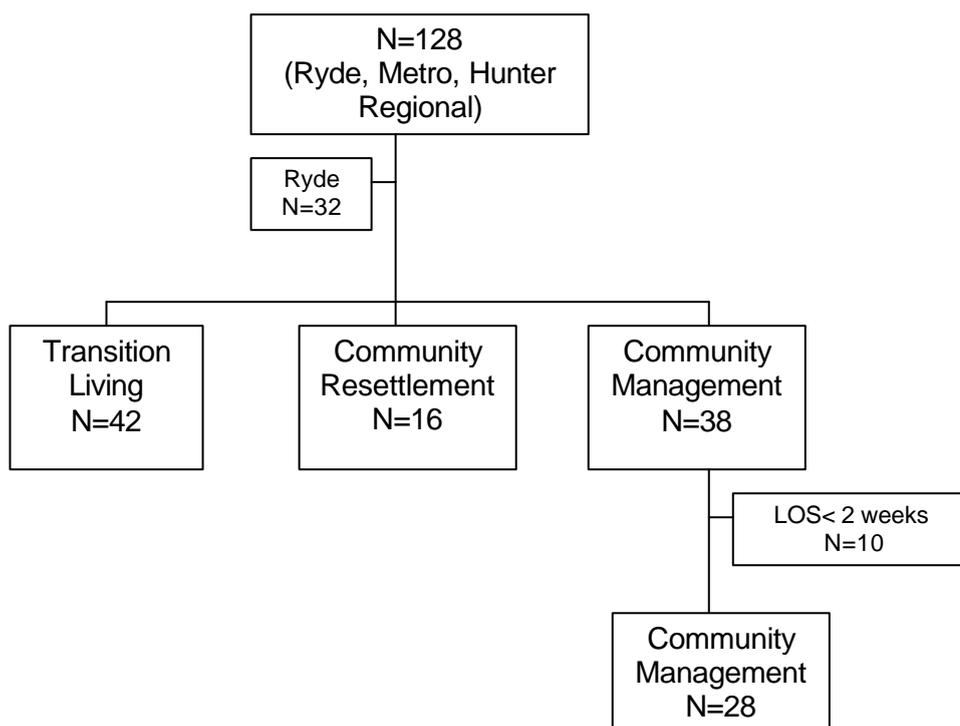
Chi square tests were used to analyse whether there were significant differences between the four program groupings. Variables examined included; client age, sex, injury severity, length of stays (LOS) and time between injury and admission to the TLP.

Objective Two: Measurement of Clinical Outcomes

To address the second aim of the pilot study (outcome measurement sensitivity) subject data from the MPAI4 was grouped and analysed according to the three rehabilitation functions performed by NSW TLPs, transitional living, community management and community resettlement (see Chapter 1 for descriptions). Data from the SMAF was analysed as a single group due to the smaller sample size for this measure.

Descriptive data from the MPAI-4 was examined and found to be normally distributed across the TLP sample. Parametric tests were therefore employed for data analysis and Bonferonni corrections were applied to multiple comparisons.

Figure 2a: Data analysis flowchart for the NSW BIRP TLP pilot study



Chapter 3: Results

Data was collected for 128 TLP admissions over the course of this study. The results of the pilot study have been reported under the following two headings; TLP Client Characteristics and Measurement of Clinical Outcomes. These headings reflect the two primary objectives of the pilot study.

3.1 Objective 1: TLP Client Characteristics

The first aim of the TLP pilot study was to identify whether TLP populations were similar enough to facilitate pooling of program data for evaluation purposes. As identified previously, program data was analysed by dividing it into four (4) program categories which were based on similarities in TLP service delivery models. These four program categories were; Ryde, Metropolitan programs, Hunter and Regional programs.

Key client characteristics were examined across the four TLP groups (see Table 1). These characteristics included subjects; age, sex, injury severity, time between injury and admission to the TLP and length of stay. Chi square tests and a one way ANOVA were performed to analyse these variables. No significant differences were found across the four TLP program groups for client age and sex, injury severity or length of stay.

Table 3.1: Client Characteristics

Programs	Ryde	Metro	Hunter	Regional	? ² / F
Characteristics	N/ Mean	N/ Mean	N/ Mean	N/ Mean	
Sex					

- Male	22	21	22	33	ns
- Female	10	5	5	10	
PTA					ns
- < 4weeks	11	8	7	12	
- > 4weeks	17	14	12	12	
-not avail.	4	4	8	19	
Age					ns
- <40	16	17	23	24	
- >40	16	9	4	19	
Time Post Injury					18.59 ** p< 0.005
- <9 months	27	18	14	22	
- >9 months	5	8	12	20	
Length of Stay (days)	40.8	64.5	34.2	40.1	ns

A statistically significant difference in the TLP cohorts was found in the time between injury and admission. Post hoc analysis found that the Ryde program was significantly different to the other three program groups with eighty five percent (85%) of subjects admitted to the Ryde TLP within 9 months of their injury. In comparison 69 %, 53% and 55% were admitted this early to the Metro, Hunter and Regional programs respectively.

The above findings demonstrate that within the study population, seven out of the eight NSW BIRP TLPs service populations demonstrated a significant similarity in key client characteristics. This suggests that client data from these programs could be validly pooled for evaluative purposes.

Data from the Ryde TLP cohort was found to be significantly different when related to the other BIRP TLP populations. This difference was primarily time between injury and admission to the program. A trend towards significant difference in injury severity was also noted for these clients (more particularly the large proportion that were admitted within 3 months) with a greater proportion of Ryde subjects having a PTA length of less than 4 weeks. These differences suggest that aggregate clinical outcome data from Ryde can not be directly compared to that of the other BIRP TLPs.

3.2 Objective 2: Measurement of Clinical Outcomes

The results of the SMAF and MPAI-4 analyses are described and discussed separately below.

Incorporating the findings from the TLP client analysis, it was decided that aggregate outcome data from the Ryde program (N=32) would not be included in the assessment of the MPAI-4 outcome measure sensitivity. This decision was based on the potential for Ryde's data to possibly over inflate any sensitivity findings. The Ryde group were found to have been admitted to the TLP more acutely and thus were potentially likely to make greater functional improvement due to natural recovery.

Mayo Portland Adaptability Inventory (MPAI-4)

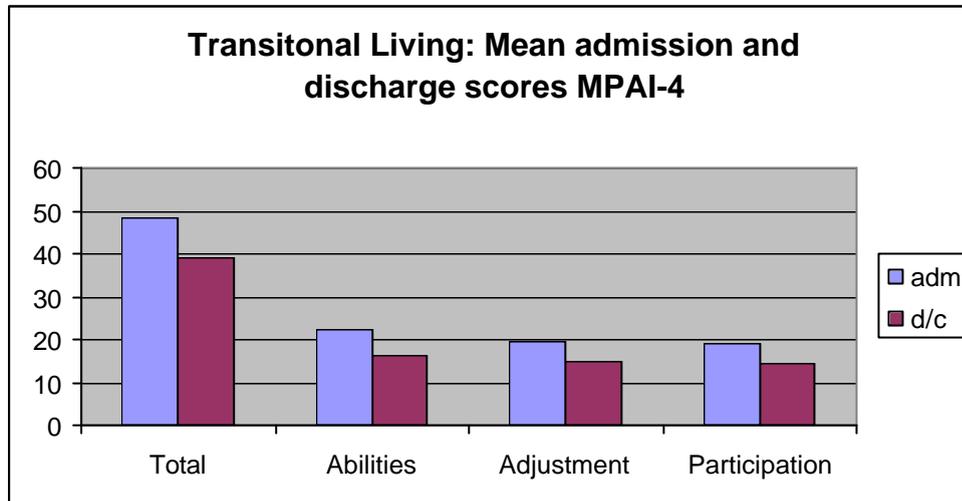
Findings from Stage one of the TLP Evaluation highlighted that NSW BIRP TLPs perform three distinct rehabilitation functions; transitional living, community resettlement and community management. Comprehensive evaluation of BIRP TLP services thus requires evaluation of each of these three functions separately.

MPAI-4 data was therefore grouped according to the three NSW BIRP TLP functions and the change in scores from admission to discharge were analysed within these three groups. The results from analysis of data from each BIRP TLP function are provided below.

1. Transitional Living (N=42)

Data for forty two participants was analysed for the transitional living function. Within this function, intensive rehabilitation programs of approximately 4-7 weeks in duration are provided to clients to facilitate their transition from hospital settings to their home.

Figure 3.1



Visual inspection of Figure 3.1 highlights that MPAI-4 scores reduced from admission to discharge across all three MPAI-4 subscales and the MPAI-4 Total score. Lower scores are indicative of lower levels of functional disability.

Paired sample t-tests were performed using the mean MPAI-4 scored at admission and discharge for this TLP cohort. Significant improvement (ie significant reduction in disability) was found across the MPAI -4 total score as well as each subscale score (see Table 3.2 below). This improvement was statistically significant following Bonferonni correction for multiple comparisons (0.05/16, alpha= 0.003).

An effect size was roughly calculated for the MPAI-4 scores using the mean change score and mean standard deviation (see Table 3.1). Effect sizes of 0.6 to 0.8 were identified across the three scales and total score, indicating a moderate to strong effect size across this transitional living cohort.

Table 3.2: Transitional Living Cohort – MPAI-4 Scores

	Mean adm	sd adm	Mean disch	t-score	Effect Size*
Total Score	48.2	16.3	37.2	5.7	0.7
Abilities	22.0	7.7	15.9	7.0	0.8
Adjustment	19.1	8.2	14.5	5.8	0.6
Participation	18.7	5.9	14.3	8.6	0.7

*(Mean admission - Mean discharge / standard deviation)

T-scores were also calculated for this cohort and compared to a national (USA) reference sample (Malec, 2005). A raw score of 48 (the mean admission score for the transitional living cohort) is equivalent to a T score of 48 while a raw score of 37 (the mean discharge score for this sample) is equivalent to a T score of 42.

Malec and colleagues (2005) identified that T scores between 40 and 60 were “typical scores” for clients who had moderate to severe injuries and were involved in community- based or residential based rehabilitation (Malec & Lezac, 2003). T scores of 30-40 were suggested to indicate that clients had milder limitations. The T scores obtained within this sample had made a significant shift towards this “mild impairment” band.

2. Community Resettlement (N= 16)

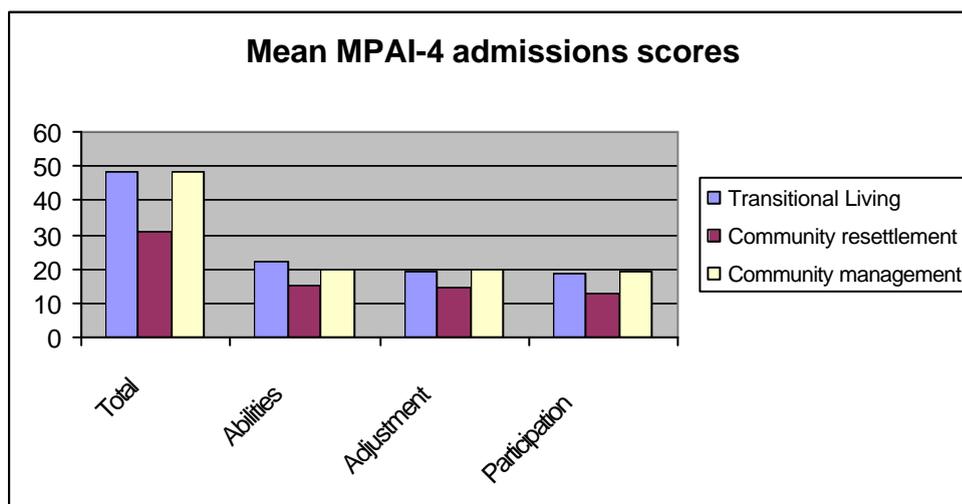
Clients participating in a community resettlement program receive a combined TLP and home based rehabilitation program. Within this function clients often have only a short admission/ TLP program (1-2 weeks) and clients in regional centres often return to the TLP for short intensive therapy blocks over a period of months.

For this group only MPAI-4 admission data was collected. Prior to the study commencement it had been determined that minimal change in MPAI-4 scores would be expected over a short residential program and thus to evaluate the program more effectively there would need to be an evaluation of the combined TLP and outreach program approach.

MPAI-4 admission data for this group was, however, compared to that obtained for the transitional living and community management cohorts (see figure 3.2). Figure 3.2 highlights a difference in MPAI-4 admission scores across the cohorts, with the community resettlement cohort displaying lower levels of functional disability across all three subscales and total score at the time of admission.

This finding indicates that subjects participating in the community resettlement function of NSW BIRP TLP’s were, on average, less functionally impaired than those participating in the transitional living or community management streams. Higher levels of functioning at admission are likely to have contributed to their more efficient move to less intensive, home based rehabilitation programs.

Figure 3.2



3. Community Management (N=38)

Results from thirty eight subjects were obtained for the community management cohort. Clients within this rehabilitation cohort were those who had been admitted from the community and were more than 12 months post injury. For most it is likely that an event or decision had often precipitated the need for a change in their living situation.

Data analysis for clients participating in a Community Management program followed the same procedures as for the transitional living group ie. Paired sample t-tests were conducted across admission and discharge MPAI-4 scores. A portion of the sample (N=10) were noted to have had a length of stay that was less than 2 weeks and thus did not have discharge MPAI-4 scores.

Significant improvement was identified across the MPAI-4 total score and individual subscales, indicating that clients within the community management streams had made improvements in functional and participation areas from admission to discharge (see Table 3.3). All changes were found to be statistically significant however improvement on the adjustment subscale was found to be non significant after Bonferonni correction (0.05/16, alpha= 0.003).

Table 3.3 Community Management Cohort - MPAI-4 scores

	Mean adm	sd adm	Mean disch	t-score	Effect Size
Total Score	49.6	13.8	42.6	3.4**	0.5
Abilities	20.5	7.6	15.9	3.5*	0.6
Adjustment	20.5	7.9	18.1	3.5 (ns)	0.2
Participation	19.8	5.6	17.8	4.1**	0.3

Effect Size= (Mean admission - Mean discharge / standard deviation)

Once again an effect size was estimated using the mean change score and mean standard deviation. Effect sizes of 0.2 to 0.5 were identified across the three scales and total score. These sizes were smaller than those documented within the transitional living cohort however indicated that clients had made improvement over their admission.

The smaller effect size noted within this cohort is not an unexpected finding, as this cohort is at a minimum of 12 months post injury. Clients greater than one year post injury have often been used as historical controls within research studies (Cope et al., 1991; Wood et al., 1991) with many authors identifying that gains made by subjects within this group are unlikely to be due to spontaneous natural recovery. Many authors claim that gains made at this point can be more readily attributed to rehabilitative interventions and supports.

Length of Stay Analysis across TLP Functions

Length of stay although not significantly different across individual programs was also compared across TLP rehabilitation functions. There was no significant difference found between the average length of stay for subjects within transitional living and community management functions (55 days and 38 days respectively). There was however a significant difference in the average LOS between these two functions and the community resettlement function (8 days) this was to be expected as length of stay was used as a defining variable for BIRP TLP functions.

(B) Functional Autonomy Measurement Scale (SMAF)

Data collection using the SMAF scale was ceased approximately half way through the pilot study. This occurred for two reasons; firstly data sheets received by the GMCT demonstrated inconsistencies in scores across individual programs and secondly because clinicians identified that the resource section of the scale was difficult to score and interpret.

Inconsistencies in Scoring

One specific SMAF administration issue that became apparent during the TLP pilot was “When?” to score the SMAF. The SMAF was designed to be implemented with populations that are community dwelling and yet clients admitted to BIRP TLPs had often not had the opportunity to “reside” in the community since their injury.

Clients entering the TLP had often not attempted to complete specific tasks such as catching public transport or managing a budget since their injury. Scoring these tasks was thus difficult and some programs elected to score clients at the lowest level (-3) indicating they had not been completing these tasks, while other programs elected to wait and complete the measure after opportunities to complete these tasks had been observed/ assessed.

Scoring resources

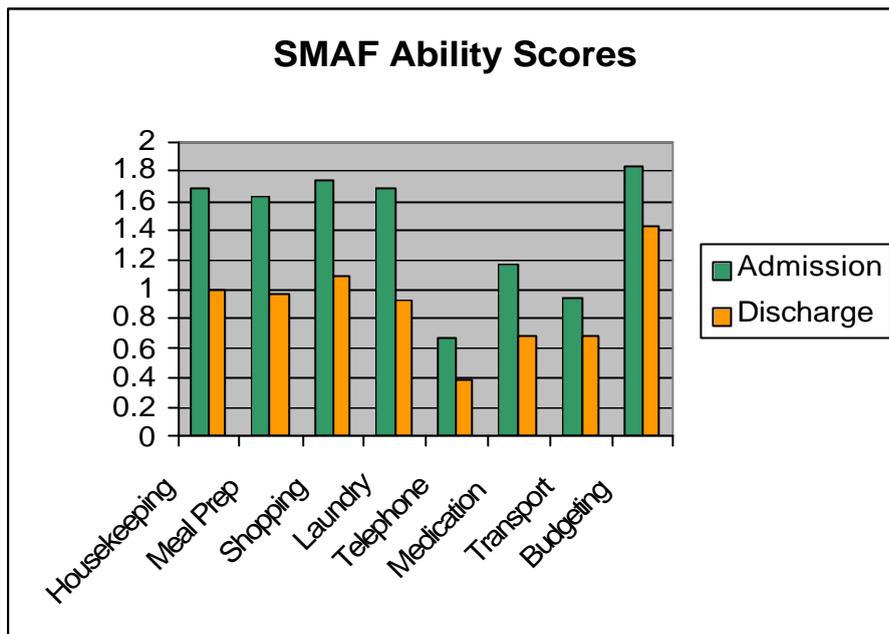
Difficulty in scoring resources was also noted during the pilot of the SMAF. The SMAF asks a clinician to assess whether clients have access to sufficient resources to overcome disabilities in IADL tasks. An example of this may be whether a client has a family member who can provide transport to activities and appointments. Eight different possible resources can be recorded within the scale. The guidelines did not provide any instruction as to how many resources should be scored or how to collate these responses for analysis.

Data Analysis

Although difficulties with administration of the SMAF were reported by BIRP clinicians, many identified that the scale items appeared to have face validity and were easy to administer. It was determined that analysis of the data collected over the first six months should be completed to look at the preliminary sensitivity of the scale for a TLP TBI population.

SMAF data from thirty four subjects was therefore analysed using paired sample t-tests. Admission and discharge scores were reviewed across each of the eight IADL task items. The mean scores at admission and discharge are displayed in Figure 3.3 (see over the page). Scores were converted to “positive numbers” to facilitate easier interpretation. Higher scores on the graph illustrate higher levels of disability. All IADL tasks demonstrated significant improvement or significant reduction in disability from TLP admission to discharge, except for budgeting which was not significant after Bonferroni correction.

Figure 3.3 Mean Admission and Discharge - SMAF IADL scale



The results for the SMAF were discussed with participating clinicians. Clinicians acknowledged that the SMAF was quick to administer and focused on the tasks/activities that were often the target of TLP interventions. Clinicians also identified that they felt the inconsistencies noted in scoring could be addressed by developing clearer administration guidelines which were relevant and appropriate for the NSW BIRP TLP settings.

In response to this feedback the TLP Evaluation Steering Committee held a workshop to develop administration guidelines specifically for the NSW BIRP TLP network. Each program was invited to participate in this workshop and the draft manual was circulated twice for feedback. A copy of the finalised administration guide can be found in Appendix 4.

Members of the TLP project steering committee agreed to pilot the SMAF using the newly developed administration guidelines for a further period of six months. Data collection using this measure was commenced August 2006.

Chapter 4: Discussion

The results of this pilot study, in combination with the findings from Stage one of the TLP Evaluation contribute important information towards the development of an effective evaluative framework for NSW BIRP TLP services.

Stage one of the evaluation has highlighted that NSW BIRP TLPs are unique, post acute rehabilitation services that perform a range of rehabilitative functions to meet the individual needs of their local BIRP services. The evaluation acknowledged that the three differing rehabilitative functions performed by BIRP TLPs, the short length of client stay and the small client numbers serviced within each individual BIRP TLP were key challenges in the development of an evaluation framework for the BIRP TLP network.

A key recommendation from Stage one of the TLP Evaluation was the need to examine whether data pooling of clinical outcome data across BIRP TLPs could be validly used to examine TLP efficacy. Analysis of the demographic data collected in this pilot study has revealed that there are significant similarities in key client variables such as age, sex, injury severity and time post injury, for seven of the eight NSW BIRP TLP populations. This finding suggests that the pooling of clinical outcome data across the seven programs is a valid methodology for examining BIRP TLP efficacy.

Client demographic data has also demonstrated that clients supported within the Ryde TLP are significantly different from the clients supported within the other NSW BIRP TLP services. This data has shown that the Ryde program services a broader TBI population than the other programs, which is on average less severely injured and generally seen more acutely. These findings suggest that it is inappropriate to directly pool or compare clinical outcome data from clients of the Ryde TLP to clients of the other seven NSW BIRP TLPs. For this group however, it may be more appropriate to evaluate outcome data by comparing it with a similar cohort of discharges from BIRP inpatient settings.

The differences in the subject characteristics of the Ryde cohort were not an unexpected finding of the pilot study as Stage One of the TLP evaluation project had documented that Ryde's TLP service delivery model was substantially different to other BIRP models. Data from this pilot study supports that these differences are significant and signal that the Ryde model of service will need to be evaluated uniquely and individually within the NSW BIRP continuum.

Findings from Stage one of the TLP evaluation highlighted that there was a consistency in the multidisciplinary staffing and interventions provided at each BIRP TLP. This combined with demonstrated TLP client similarities suggests that program comparisons are an effective and valid tool for benchmarking across programs. The establishment of benchmarking practises would require the continued collection of standard data across the seven programs. This data would then need to be analysed by BIRP clinicians with respect to key service delivery differences (eg 5 day versus 6 day programs).

Over the course of the TLP Evaluation the Westmead Transitional Living Unit was relocated from its community based residence to accommodation on the Westmead Hospital campus. Changes in service delivery, such as this, will need to be monitored as they have the potential to change referral patterns and thus impact on client

characteristics. It is therefore recommended that continued review of key client characteristics are performed on a regular basis.

The second objective of the TLP pilot study was to examine the efficacy of two standardised clinical outcome measures, the MPAI-4 and the SMAF for a NSW BIRP TLP sample. The two outcome measures were selected by clinicians working in BIRP TLPs following literature review, researcher consultation and clinician discussion. Of these measures one, the MPAI-4 is a broad measure that has been designed for a post acute brain injury rehabilitation population while the second measure, the SMAF is targeted at specific IADL skills that were identified as a major focus of BIRP TLP intervention.

Results from the pilot of these two measures demonstrate that, on average, clients made significant gains in functional, psychosocial and participation areas over the course of their BIRP TLP rehabilitation program.

To more specifically analyse outcomes across the three discrete rehabilitative functions of performed by BIRP TLPs, MPAI-4 subject data from this study was examined in more detail.

Within the transitional living sample cohort, the MPAI-4 data demonstrated that subjects had, on average, made statistically significant gains in the three areas of; abilities, adjustment and participation. Effect sizes of 0.6-0.8 were found across the three scales indicating that a moderate to large change in functional status had occurred over the course of the TLP. As there was no comparison group within this study this change cannot be automatically attributed to the TLP. It paves the way however for providing data that could potentially be compared to other post acute rehabilitation populations that have demonstrated similarity in key population variables.

Within the community management cohort, data from the MPAI-4 demonstrated that community management subjects had, on average, made statistically significant functional gains over the course of their TLP. Effect sizes in this population were smaller than those noted in the transitional living cohort (0.2-0.5) however these changes were still significant. Subjects within this cohort were greater than a year post injury and thus were considered to be less likely to be influenced by the process of natural spontaneous recovery.

Combined these two findings provide support for the efficacy of transitional living programs for clients with brain injuries. They also confirm that the MPAI-4 can be utilised to measure outcomes across two of the rehabilitation functions performed by BIRP TLPs, transitional living and community management.

Use of the SMAF standardised measure was however less well supported by the pilot study findings. Review of the subject data collected using the SMAF uncovered significant differences in scoring of this measure across the eight NSW BIRP TLPs. An investigation of these differences identified that they had arisen from differences in the timing of the administration of these measures by BIRP clinicians. The results were discussed with TLP clinicians and a consensus was obtained to re-trial the measure using a set of administration guidelines developed specifically for NSW BIRP TLP settings. The SMAF is therefore currently being re-trialled for a period of six months across the network.

A final finding that warrants mention within this discussion is the average length of a NSW BIRP TLP admission. Although there was a broad range of program lengths (2 – 298 days) documented within this pilot study, the average program length was only forty four days. This length of stay is significantly shorter than the average length of stays documented and reported by other national and international TLP and residential programs (Simpson et al. 2004).

Looking at this short length of stay in more detail the framework of the NSW BIRP continuum must be acknowledged. The NSW BIRP is a comprehensive continuum of rehabilitation services in which the TLP is single part. Clients participating in a TLP are almost always referred on to outpatient and outreach programs and thus it is not the end-point of their rehabilitation. The role of the TLP is thus significantly different from a number of national and international models where residential rehabilitation is often the “last step” or final rehabilitation opportunity for persons with TBI. It is this fact that is likely to influence the longer length of stay within these programs.

What has been encouraging to note is that the standardised measures piloted in this trial have been able to detect functional changes even over the short admissions of NSW BIRP TLPs.

In summary this pilot study has provided the BIRP with data that supports the use of data pooling strategies amongst seven of the eight BIRP TLPs. It has confirmed that the Ryde TLP service delivery model is sufficiently more acute than the seven other TLP models and thus needs to be evaluated independently. It has also replicated findings which indicate that BIRP TLP programs are significantly shorter in duration than other national and international models (Simpson et al 2004).

Results from the piloted outcome measures have been successful in documenting change in functional and participation levels within clients of BIRP TLPs. The data thus supports that these measures may be appropriate for implementation within a standard clinical dataset for the NSW BIRP TLP network. Using the results from this pilot study, a set of recommendations has been made to establish a preliminary evaluative framework for NSW BIRP TLPs.

Chapter 5: Recommendations

1. The MPAI-4 is collected routinely as part of a state wide clinical data set for NSW BIRP TLPs.
2. The SMAF is piloted for a further six months utilising the new administration guidelines. It should then be reviewed for suitability for its ongoing use within the NSW BIRP TLP clinical dataset.
3. If the SMAF is incorporated as part of the state wide clinical data set for NSW BIRP TLPs, then validation of the modified SMAF should be completed as part of a Masters student project supported by the GMCT Directorate
4. An annual TLP outcomes report should be generated by the GMCT and circulated to each BIRP TLP. This report should provide each BIRP TLP with a summary of their clinical outcome data and the mean clinical outcome data from the BIRP TLP network.
5. The GMCT establish a TLP working party that meets on a bi-annual basis to review the TLP outcome data and complete appropriate comparative data analysis. Within this group it is envisaged that service benchmarks and best practises could be discussed and analysed and key factors influencing client outcomes could be identified.
6. Bi-annual review of the standardised clinical outcome measures utilised within the TLP dataset is completed. As part of this review process newly developed outcome measurement tools should be circulated and reviewed by TLP staff. Discussion should then be facilitated about modifying the clinical dataset as deemed appropriate by the TLP working party.
7. There is a need to develop an effective evaluative strategy for the community resettlement function of BIRP TLP's. It is likely that this function may require analysis at an individual program level as the cost effectiveness of providing intensive services in this manner will be influenced by the geography and population size of each region.
8. To assess the cost effectiveness of TLPs compared to alternative post acute rehabilitation models there is a need for further research. It is recommended that a project officer be employed to investigate alternate service models and to contribute to the ongoing development and review of the TLP evaluative framework.

Appendix 1

Brain Injury Rehabilitation Directorate GMCT Transitional Living Program Project (Data collection form)

Participant Code: _____

Date of injury: _____

Sex: M F

Cause of Injury:

MVA Driver	
MVA Passenger	
MBA	
Pedestrian	
Bicycle	
Skateboard / Roller Blade / Scooter	
Assault	
Gunshot	
Fall (other than sport)	
Sport	
Hypoxia	
Cerebral Bleed/CVA	
Other Traumatic Brain Injury	
Other Non Traumatic Brain Injury	

Date of Admission to TLP:

Date of Discharge from TLP:

Injury Severity:

<1 day
2-7 days Severe
1-4 weeks Very Severe
1-6 months Extremely Severe
>6 months Chronic Amnesia State
Not Applicable
Not Available

Age at Injury (please circle)

- 15-19
- 20-24
- 25-29
- 30-34
- 35-39
- 40-44
- 45-49
- 50-54
- 55-59
- 60-64
- 65+

Outcome Scores

Admission MPAI-4

Raw score Abilities _____
 Raw score Adjustment _____
 Raw score Participation _____
 Total Score _____

Discharge MPAI-4

Raw score Abilities _____
 Raw score Adjustment _____
 Raw score Participation _____
 Total Score _____

Pre-existing /associated conditions

- 30 - Alcohol _____
- 31-Drug Use _____
- 32- Psychotic Symptoms _____
- 33- Law Violations _____

Admission SMAF

IADL Activity	Disabilities	Handicap	Resources *
Housekeeping			
Meal preparation			
Shopping			
Laundry			
Telephone			
Transportation			
Medication Use			
Budgeting			

Discharge SMAF

IADL Activity	Disabilities	Handicap	Resources *
Housekeeping			
Meal preparation			
Shopping			
Laundry			
Telephone			
Transportation			
Medication Use			
Budgeting			

* Resources: 1= Family, 2= Neighbour, 3= Employee, 4= Aides/Carer, 5= Nurse, 6= Volunteer, 7= Other

Appendix 2

	Services who had trialled	Time to administer	Advantages	Disadvantages
CIQ	2	10mins	<ul style="list-style-type: none"> * Involves the client * Easy to administer * Nicely worded questions * Short * Relates well to TLP 	<ul style="list-style-type: none"> * Hard for clients with limited insight * Better as an outreach outcome measure * Limited ability to detect change over TLP admission * Ceiling effects have been observed * Wording of questions not applicable for those coming to TLP from acute inpatient setting

	Services who had trialled	Time to administer	Advantages	Disadvantages
ALSAR	1	10mins	<ul style="list-style-type: none"> * very functional * sensitive to change * easy to score * scores resources as well as ability 	<ul style="list-style-type: none"> * Doesn't cover emotional, cognitive or psychosocial areas * not specifically designed for TBI pop * 3 point scale offers minimal ability to measure change(x2 comments) * could see limited use for the scale

	Services who had trialled	Time to administer	Advantages	Disadvantages
MPAI-4	4 – services had used version 3	10-15mins	<ul style="list-style-type: none"> * good resource for case management * easy to score * developed for TBI population * 5 point scale increases sensitivity * covers wide range of areas: adjustment, fatigue and anxiety 	<ul style="list-style-type: none"> * ? sensitivity for short TLU stay * subject to clinician bias * a number of items don't change eg driving status*reliant on client self report (unless scored by clinician who is familiar with client) * does not include financial info * not enough IADL items * time consuming

	Services who had trialled	Time to administer	Advantages	Disadvantages
CHART	1 (not with TLP clients)	30 mins	*widely used in TBI research	* difficult to score and administer * ? clients ability to provide information (limited insight) * Takes a long time to administer *focuses on quantity not quality for activity levels * will it measure change for short stay admissions? *severe disability focus

	Services who had trialled	Time to administer	Advantages	Disadvantages
SPRS	4	1 hour (one service) 10 -15mins (2 services)	*sensitive to TLU outcomes *quick and easy to administer * not a lot of detail of IADL skills *could be useful	* difficult to administer with client as wordy (x2) *not sensitive for TLU outcomes * takes a long time to administer *Staff queried whether it would detect change in anxiety/stress related to activities

	Services who had trialled	Time to administer	Advantages	Disadvantages
CANS	1 (not with TLP clients)	20 mins (if unfamiliar with client)	* quantitative *measures support levels in a standardised way *easy to score	* not sensitive enough to measure client change in TLU (x2) * does not measure IADL in detail

Appendix 3

Scale	Scale Items	Psychometric Properties
FIM/FAM (Hamilton et al., 1987)	30 items (FIM) 12 additional items (FAM) 7 point rating scale	Median inter-rater reliability =0.95 (Granger et al., 1993) High correlations with other ADL scales eg Barthel Index
Nottingham Extended ADL Scale (Nouri & Lincoln, 1987)	22 items rated on a 4 point scale	Test retest r = 0.81- 0.90 (Nicholl et al., 2002) Suggested that sensitivity could be improved by expanding range of items (Nicholl et al., 2002)
Frenchay Activities Index (de Haan, Limburg & Groenier, 1993)	15 items rated according to frequency they have been performed over past 6 months	Inter rater coefficient = 0.8 Reported to correlate to Bathel Index and depression scales
Handicap and Resource Assessment Tool Vertesia, Barzins et al., 2000)	41 items rated on a 3 point scale	Currently undergoing testing (Smith et al 2001)
Functional Autonomy Measurement Scale (Herbert et al., 1988)	29 items for complete scale 8 items in IADL subscale rated on 5 point scale	Inter rater reliability = 0.95 Test- retest reliability = 0.96 Correlations: FIM r = 0.95 and Barthel Index r =0.92 (Herbert et al, 2001)
Return to Normal Living Index (Wood-Dauphinee, Opzoomer et al., 1988)	11items scored on a 10cm visual analogue scale	Reliability- Cronbach's alpha = 0.61 (client) and 0.92 (significant other)
London Handicap Scale (Harwood et al., 1994)	6 items rated on a 6 point rating scale	Reliability – Cronbach's alpha = 0.83

Appendix 4

Functional Autonomy Measurement System (SMAF)

**NSW BIRP TLP Clinical Data Set
- Administration Guide –
May 2006**

Developed by:
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GMCT Brain Injury Rehabilitation Directorate
NSW Australia

Purpose

The SMAF –Functional Autonomy Measurement System was developed by Herbert, Carrier and Bilodeau at the Expertise Centre, Shebrooke Geriatric University Institute Quebec, in Canada in 1983.

It is a twenty nine 29 item measure that has five (5) subscales which are used to evaluate the autonomy of community dwelling adults. The sub scales include: activities of daily living (ADL), mobility, communication, mental function and instrumental activities of daily living (IADL).

The SMAF was primarily designed for older adults and has been widely validated for this population. Each SMAF function is scored on a scale from 0 to -3. The following provides a general guide to function scoring:

0	Independent
-0.5	Independent but has difficulty carrying out the activity
-1	Needs supervision or stimulation to carry out the activity
-2	Needs some assistance to carry out the activity
-3	Needs complete assistance to carry out the activity

The SMAF evaluates a person's ability in functional tasks and also their level of handicap/ participation restriction by assessing their level of access to resources.

For example:

If a person scores a 0 or -0.5 for an IADL function they are deemed independent and thus have a handicap score of "0".

If, however a person scores a -1, -2 or -3 for an IADL function then the "resource" section of the SMAF is scored. If a person has access to adequate resources to overcome their reduced function then they are scored as "0" (no handicap). If they do not have access to resources then their score remains -1, -2 or -3 indicating they have a handicap / participation restriction.

The NSW Brain Injury Rehabilitation Program has piloted the IADL sub scale from the SMAF with a population of individuals with acquired brain injury (ABI). The IADL sub scale was selected as it is comprised of eight functional activities which are often the primary focus of rehabilitative intervention within NSW BIRP transitional living programs. Preliminary results from this pilot study suggest that the measure is sensitive and appropriate for use with this population.

Results from the SMAF pilot, did however, highlight discrepancies in scoring of the SMAF across NSW TLPs. These discrepancies centred on differing interpretations of the published administration guidelines. To address this issue clinicians from each of the NSW BIRP TLPs attended a workshop and developed a set of standard administration guidelines for using the SMAF within the NSW BIRP.

This publication documents the guidelines that were developed at the BIRP SMAF workshop. It also provides enhanced scoring descriptors (using descriptions of impairments that are commonly seen within the ABI population).

Administration Guidelines

1. When to score?

Many clients enter NSW BIRP transitional living programs from acute hospital settings. For these clients, it was found to be difficult to score their IADL status directly on admission, as clients had not often had the opportunity to perform IADL tasks since their injury.

To ensure that an accurate assessment of IADL performance skills is obtained using the SMAF the scale is not completed until the second week of a client's TLP.

2. What to score?

During the pilot study, clinicians identified that it was often difficult to determine whether to score a client's observed IADL performance (while at the TLU) or their predicted IADL capacity. Published guidelines for the SMAF recommended rating performance and/or capacity.

One example of the difference between performance and capacity is that a client may be completing his laundry independently each week at the TLU but when he returns home he is observed to be unable to initiate this task without the structure and environmental cues that were an inherent part of the residential setting.

In discussion with clinicians at NSW TLPs it was determined that **the evaluator must base their rating on what they have observed the client to do at the TLP/ TLU and/ or what the client's family have reported regarding the client's functional performance on weekend leave.**

If certain IADL tasks are not expected to be completed as part of a client's life roles (eg the client whose wife completes all meal preparation tasks) and these skills are not the focus of rehabilitative intervention then these tasks should be scored as a – 3 as the client "does not complete" this IADL task.

3. Scoring Resources

Following the pilot study, clinicians identified that the resources section had been difficult to complete as it was heavily reliant on what services were available in the local community (a factor that was outside each services control). TLP services deemed that they would like to use the resources section of the SMAF to document the "gaps" in community services ie the frequency that services or supports were required but were not available.

To record these service gaps an extra box has been added to the SMAF IADL rating form which asks clinicians to identify resources required. A list of nine relevant resources has been developed and can be found on top of the rating form. They include: family, friends, attendant carer, purchased services, DADHC - Home Care, DADHC- Community services, community nurse, volunteer.

SMAF- Instrumental Activities of Daily Living

1. Housekeeping

Rate the person's observed performance in looking after a house. This includes completing daily housework as well as occasional big jobs.

Regular housework: does the person complete usual daily domestic tasks such as tidying dusting, ironing, cleaning the top of the stove, cleaning the fridge, cleaning the kitchen and bathroom, vacuuming, taking out the garbage, etc.

Heavy duty cleaning: does the person complete heavy jobs related to looking after the house such as washing the floors, moving furniture and mowing the grass, etc.

- 0 **Does housekeeping alone**
Is observed/ reported to do daily housework independently (dusting, washing the dishes) as well as heavy jobs (washing the floors). Maintains his/ her home inside and out without direct or indirect help.
- 0.5 **Does housekeeping alone but with difficulty**
Completes housekeeping jobs alone but with difficulty, which may be physical or cognitive. Takes a long time to do housework, breaks up the tasks because tires quickly.
- 1 **Does housekeeping but needs supervision or stimulation
Or needs help for heavy jobs.**
Completes housekeeping tasks but must be reminded regularly to ensure that it is done properly **OR** is able to do regular housework but needs help with the heavy jobs only. Use this score if there is evidence that housekeeping is neglected and that supervision appears to be needed.
- 2 **Needs help for daily housework**
Able to participate in daily housework but needs help to complete the task. Washes the dishes and counters but needs help with dusting, sweeping or vacuuming and washing the floors.
- 3 **Does not do housework**
Total inability to look after the house or does not participate in any household tasks- Housekeeping is done by someone else.

2. Meal Preparation

Rate the person's observed performance in meal preparation tasks. This includes chopping, preparing and cooking food.

- 0 **Prepares a variety of meals independently**
Is observed/ reported to make breakfast, lunch and dinner. Collects the necessary ingredients, prepares them and cooks them without stimulation or supervision.
- 0.5 **Prepares own meals independently but with difficulty**
Prepares meals but breaks up the activity because they tire easily, work slowly etc. For example prepares meals in stages, uses a structured meal plan or uses adaptive equipment.
- 1 **Prepares meals but needs stimulation or supervision**
Able to prepare meals but may require prompting to initiate or to keep on task. May require supervision for safety or the caregiver guides the client in the choice of menu and the client prepares it.
- 2 **Only prepares light meals or reheats pre-prepared meals**
Unable to prepare meals that require prolonged cooking, requires physical assistance for task steps. Can make breakfast independently but heats up food prepared by a family member or Meals on Wheels for other meals.
- 3 **Does not prepare meals**
Totally unable to prepare meals including heating pre-prepared meals or lives in a residence where meals are provided or purchases take away food.

3. Shopping

Rate the person's observed performance in making a shopping list, purchasing needed items (food and clothes) and bringing them home. (Note: do not evaluate capacity to get to and from the store)

- 0 **Plans and does shopping independently**
Is observed/ reported to shop for all necessary items independently without help, stimulation or supervision. This can include shopping "on line".
- 0.5 **Plans and does shopping independently but with difficulty**
Completes necessary shopping but occasionally forgets things or has difficulty relating to a physical weakness. May require help to bring items home but can arrange home delivery independently.
- 1 **Shops independently but requires assistance to plan a shopping list or to initiate this task**
- 2 **Needs help to plan and shop**
The person needs help to make a shopping list and someone must accompany them to the store or shop. The client may have difficulty finding what he/ she needs within the supermarket and ensuring they purchase the necessary items from the shopping list.
- 3 **Does not shop**
Some one else decides what to buy and does the shopping.

4. Laundry

Rate the person's observed performance in sorting the laundry, operating the washing machine, drying and folding the laundry.

- 0 **Does all laundry independently**
Is observed/ reported to sort, wash, dry and fold the laundry. Does not need supervision or stimulation for the task.
- 0.5 **Does all laundry independently but with difficulty**
Is able to sort, wash, dry and fold the laundry with difficulty. For example has difficulty folding the washing, forgets to bring in the washing or needs to use a clothes drier or occasionally runs out of clean clothes.
- 1 **Does laundry but needs stimulation or supervision**
Indicates a need to be regularly reminded to do the activity or caregiver must supervise the activity directly; otherwise the client may make mistakes.
- 2 **Needs help to do laundry**
Indicates the capacity to participate in doing the laundry, either by folding it or separating whites from colours, but does not complete the whole task.
- 3 **Does not do laundry**
Caregiver does the laundry every week.

5. Telephone

Rate the person's observed performance in finding a telephone number (in a physical directory or using directory assistance), dialling it and communicating by telephone independently.

- 0 **Uses telephone independently**
Finds a number and communicates with that person by telephone.
- 0.5 **Uses the telephone independently but with difficulty**
Finds a number, dials it and talks on the phone, but with difficulty. Occasionally dials the wrong number or has to call a person twice to gain all required information. May not be able to use all functions on a mobile phone eg SMS, calendar or alarm.
- 1 **Answers the telephone and initiates making phone calls using programmed numbers**
May need assistance to find and/ or program a novel telephone number into the phone.
- 2 **Requires prompting and or physical assistance to use the telephone**
Needs assistance to dial a number or requires prompting to call family and friends on a regular basis.
- 3 **Does not communicate via the telephone**
Caregiver makes calls for the client.

6. Transportation

Rate a persons observed performance when using transportation to get around

- 0 **Able to use transportation alone**
Person plans, organises and uses transportation alone. Can drive independently, knows which bus/ train to take and get on/ off independently.
- 0.5 **Able to use transportation alone but with difficulty**
Is able to travel alone but experiences occasional difficulties using transport eg. Gets on the wrong bus, can't take all forms of public transport, has had their licence suspended.
- 1 **Can use transport to make short familiar trips**
Person can use transport independently for familiar journeys. May require some initial training.
- 2 **Needs assistance to plan and use transport**
Indicates an inability to arrange transport and/ or to get on and off transport. Can travel independently within transport if someone available to assist at each end of the journey.
- 3 **Must be accompanied to use transportation**

7. Medication Use

Rate the person's observed performance in managing their medication. This includes organising and taking medication independently, appropriately and safely.

- 0 **Takes medication unaided according to prescription OR Does not need medication**
Person takes their medication without mistakes. Takes medication from bottles independently or with a medication aid that they have prepared themselves. Can organise repeat scripts independently.
- 0.5 **Takes medication unaided, but with difficulty**
Person takes medication independently but with occasional mistakes eg takes it at the wrong time or misses a tablet. Uses a dosette box or medication aid independently.
- 1 **Needs monitoring to ensure compliance with prescription or medication dispenser (can be supervision from afar)**
Needs prompting to organise repeat prescriptions. Manages blister pack/ dosette box with supervision, may need compliance to be monitored on a regular basis.
- 2 **Needs regular supervision and prompting to take daily medication**
Requires assistance to obtain repeat prescriptions also requires daily prompting to manage medication which may include a phone call or visit from family members.
- 3 **Must be given each dosage of medication as prescribed**
Client does not have access to their medication or an alternative form of medication may be required eg monthly injection.

8. Budgeting

Rate a person's observed performance in money management. This includes: paying bills on time, doing minor and major transactions and managing pocket money.

- 0 **Manages budget independently**
Observed or reported to manage all necessary transactions independently, pay bills and manage pocket money. Makes financial decisions independently.
- 0.5 **Manages budget independently but with difficulty**
Manages all the necessary transactions but has some difficulties eg. Occasionally pays bills late or requires direct debits to pay utilities.
- 1 **Needs help for financial transactions**
Able to manage day to day transactions but requires assistance to plan a budget. Able to generally stick to the budget once established.
- 2 **Needs help to pay bills**
Able to manage a weekly amount for personal expenses. Receives assistance to manage bills, loans etc. Accounts may be managed by an external person (family or a statutory body eg. Office of the Protective Commissioner).
- 3 **Does not manage budget**
Indicates a total inability to manage finances. Client may be provided with pocket money on an as needs basis or every 1-2 days. A family member or an external agency manages financial assets.

Resources

1= Family member

2= Friend/ neighbour

3= Attendant Carer (private/ insurer funded)

4= Purchased Services (Taxis, House cleaning, ironing, gardening)

5= DADHC Services– Home Care

6= DADHC Services- Community Access

7 = Community Nurse

8 = Volunteer

SMAF IADL Scoresheet

IADL Task- Abilities	Handicap	Resources/ Resources Required
<p>1. Housekeeping</p> <p><input type="checkbox"/> 0 Does housekeeping independently</p> <p><input type="checkbox"/> -0.5 Does housekeeping independently with difficulty</p> <p><input type="checkbox"/> -1 Needs supervision or cueing</p> <p><input type="checkbox"/> -2 Needs assistance</p> <p><input type="checkbox"/> -3 Does not perform</p>	<p>If Ability < -0.5 Does the client have access to adequate resources?</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p>1=Family <input type="checkbox"/></p> <p>2= Friend <input type="checkbox"/></p> <p>3= Attendant Care <input type="checkbox"/></p> <p>4= Purchased Care <input type="checkbox"/></p> <p>5=DADHC (HomeCare) <input type="checkbox"/></p> <p>6= DADHC (CM/ respite) <input type="checkbox"/></p> <p>7= Nurse <input type="checkbox"/></p> <p>8= Volunteer <input type="checkbox"/></p>
<p>2. Meal Preparation</p> <p><input type="checkbox"/> 0 Prepares meals independently</p> <p><input type="checkbox"/> -0.5 Prepares meals independently with difficulty</p> <p><input type="checkbox"/> -1 Needs supervision or cueing</p> <p><input type="checkbox"/> -2 Needs assistance</p> <p><input type="checkbox"/> -3 Does not prepare meals</p>	<p>If Ability < -0.5 Does the client have access to adequate resources?</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p>1=Family <input type="checkbox"/></p> <p>2= Friend <input type="checkbox"/></p> <p>3= Attendant Care <input type="checkbox"/></p> <p>4= Purchased Care <input type="checkbox"/></p> <p>5=DADHC (HomeCare) <input type="checkbox"/></p> <p>6= DADHC (CM/ respite) <input type="checkbox"/></p> <p>7= Nurse <input type="checkbox"/></p> <p>8= Volunteer <input type="checkbox"/></p>
<p>3. Shopping</p> <p><input type="checkbox"/> 0 Shops independently</p> <p><input type="checkbox"/> -0.5 Shops independently with difficulty</p> <p><input type="checkbox"/> -1 Needs help to plan or initiate</p> <p><input type="checkbox"/> -2 Needs assistance</p> <p><input type="checkbox"/> -3 Does not shop</p>	<p>If Ability < -0.5 Does the client have access to adequate resources?</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p>1=Family <input type="checkbox"/></p> <p>2= Friend <input type="checkbox"/></p> <p>3= Attendant Care <input type="checkbox"/></p> <p>4= Purchased Care <input type="checkbox"/></p> <p>5=DADHC (HomeCare) <input type="checkbox"/></p> <p>6= DADHC (CM/ respite) <input type="checkbox"/></p> <p>7= Nurse <input type="checkbox"/></p> <p>8= Volunteer <input type="checkbox"/></p>
<p>4. Laundry</p> <p><input type="checkbox"/> 0 Does laundry independently</p> <p><input type="checkbox"/> -0.5 Does laundry independently with difficulty</p> <p><input type="checkbox"/> -1 Needs supervision or cueing</p> <p><input type="checkbox"/> -2 Needs assistance</p> <p><input type="checkbox"/> -3 Does not do laundry</p>	<p>If Ability < -0.5 Does the client have access to adequate resources?</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p>1=Family <input type="checkbox"/></p> <p>2= Friend <input type="checkbox"/></p> <p>3= Attendant Care <input type="checkbox"/></p> <p>4= Purchased Care <input type="checkbox"/></p> <p>5=DADHC (HomeCare) <input type="checkbox"/></p> <p>6= DADHC (CM/ respite) <input type="checkbox"/></p> <p>7= Nurse <input type="checkbox"/></p> <p>8= Volunteer <input type="checkbox"/></p>

IADL Task - Abilities	Handicap	Resources/ Resources Required
<p>5. Telephone</p> <p><input type="checkbox"/> 0 Uses telephone independently</p> <p><input type="checkbox"/> -0.5 Uses telephone independently but with difficulty</p> <p><input type="checkbox"/> -1 Makes calls using programmed numbers</p> <p><input type="checkbox"/> -2 Needs assistance to use the phone</p> <p><input type="checkbox"/> -3 Does not communicate via phone</p>	<p>If Ability < -0.5 Does the client have access to adequate resources?</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p>1=Family <input type="checkbox"/></p> <p>2= Friend <input type="checkbox"/></p> <p>3= Attendant Care <input type="checkbox"/></p> <p>4= Purchased Care <input type="checkbox"/></p> <p>5=DADHC (HomeCare) <input type="checkbox"/></p> <p>6= DADHC (CM/ respite) <input type="checkbox"/></p> <p>7= Nurse <input type="checkbox"/></p> <p>8= Volunteer <input type="checkbox"/></p>
<p>6. Transportation</p> <p><input type="checkbox"/> 0 Uses transport alone</p> <p><input type="checkbox"/> -0.5 Uses transport alone but with difficulty</p> <p><input type="checkbox"/> -1 Uses transport alone for short familiar journeys</p> <p><input type="checkbox"/> -2 Requires assistance to use transport</p> <p><input type="checkbox"/> -3 Does not use transport alone</p>	<p>If Ability < -0.5 Does the client have access to adequate resources?</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p>1=Family <input type="checkbox"/></p> <p>2= Friend <input type="checkbox"/></p> <p>3= Attendant Care <input type="checkbox"/></p> <p>4= Purchased Care <input type="checkbox"/></p> <p>5=DADHC (HomeCare) <input type="checkbox"/></p> <p>6= DADHC (CM/ respite) <input type="checkbox"/></p> <p>7= Nurse <input type="checkbox"/></p> <p>8= Volunteer <input type="checkbox"/></p>
<p>7. Medication</p> <p><input type="checkbox"/> 0 Takes medication independently</p> <p><input type="checkbox"/> -0.5 Takes medication independently but with occasional difficulty</p> <p><input type="checkbox"/> -1 Requires supervision</p> <p><input type="checkbox"/> -2 Requires daily prompting</p> <p><input type="checkbox"/> -3 Must be given each dose</p>	<p>If Ability < -0.5 Does the client have access to adequate resources?</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p>1=Family <input type="checkbox"/></p> <p>2= Friend <input type="checkbox"/></p> <p>3= Attendant Care <input type="checkbox"/></p> <p>4= Purchased Care <input type="checkbox"/></p> <p>5=DADHC (HomeCare) <input type="checkbox"/></p> <p>6= DADHC (CM/ respite) <input type="checkbox"/></p> <p>7= Nurse <input type="checkbox"/></p> <p>8= Volunteer <input type="checkbox"/></p>
<p>8. Budgeting</p> <p><input type="checkbox"/> 0 Manages budget independently</p> <p><input type="checkbox"/> -0.5 Manages independently but with difficulty</p> <p><input type="checkbox"/> -1 Needs help to plan budget</p> <p><input type="checkbox"/> -2 Manages weekly spending money but is assisted with bills and major transactions</p> <p><input type="checkbox"/> -3 Does not manage own finances</p>	<p>If Ability < -0.5 Does the client have access to adequate resources?</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p>1=Family <input type="checkbox"/></p> <p>2= Friend <input type="checkbox"/></p> <p>3= Attendant Care <input type="checkbox"/></p> <p>4= Purchased Care <input type="checkbox"/></p> <p>5=DADHC (HomeCare) <input type="checkbox"/></p> <p>6= DADHC (CM/ respite) <input type="checkbox"/></p> <p>7= Nurse <input type="checkbox"/></p> <p>8= Volunteer <input type="checkbox"/></p>

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