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Evaluation of the LIAISE Program

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- Alan Dayman, Southern Region, Department of Human Services
- Alan Blackwood (former CEO) and Victoria Chipperfield, Headway Victoria
- Susan Follett, former LIAISE client
- Ken Ouw, former LIAISE client
- Stephanie Gottlieb, ARBIAS
- Kate Rickard, Hampton Rehabilitation Hospital.

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ABSTRACT

This is an evaluation of a three year pilot program, LIAISE, which provides independent living skills training and community integration assistance to people with acquired brain injury who are living in the Victorian Department of Human Services' Southern Metropolitan Region. A combination of methods, including program theory, quantitative and qualitative data collection and analysis, and case studies were used in the evaluation. It was found that LIAISE has gradually shifted from primarily providing independent living skills training to a more holistic focus with a substantial increase in the amount of case management services provided. The need for a more holistic approach was substantiated by the literature. In regards to the value and usefulness of LIAISE to its clients and their families, the evaluation was overwhelmingly positive. Many of these people had been living for many years with little or no assistance from the health and community services sector, and found that the quality of their lives substantially improved with their involvement in LIAISE. Service providers interviewed also clearly valued LIAISE and emphasised the gap in services that it now fills. It was therefore recommended that the LIAISE program continue. Recommendations were also made regarding the need to maintain a flexible and holistic approach to meeting the needs of people with ABI living in the community.

It is less clear whether LIAISE represents value-for-money and will be viable under the Victorian Department of Human Service's unit costing funding system. Typically unit costing is based primarily on the hours of direct service provision (direct being defined as time spent with the client). LIAISE's direct client hours as a proportion of staff time is approximately half that of other similar services. Given the level of client and service provider satisfaction with the service it may be that the mix of client and non-client time currently provided is generally appropriate, but it was recommended that some small improvements be made to increase direct client time. It was also noted that the application of unit cost funding to LIAISE needed to support rather than restrict its flexibility and the range of services provided.

EXECUTIVE SUMMARY

This evaluation was commissioned by the LIAISE Program. Initially it was to be a process evaluation, but over time it has also become an outcome evaluation. This report provides a description of the LIAISE Program and its clients, evaluates its success in meeting its stated objectives and makes a number of recommendations for its future. It is primarily a client focused evaluation centred on how well LIAISE has met the needs of its clients.

The LIAISE Program began accepting clients in September 1994. The acronym LIAISE stands for Living, Independence, Access, Integration, Support, Empowerment. LIAISE is auspiced by three agencies: Community Disability Support Southern (in Bentleigh); Cranbourne and District Community Health Centre; and Peninsula Community Health Service (in Mornington). LIAISE is a three year pilot program, funded by the Victorian Human Services Department through the Commonwealth/State Disability Agreement Growth Funding 1993/94 Grants Program. The primary purpose of LIAISE is to provide independent living skills training and community integration assistance to people with acquired brain injury (ABI) who are living in the Southern Metropolitan Region.

The Evaluation

The purposes of this evaluation were:

1. to clarify the objectives, principles and theory of the LIAISE Program and to ensure that it is appropriately focused;

2. to provide feed-back on LIAISE at an early date to facilitate program improvement;

3. to assess the effectiveness of the program in meeting the needs of people with ABI who have low support needs, in particular to determine whether LIAISE is encouraging and facilitating client independence, community

integration and skills development (in accordance with the 'Whatever It Takes' model of community based rehabilitation/community integration);

4 to make recommendations regarding the ongoing support needs of people with acquired brain injury; and

5 to assess the viability of replicating this model in other locations.

Evaluation Framework and Methods

The evaluation framework employed multiple methods and multiple sources of information. This was necessary to fulfil the multiple purposes of the evaluation, and to ensure that the results were as valid and reliable as possible. Information for the evaluation was collected through:

- client population statistics;
- program documentation;
- 22 interviews with service providers and policy makers;
- interviews with LIAISE staff and meeting with LIAISE managers;
- 12 in-depth case studies of LIAISE clients.

The LIAISE Program

The following principles underpin the LIAISE Program and the activities of the LIAISE staff:

- that clients should have control over the decisions that affect their lives, including the activities undertaken with/by LIAISE;

- that LIAISE methods and activities should focus on the quality of clients lives, must be holistic and take into account the client's beliefs, values and culture;

- that clients should be empowered, not made dependent on LIAISE;

- that clients can fulfil valued roles in society;

- that working with clients within their homes and in the community is essential to providing high quality and relevant support and assistance.

At the simplest descriptive level the LIAISE activities undertaken with or for individual clients include:

- intake and Assessment (these are done by the Coordinators);
- goal Setting with clients;
- independent Living Skills Training;
- access to Other Services for clients and families;

- support to clients and families.

The LIAISE Program was conceived to meet local needs and as part of its development available models of best practice were examined for their relevance. The model having the most influence on LIAISE is the 'Whatever It Takes' (WIT) model of service delivery to people with ABI developed by Willer and Corrigan (1994), in Buffalo, New York. The WIT model has won widespread support from both providers and consumers because of the flexible, client focused and pragmatic approach it espouses. Fundamental to the WIT approach is the abandonment of rigid categories of service delivery that hinder flexible problem solving.

The literature review undertaken by the evaluators also demonstrated that narrow categories of service provision are artificial and can inappropriately restrict an agency's ability to provide the range of services that are necessary to meet their clients' needs. Skills training does not necessarily precede community integration nor is it necessarily the case that people can be given a set of skills and then left to their own devices. Both the literature and the data from this evaluation demonstrate that social isolation and the need to have someone to 'be there' are critical problems affecting the ability of people with ABI to function in the community. Although precisely targeted, short-term skills training may sometimes be appropriate, more typically skills training, community integration and case management blur into a general commitment to find solutions appropriate for individual clients whatever it takes.

LIAISE Clients

The number of clients increased over a period of about six months after the establishment of LIAISE, and the number of clients has been more or less steady since July 1995. Since July 1995 the program has had an average of 40 clients at any one time. This average falls just short of the 1995-96 service agreements targets of servicing 15 clients per site at any one time. From its inception to the end of October 1996 LIAISE has worked with a total of 88 clients.

LIAISE has achieved a regular rate of discharge averaging approximately four per month since July 1995 with an equivalent number of new admissions to the program.

The average age of clients varied somewhat across each of the sites: Bentleigh-43; Cranbourne 37; and Mornington-40. At each site the largest age group was 45-50. Although there are larger numbers of males overall (74%), the proportion of females increases with increasing age due to the relatively more equal numbers who suffer strokes. The peak in the 45-50 year age group reflects the fact that a number of LIAISE clients have had their injury for many years. Approximately one-third of the clients for whom the information was available had had their head injury for ten or more years.

Case Studies

Twelve detailed case studies were undertaken as part of the evaluation. With only one exception, every client and family member/carer interviewed stated quite strongly that they would recommend LIAISE to anyone in a similar situation. Outlined below are some of the other key points they made in relation to:

- independent living skills training;
- emotional support;
- information;
- accessing other services;
- aids and strategies for daily living;
- social isolation.

What emerges from these twelve case studies are numerous accounts emphasising not so much the independent living skills that have been gained, but rather how working towards these have helped clients and families to feel that things can move forward. This in turn appears to help generate a sense of accomplishment and increase the confidence clients have in themselves.

Also figuring prominently in most case studies is the importance that emotional support and informal counselling has in assisting clients and their families in being able to cope with daily life after an ABI. Intrinsic to this was a pervasive feeling that the community support workers and the coordinators were ‘there for them’. Just knowing that some help was available - even if they did not need it - helped to make them feel more secure.

Social isolation was a major issue for every case study client (with one exception). Given the level of need for assistance to reduce their isolation, and the importance of this in relation to facilitating other improvements for clients (eg reduced isolation can generate increased interest and motivation for achieving goals related to activities of daily living) this is a legitimate and essential activity for LIAISE. LIAISE used a number of strategies, often in combination, to help clients with this. These included trying to identify work, recreation, leisure, education and self-help group options that might interest a particular client.

A Case Study Summary

In 1992, when Tara was 19 years old, an aneurism burst. After leaving hospital she spent three months in a rehabilitation centre. She was referred to LIAISE by Headway. When LIAISE began working with Tara in May 1996, her major goal was to be able to move out of the family home and live independently. The other major issue was social isolation. As the support worker noted when she first started working with Tara: ‘A once active individual, she now reports being socially isolated. Friends have dropped away, with reduced social contacts and activities...Is no longer able to continue nursing studies.’

A number of related needs and issues were subsequently identified by LIAISE and Tara. These included:

- lack of confidence/self esteem;
- need to cook a range of meals;
- need for recreational, leisure and educational opportunities/activities, and/or part-time work.

While the community support worker was assisting Tara with cooking skills, this time was also used to by Tara to talk about what was going on in her life, her feelings, her problems and her successes. In addition, the worker also used cooking to help increase Tara's overall cognitive functioning, and to create opportunities for Tara to monitor her own increasing skills thereby helping her to gain confidence in her own abilities. Informal counselling and 'being a friend' also helped the community support worker to provide the support that has enabled Tara to make considerable gains in her view of herself and her abilities to cope with and enjoy life. Tara was interviewed twice for this evaluation - first when she started working with LIAISE and again four months later. Her increased confidence was readily apparent in the second interview.

In discussing what had been important about having a LIAISE community support worker, Tara stated that:

'She has been important in helping me to get myself ready for the future.'

'Most important is [the community support worker's] understanding. I'm able to talk to her and get my feelings out...I would have been lost without a shoulder to cry on.'

'They've been a life saver. Taught me how to rebuild my life....'

Tara and her mother also observed that in the four years since Tara's ABI, this is the first time that anybody has ever really been there to help them. Tara's mother observed that: 'We've been in a boat, rowing with no oars. They are an advocate, I don't feel all alone....Someone to lean on.'

Tara recently completed a TAFE course, and when last interviewed was about to begin working as a volunteer with other people in situations similar to hers. To assist her in finding work as a volunteer the support worker provided encouragement and also found out who Tara should contact in a number of hospitals about doing volunteer work. The community support worker also undertook a range of activities to help Tara become less isolated. This included contacting numerous organisations in the local area to identify recreational and leisure opportunities to pass onto Tara. Probably the most successful action was arranging for Tara to meet someone else, a woman about her age, in a similar situation, and they quickly became friends.

Tara and her mother emphasised two other issues that were very important to them. The first was the ‘caring attitude’ of all the LIAISE staff with whom they had come into contact. The second point was the importance of LIAISE as information providers - ‘They know what families can’t know’. This information was both about ABI and about possible options (work, recreation, education etc) for now and the future.

The Effectiveness of LIAISE

Several sources of information have been used to identify the essential elements for LIAISE’s success, including examining the theory of the LIAISE program; a literature review; client case studies and interviews with service providers and policy makers. A summary list of the key elements of an effective program for this client group is presented below:

1 The capacity to be flexible in delivering a range of core services including:

- independent living skills (ILS) training;
- emotional support/informal counselling to clients and their families/carers;
- information - on ABI and available services/options for clients and families/carers;
- development, training in the use of and provision of aids and strategies for clients/families for daily living;
- provision of skills training and assistance with access to services and other options to help ameliorate social isolation;
- assistance to clients and families in accessing other services/case management;
- community development/community education activities in the general community and with service providers to increase understanding of ABI and thereby increase access, acceptance and participation in community life.

2 The way in which these core services are delivered is a critical element in relation to effectiveness. Major issues include:

- clients having control over decisions that affect their lives - clients have the right and the need to make their own ‘mistakes’;
- work with clients must be sensitive to the client’s beliefs, values and culture;
- a good knowledge of ABI (including its impact on individuals and families and strategies for working with people with ABI) is essential to working effectively with people with ABI;
- the quality of the relationship between staff and clients is a major determinant of the programs effectiveness;

- natural supports last longer than professional interventions and must therefore be acknowledged and supported;
- flexibility is paramount to ensure that the program delivers what the client needs thereby maximising the potential for effectiveness, rather than delivering what the program is 'able' to deliver ('able' in the sense of available skills and resources): basing the capacities of the service on the needs of the client rather than determining the needs of the client based on the capacities of the service.

According to the evidence gathered throughout this evaluation, the LIAISE program has consistently met the above criteria for effectiveness. The only major exception has been their limited capacity to deliver community development/community education services, and this has been primarily the result of their funding limitations rather than a lack of skills or interest.

Evidence was gathered regarding outcomes. In relation to the service system one of the major outcomes of the establishment of LIAISE has been the filling of what many service providers described as 'an enormous gap in service provision in the Southern Region'. Service providers consistently emphasised the importance of having a specialised ABI service with the expertise necessary for working with this client group. This was echoed in the case studies by people who had been living with their ABI for several or many years without access to a service such as LIAISE.

In relation to outcomes for clients, all of the case studies (with one exception) contained evidence that LIAISE had made positive, and often significant, contributions to their lives. Examples of this from the individual case studies described in detail in the report include:

> Tara - increased confidence and self esteem, maintenance of previously precarious living situation, a hopeful and positive attitude about the future, and reduced social isolation.
>
> Charles - significant gains in overall cognitive abilities (much of this is attributable to Charles' and his family's hard work, but the availability of LIAISE in supporting Charles and his family was a vital element in avoiding Charles being placed in a nursing home upon discharge from hospital)
>
> Samuel - moderately increased satisfaction with life arising from increased knowledge, skills and ability to organise his time in order to complete activities of daily living such as cleaning the house and doing the laundry to his satisfaction, more understanding of his ABI, improved communication skills and reduced social isolation.
>
> Elizabeth - significantly increased communication skills, moderate increase in confidence, access to counselling and strategies to help deal with depression, a somewhat more positive view of the future based on progress she has made - particularly regarding communication skills, and increased understanding by her family of Elizabeth's ABI and some strategies to help Elizabeth and her family.

LIAISE as a Learning Organisation

Criticisms, comments and suggestions from service providers, policy makers and the evaluators were consistently responded to by positive changes in program policies. Additionally, staff within the program consistently examined their own practices and sought improvements.

One of the results of this has been a gradual shift in the focus of the program from an initial concern primarily with the provision of independent living skills training to a more flexible and holistic approach. This gradual change was driven primarily by the staff of LIAISE as they gradually found out what was necessary to fulfil the primary goals of LIAISE: to assist clients to increase their quality of life by facilitating client independence, increasing participation in community life, and improving self-esteem and confidence.

The Current Activity Mix and Funding

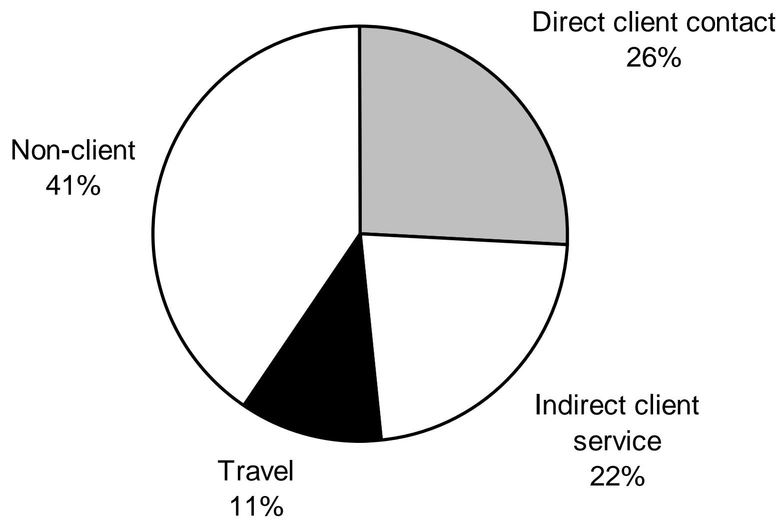
The program currently has high levels of non-client and indirect client related time. This is not viable under current unit costing proposals for LIAISE, particularly if the unit costing system values hands on independent living skills training above other services. Increasing the viability of LIAISE as an ongoing program will require changes in the current unit costing proposals (to bring them into line with what is the appropriate mix of services that such a program should be delivering), and to make some modest increases in the time LIAISE spends working directly with clients.

If a capitation payment system were adopted efficiencies achieved through more extensive use of groups and other mechanisms may offset the need for increases in the total budget. The cost per client of the program to date has been approximately $3,250. An effective funding formula, involving equivalent per capita costs, could be $20,000 per year per site for infrastructure support and $2,250 per client. Such a system would need to be supported by appropriate service monitoring and performance indicators and would need to allow some adjustment for out-liers (eg people who stayed with the program for more than a year).

Time and Activities

The low proportion of direct client contact time (defined as time actually spent with a client face-to-face or on the telephone) is a concern both in terms of the efficiency of the service and its viability under unit costing.

Time utilisation across all sites from Nov 95 to Oct 96



The graph also enables us to explore the issue of what should be included in any unit funding formula for this program. Current unit costing formulas for independent living skills training have been developed for centre-based work with people with intellectual disabilities. Under this formula payment is based on the number of direct client hours services provide, with an allowance of 12-15% for indirect client-related activities including such things as writing assessments, preparation for therapy session with a client, travel to and from client, and phone calls to other professionals regarding a client. Typical unit costing for independent living training (ILT) services is $22.80 per hour (the rate for 'Community Support - Client Support Services' established by Department of Human Services, objectives for this unit cost are maximising independence, community participation, personal organisation etc., and it includes a 15% allowance for indirect activities). Under this formula the current LIAISE program would not be viable: it does not provide enough direct service to clients and the hourly rate is inadequate.

A similar service working in the Northern and Eastern Regions, Community Access Service, did a 'snapshot' audit over a two week period in December 1996 of how the workers spent their time. This audit found that they spent 33% of their time in direct contact with clients or undertaking case management activities (such as contacting other service providers and helping clients gain access to other services) on behalf of clients. This compares with LIAISE's 32% (26% direct time plus 6% case management). This comparison suggests that this proportion of direct and case management time may be appropriate, especially as both services are working to a similar 'whatever-it-takes' model and providing a mix of independent living skills training and case management services.

There is also evidence from a number of other sources that the current mix of activities is approximately right. First, there was overwhelming evidence from the case studies that LIAISE is meeting the needs of clients. Both clients and families made it clear that LIAISE had provided them with information and help that was of great value and that no other program had been able to provide. Second, the things that clients said were of most importance included more than independent living skills training. In particular they emphasised the importance of having informed support available as needed and the increased confidence that getting the opportunity to try things out afforded.

The statistical information indicates that the relative proportion of time spent on direct and indirect client service and on travel was remarkably constant over time. Although this may reflect some inappropriate (but consistent) activities, the regularity of the proportions suggests that this mix may actually reflect what this population group needs in terms of service provision. Certainly the literature suggests that an approach that involves much more than one-to-one skills training is required, and that often this will involve networking with a wide variety of groups on behalf of the client. It seems probable that a high proportion of indirect client-related time is an inevitable aspect of meeting the needs of this client group.

The proportion of time spent on non-client related activities is of more concern. Nonetheless a breakdown of the various coded activities indicates that much of the time was probably appropriately spent. The absolute time devoted to marketing and to networking activities to educate the community and other agencies about ABI was small relative to the need in this area. However it occupied a substantial proportion of staff time because of the low staffing levels. Training and supervision occupy a substantial proportion of time but the community support workers are employed in a diverse and difficult job at very low salaries (Class 1 salary is $536.50/40 hr week). Salary cost savings gained from employing staff at this level must be supported by adequate amounts of training and supervision. Indeed there is some evidence from the case studies that supervision should be increased to prevent time being spent pursuing inappropriate goals (this should probably be in the form of ‘case-review’ that can be classified as indirect client related time).

Although there is evidence that much of the current activity mix is appropriate there is also evidence of specific areas where changes may be needed or where efficiency could be improved. Some of the changes are changes at the margins which may lead to small but useful improvements in overall efficiency. Large improvements, particularly as regards non-client time, may require significant structural reorganisation.

The case studies, the interviews with staff and the statistical data also indicate that time savings could be made in recording both client file notes and work statistics, and probably in the time spent in meetings.

Changes of this sort are changes at the margins but cumulatively may be able to release 5-10% of staff time to be spent on direct client services. This is nowhere near enough to make the service financially viable under the proposed unit costing

arrangements. As indicated, current performance, even with the most favourable assumptions, would only attract an annual budget of $26,430 per site. Attaining financial viability will require changes to be considered in one or all of the following areas:

- staffing arrangements;
- organisational structure;
- funding arrangements.

These issues are dealt with in detail in the report, and many of the recommendations are relevant to these. However, the authors wish to strongly note that we believe that unit costing is a completely inappropriate mechanism for funding services of this complexity and strongly urge the consideration of other options.

Recommendations

The following recommendations arise from the analysis and conclusions presented in the report. The detailed rationale for these recommendations forms part of that discussion. These recommendations relate to the continuation and replication of the program including funding as well as some changes for the LIAISE's program itself.

10.1 Continuation of the program

10.1.1 There is a need for the program in all of the locations it is currently operating and the program should be continued at the same or an increased level of funding.

10.1.1 The program is not viable if it is to be purely an independent living skills training program. Continuation will require formal recognition of the broader scope that the program has adopted.

10.2 The scope of the program

10.2.1 Case management, emotional support and group programs should all be formally recognised and accepted as important functions of the program that should be specifically funded and probably expanded.

10.2.2 The program should actively seek to define, and where appropriate meet the needs of people of non-English speaking background. It should be noted that this would increase the overall cost of the program.

10.2.3 The program should actively seek to define, and where appropriate meet the needs of people with more severe disabilities. These people frequently require the same sorts of socialisation, emotional support and case

management services as those who are less disabled. It should be noted that this would increase the overall cost of the program.

10.2.4 The program should expand its role in community education either on its own or by strengthening its relationships with Headway Victoria. Appropriate funding mechanisms to support these activities should be identified.

10.3 Funding mechanisms

10.3.1 If the program is to be funded under a unit costing system great care must be taken to ensure that the funding system supports flexible involvement in the full range of activities necessary to meet a client's needs. (This includes a range of activities which are currently considered to be 'indirect' client services. Furthermore, mechanisms need to be developed to encourage group activities, community education and the use of students and volunteers.)

10.3.2 Consideration should be given to alternative funding mechanisms. In particular a system where the client is the unit rather than hours (ie a capitation payment system) should be considered. Combinations of capitation and unit payment systems are possible and should be investigated. (For example an infrastructure grant of $20,000 per site and a capped payment of $2250 per client plus $800 per year for clients staying with the program for more than one year would approximately maintain current funding levels.)

10.3.3 A much less detailed statistical recording system that allows staff to accurately account for all of their time should be developed and implemented. This system must reflect the funding definitions agreed with the Department of Health and Community Services.

10.4 Organisational structure and staffing

10.4.1 LIAISE should probably be incorporated as one of the activities of the auspicing agencies rather than as a free-standing program. Mechanisms for sharing information, tools and experience between the ABI programs at each site should be maintained.

10.4.2 Having said the above, ABI is a sufficiently specialised area that it warrants a team of specialised staff and a particular commitment of resources: the program should not disappear into the routine activities of the auspicing agency.

10.4.3 Standards should be developed to protect the funding allocated to ABI. These standards should address at a minimum, required staff expertise and the range of services to be provided as well as service targets.

10.5 Improving the program

10.5.1 Procedures by which coordinators review cases should be formalised and made uniform. This should be considered part of the client service time as it allows LIAISE to function effectively using very lowly paid staff.

10.5.2 Mechanisms to allow clients to access the program at any time during the working week and where necessary out of hours should be established (eg. for those who work).

10.5.3 A source of petty cash should be established to allow the purchase of simple items for clients. A capitation payment system would resolve this and other problems.

10.5.4 There should be a continued expansion of group activities. In particular the establishment of peer support groups and other peer support mechanisms (partnering, mentoring) should be encouraged and financially supported.

10.6 Improving efficiency

10.6.1 The recording (client notes) and statistical systems should be streamlined. Together these activities should occupy less than 5% of total staff time.

10.6.2 Time spent in meetings other than case review should be reviewed. Some meetings fulfil particular service functions (eg community education) and should be funded appropriately

10.6.3 Further efficiencies may be able to be achieved by closer integration of the LIAISE program into the activities of the auspicing agency.

10.6.4 At best the proposed reforms may release 5-10% of staff time from non-client related activities for direct client service. These improvements should be made but cannot compensate for the need for an appropriate funding system.

10.7 Replication of the LIAISE model at other sites

10.7.1 The LIAISE model is appropriate for implementation at other sites providing that auspicing agencies that are sufficiently supportive can be found. There are advantages in locating the program within Community Health centres in areas that are not well served by other agencies.

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CHAPTER 1

Introduction

This evaluation was commissioned by the LIAISE Program. Initially it was to be a process evaluation, but over time it has also become an outcome evaluation. This report provides a description of the LIAISE Program and its clients, evaluates its success in meeting its stated objectives and makes a number of recommendations for its future. It is primarily a client focused evaluation centred on how well the LIAISE Program has met the needs of its clients.

The following account generally reads as though LIAISE is a single united program. While at a philosophical level, and in terms of providing assistance and support to each other this is true, each site is in many ways different from the other sites. The auspicing organisations are different. The skills and experience of the workers vary within and across sites. The local context of each site is different regarding: community demographics; type and range of other service providers; client characteristics. The result is that, although it is in many ways a single program, there are differences in the activities of staff at each site. Also, while the program began as a single program auspiced at three different sites, it has gradually evolved (as was anticipated in the proposal to establish LIAISE) to become three related but independent programs.

The LIAISE Program began accepting clients in September 1994. The acronym LIAISE stands for Living, Independence, Access, Integration, Support, Empowerment. LIAISE is auspiced by three agencies: Community Disability Support Southern (in Bentleigh); Cranbourne and District Community Health Centre; and Peninsula Community Health Service (in Mornington). The Victorian Human Services Department suggested the establishment of an ABI service in the Southern Metropolitan Region in response to the need for independent living and community integration services for people with ABI in the region, as identified in the Head Injury Impact Project (1989). The auspicing organisations responded by proposing the establishment of LIAISE. LIAISE is a three year pilot program, funded by the Victorian Human Services Department through the Commonwealth/State Disability

Agreement Growth Funding 1993/94 Grants Program. The primary purpose of LIAISE is to provide independent living skills training and community integration assistance to people with acquired brain injury (ABI) who are living in the Department's Southern Metropolitan Region.

1.1 The Evaluation

The purposes of this evaluation were:

1. to clarify the objectives, principles and theory of the LIAISE Program and to ensure that it is appropriately focused;
2. to provide feed-back on LIAISE at an early date to facilitate program improvement;
3. to assess the effectiveness of the program in meeting the needs of people with ABI who have low support needs, in particular to determine whether LIAISE is encouraging and facilitating client independence, community integration and skills development (in accordance with the 'Whatever It Takes' model of community based rehabilitation/community integration);
4. to make recommendations regarding the ongoing support needs of people with acquired brain injury; and
5. to assess the viability of replicating this model in other locations.

1.2 Evaluation Framework and Methods

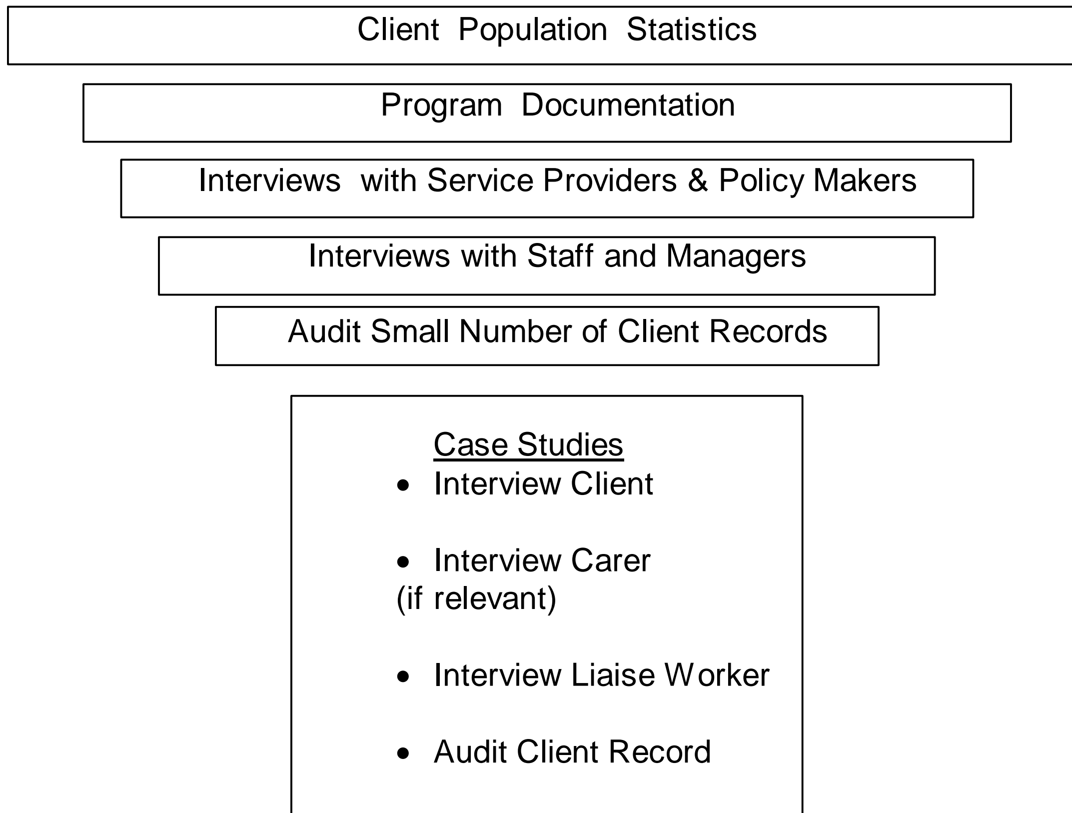
The evaluation framework employs multiple methods and multiple sources of information. This is necessary to fulfil the multiple purposes of the evaluation, and to ensure that the results are as valid and reliable as possible. The diagram below, Figure 1, represents both the breadth and the depth of the information being collected.

A few details are helpful in understanding Figure 1. A wide range of client statistics on the whole client population was collected. Additionally much of the documentation used to establish LIAISE (ie. funding submissions), administrative forms and reports, and policies have also been collected. Twenty-two interviews with a wide range of relevant service providers and policy makers were undertaken. Numerous meetings and discussions took place between the evaluators and the LIAISE staff and managers, and formal in-depth interviews were conducted with staff.

The Case Studies were the heart of the evaluation. Twelve were done, four at each site. These were done with clients at different stages of their involvement in LIAISE. Four were done with clients who had just begun working with LIAISE, and two of

these had follow-up interviews. Two were done with people who had previously been clients, left the program and returned. Six were done with clients that were finished or nearly finished working with LIAISE.

Figure 1: Information Sources for the Evaluation



There were three additional dimensions to our multiple methods approach:

1. a range of analytical methods, both quantitative and qualitative were used;

2. the analysis was done by two people which helps to increase both the reliability and validity of the process; and

3. throughout the evaluation information, ideas and results were discussed with stakeholders. This provided not only additional information but also opportunities to validate results and make sure that the evaluation met their needs.

Information from each of these sources was analysed independently and in relation to each other. This was essential to understanding and assessing the LIAISE Program. The different purposes of the evaluation outlined above required that information be collected from this range of sources, and then be analysed in relation to each of the purposes. It is also important to note that the different purposes of the evaluation are interrelated.

1.3 Reference Group

As part of ensuring that the evaluation was relevant and useful to the major stakeholders in the LIAISE Program, a Reference Group was established by the evaluators. The membership of the Reference Group includes:

2 clients or former clients of the LIAISE Program;
1 LIAISE Community Support Worker;
1 LIAISE Co-ordinator;
1 Manager from one of the organisations auspicing LIAISE;
1 Disability Services Project Officer from Human Services, Southern Region;
1 Representative from Headway;
2 Representatives from other service providers working with people with ABI.

One meeting was held with this group to discuss the general structure and direction of the evaluation in May 1996. Another meeting was held in August 1996 to discuss the results of the Interim Report. A final meeting was held in January 1997 to discuss a draft of this final report.

1.4 Ethical Issues

In accordance with good research practices, ethics approval for this evaluation was sought and received from Melbourne University. This entailed providing a detailed description of the proposed evaluation; its potential impact on LIAISE clients; and copies of the proposed ‘Consent’ forms and plain-English explanation of the evaluation to be used when seeking consent from LIAISE clients for their participation in the evaluation.

CHAPTER 2

The Liaise Program

The structure and content of this section draws extensively on a workshop conducted with LIAISE staff in December 1995. The workshop, along with a content analysis of documents related to the establishment and running of LIAISE, was undertaken to achieve the first purpose of the evaluation: to clarify the objectives, principles and theory of the LIAISE Program and to ensure that it is appropriately focused. Subsequent interviews with LIAISE staff, other service providers and the case studies have been used to establish how closely the actual activities of LIAISE reflect results of the workshop and the content analysis. What has emerged from these interviews and case studies is generally a high degree of congruence between the stated and the actual.

It should be noted that the LIAISE Program is not static and has gradually evolved into a program that is increasingly placing more emphasis on providing case management and emotional support to clients, rather than focusing almost solely on independent living skills training. The following account of the program structure of LIAISE is located mid-way in this evolution, having been based primarily on the December 1995 workshop.

The workshop and the content analysis of relevant documents utilised program theory, and covered six main areas:

1 The mission/goals of LIAISE

2 Inputs

- clients and their needs;
- staff skills and experience;
- program resources - time, money, infrastructure, etc;
- program flexibility, capacity of staff to take initiative;
- physical and social environment in which program operates.

3 Philosophy, principles, overall approach

4 Activities: what activities are planned/undertaken by the program

5 Causal processes: what are the links between the planned or actual activities and the desired outcomes?

6 Outcomes

- what are they/what should they be?
- relationships between immediate, intermediate and long-term outcomes.

2.1 The LIAISE Program Goal

The primary goal of the LIAISE Program is to promote the integration of people with ABI into the community. This goal is clearly stated in the LIAISE documentation and was widely and consistently expressed in the workshop with LIAISE staff, and throughout subsequent interviews and discussions with LIAISE staff and management.

2.2 Eligibility for LIAISE

Eligibility requirements for LIAISE are:

- people with ABI;
- living in the Southern Region;
- adults aged 16-64;
- effectively non-compensable;
- not eligible for other services (especially those with dual disabilities ie. intellectual disabilities or psychiatric disabilities);
- medically stable;
- people who are interested in working with LIAISE to help improve the quality of their lives.

2.3 Needs of People with ABI

The Head Injury Impact Report (1991) and the Evaluation of the Melbourne City Mission Case Management Service for People with ABI (1996) both identified a similar range of needs amongst people with ABI, particularly those without compensation. These include:

- lack of information about available/appropriate services;
- lack of access to community-based services;
- need for support, both emotional and practical;

- frequent difficulty fulfilling daily living tasks, including things such as banking, cooking, laundry, holding conversations, and transportation;
- lack of meaningful daily activities such as employment and recreation;
- social isolation;
- risk of institutionalisation;
- lack of appropriate accommodation options.

In the workshop, LIAISE documents and interviews/discussions with LIAISE staff a similar range of needs were identified, and form the focus of the LIAISE Program. Also of importance is the recognition by LIAISE staff that these needs are not separate, but are interrelated and therefore a holistic approach to working with clients is required.

2.4 Staff Skills and Experience

The structure of LIAISE provides for a Coordinator and two Community Support Workers at each site. The initial and subsequent attempts to recruit qualified staff with experience in working with people with ABI revealed that there is a dearth of suitable people. Consequently recruitment was, and continues to be, difficult. Notwithstanding this, LIAISE currently employs a qualified and dedicated staff.

The Coordinators have considerable experience in working with people with ABI. Two are qualified occupational therapists and one is a qualified psychologist.

The community support workers all have bachelor degrees in relevant disciplines such as disability studies, but (with one exception) had little or no experience in working with people with ABI when they began working at LIAISE.

2.5 Program Resources

Program resources include issues such as time, money, structure of the program, infrastructure, work environment, staff training, program flexibility and the capacity of staff to take the initiative when working with clients.

The overall recurrent budget for the program is approximately $195,000 per year, which is equally divided across the three sites. For each site the $65,000 budget is distributed approximately along the following:

Salaries and salary on-costs	**$54,552**
Operating costs	
Staff training	500
Rent	2,300
Postage & Telephone	700
Printing & Stationary	848
Sundries	500
Admin Support	2,500
Travel	3,000
	$10,448
Total recurrent budget	**$65,000**

Additionally, it was found soon after the commencement of LIAISE that the travel budget was seriously under-budgeted. In the auspicing organisations' original proposal travel was estimated at $6,000 per year for each site. These figures were reduced to meet the set budget of $65,000 per year for each site, and when the Human Services Department was informed that this would not be enough their response was that this budget was a starting point and would be increased based on demonstrated need. These additional costs are currently being met through the auspicing organisations' operating budgets. These extra travel costs vary across the three sites depending on the number of kilometres travelled (see Table 4). The Cranbourne and Mornington sites have access to cars provided by the auspice agencies - when available. There is significant use of private cars, which is reimbursed based on mileage.

Also, there are some non-recurrent costs primarily associated with the establishment of LIAISE. This included items such as advertising, computer hardware and software, and training for staff. Each site received $7,500 for establishment to meet establishment costs..

At each site the Coordinators are employed for 16 hours per week, and the two Community Support workers for 24 hours per week each.

The physical infrastructure support at each site varies, but in general office space is limited and crowded (note the low rental rate in the above program budget - $2300). Access to essential tools such as mobile telephones and computers also varies, and at some sites may limit/reduce the effectiveness and productivity of staff.

The flexibility of staff and their ability to take the initiative when working with clients is generally good, however there are some limitations. Being part-time restricts staff availability during normal working hours. This and other program restrictions mean that clients (and potential clients) who would benefit from assistance on week-days when staff do not work, after hours or on weekends (for instance if they work full time or go to school) have limited or no access to LIAISE staff. Additionally, the Coordinators are the most experienced and skilled staff members. Because they are

available only two days per week this reduces both client and Community Support Worker access to these skills. To a large extent these limitations reflect the ever-present tension between the resources of a program and the desire to meet client needs.

2.6 Principles

The following principles underpin the LIAISE Program and the activities of the LIAISE staff:

- that clients should have control over the decisions that affect their lives, including the activities undertaken with/by LIAISE;
- that LIAISE methods and activities should focus on the quality of clients lives, must be holistic and take into account the client's beliefs, values and culture;
- that clients should be empowered, not made dependent on LIAISE;
- that clients can fulfil valued roles in society;
- that working with clients within their homes and in the community is essential to providing high quality and relevant support and assistance.

It should be emphasised that these principles are not simple rhetoric, but are views/beliefs that the LIAISE staff are strongly committed to. There is considerable support for these views, particularly within Wolfensberger's (1991) social role valorisation theory and practice, and in Willer and Corrigan's (1994) whatever-it-takes model for community based services for people with ABI.

Wolfensberger's (1991) social role valorisation theory and practice (previously called 'normalisation') has been an important influence in human services for over 20 years. The central idea is that Western society as a whole devalues certain groups of people, and with this devaluing comes 'poor treatment at the hands of their fellows in society and at the hands of societal structures - including human services'. One result is that 'good things which are enjoyed by valued persons will be denied or taken from a devalued person, including supportive relationships, respect, autonomy and participation in the activities of valued persons'.

People's expectations of each other create role expectations. Devalued people are assigned negative role expectations, these then become internalised and poor performance is the result. Poor performance confirms the devaluation and the negative role expectation which creates a circularity that is hard to escape. Social roles determine people's behaviours and place in society.

Willer and Corrigan (1994) outline a set of ten principles which, in their view, will promote maximum self determination and community integration for people with ABI. Some of these principles are:

- no two individuals with ABI are alike (consequently services need to be flexible enough to work with the particular needs of each individual, and not treat everyone the same);
- environments are easier to change than people;
- natural supports last longer than professionals (therefore existing social supports need to be actively assisted and encouraged to stay involved);

- the service system presents many of the barriers to community integration (for example, limitations are often imposed on the type or duration of a service that will be provided irrespective of the needs of the person with ABI);
- respect for the individual is paramount;
- the needs of individuals with handicaps last a lifetime (few services are designed to meet long-term needs and few funders are willing to pay for services over a life-time).

2.7 Client-Related Activities

LIAISE client-related activities are primarily undertaken on a one-to-one basis between staff and clients, although working with clients in groups is a significant activity. LIAISE has established a number of group programs for clients, and has assisted in the formation of several client and carer self-help groups. Group work fulfils several very useful purposes: more time can be spent with clients using fewer resources; it helps to alleviate one of the most common problems for people with ABI - social isolation; and assists clients to develop communication and social skills. Group work can also help clients to realise that they are not alone, that their problems are common problems, and solutions can be shared. At the simplest descriptive level the LIAISE activities undertaken with or for individual clients include:

- Intake and Assessment (these are done by the Coordinators)

  – receiving referrals;
  – receiving, collecting and developing information on prospective or actual clients;
  – meeting with clients;
  – undertaking and arranging for assessments of client's ABI, needs, abilities and situation;
  – deciding whether or not to accept referrals.

- Goal Setting

  – work with client to establish goals and identify methods for achieving them;
  – writing case plans, subject to change as necessary;
  – goals regularly reviewed.

- Independent Living Skills Training

  – helping clients develop skills, routines and prompts to assist them with things such as cooking, cleaning, personal hygiene, memory training, banking, travel, communication, and planning.

- Access to Other Services

  – information about services, both generic and ABI specific;
  – assistance, referral and advocacy in accessing services;
  – facilitating meetings between clients and service provider staff;
  – when necessary, coordinating a range of services for a single client.

- Support to Clients & Families

  – particularly emotional support and informal counselling;
  – information about ABI;
  – ‘being there’ for clients and families.

Figure 2: Work with Individual Clients

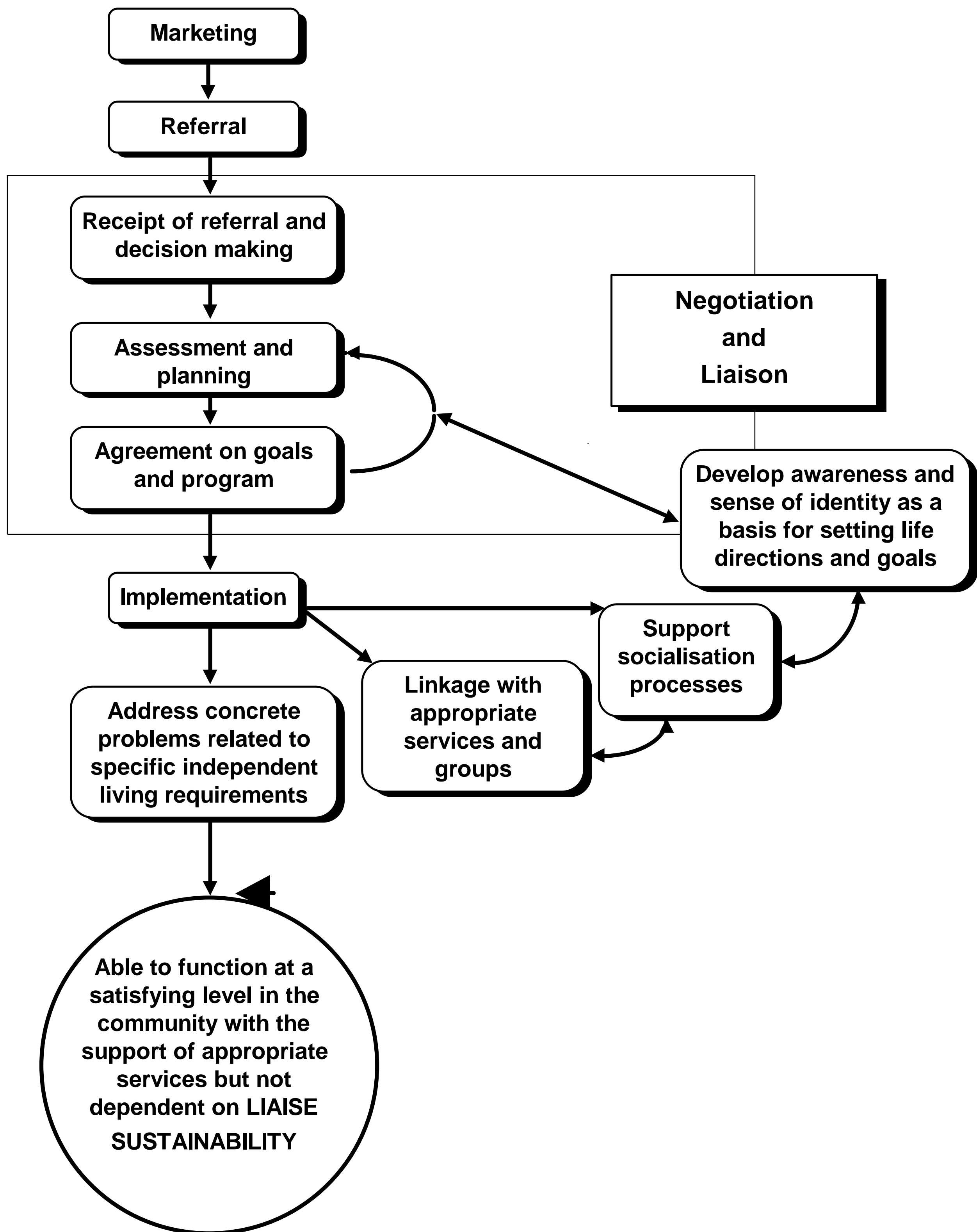


Figure 2, above, is a flow chart of the typical activities undertaken with clients. On the left side of the diagram (with the vertical arrows) is a relatively standard linear process of referral, assessment, planning, and implementation. However, the process is neither so simple nor so straightforward. The boxes on the right side of the diagram emphasise the negotiated and circular nature of the process. For example, many clients do not already have goals in their lives, may not immediately feel able to identify goals, and may have one or several immediate crises at hand that must be resolved before things like goals can even be considered. Also, the provision of social support and encouragement by LIAISE is an essential part of the process. Many of these people have been ignored (or worse) by services in the past and are often cynical, fearful and/or distrustful of attempts to 'help' them. The establishment of a relationship between the LIAISE worker and the client is often essential before any other significant activities can be undertaken.

2.8 Work with Service Providers

LIAISE works with other service providers, both generic services and ABI specific services, on three different levels. First, some work is undertaken assisting and supporting service providers to work with particular LIAISE clients. Second, staff have given general presentations for a number of organisations about ABI and working with people with ABI. Third, these presentations and other activities with service providers are used to raise the profile of LIAISE. One of the most significant aspects of this is that other services are more likely to make referrals to LIAISE if they know the LIAISE staff and have confidence in them. Working with other service providers is the main way of achieving this.

2.9 Getting Known

When LIAISE was first established considerable time and effort went into getting the service known. As the number of clients has grown, the time and resources to do this have diminished but some work is still regularly undertaken such as mail-outs to other local health and community service providers such as GPs. Also, assisting individual clients to access other services helps to raise/maintain the profile of LIAISE with no additional demand on resources.

Activities undertaken to raise and maintain the profile of LIAISE have included:

- newspaper stories;
- radio interviews;
- mail-outs;
- development of a LIAISE flyer/pamphlet;
- presentations to numerous service providers such as local hospitals, and committees of service providers;
- participating in Brain Injury Awareness Week;
- stalls in local shopping centres.

The wide range of referral sources seen in Figure 11 (below) indicate that these public relations activities have been relatively successful. However, in spite of this evidence there is a perception both within LIAISE and outside it that the service is not well enough known.

2.10 Internal Management and Maintenance

Internal management and maintenance activities include things such as developing LIAISE policies, data collection methods, record keeping systems, staff training, and lines of accountability and decision making.

LIAISE has developed and implemented a wide range of policies since its inception relating to issues such as client eligibility and decision making processes (and responsibilities) for program policies.

LIAISE staff put considerable effort into designing data collection forms for client statistics, and activity logs recording how staff spend their time on client and non-client related activities. This has been necessary and invaluable for the evaluation, but much of it will be unnecessary for the ongoing operation of LIAISE.

The client records system appears to be working well. The client records related to the twelve case studies, while not perfect, are generally complete and well done. Comments by staff in interviews suggests that staff find the current system workable and of value to them in working with clients.

Staff training needs have recently been reviewed by an independent consultant, and a LIAISE staff training plan has been developed. Through the Non-government Disability Training Unit funds are being made available to implement the training plan.

Lines of accountability and decision making were complex and unclear. The complexity arose from the structure of a single program delivered across three sites with three managers and three coordinators. The lack of clarity arose from a lack of clear policies about who was responsible for making which decisions. The complexity of the program has been reduced as it has moved from being a single program auspiced at three sites, to being three related but different programs - thus requiring less coordination across the sites. New policies have also been introduced which clarify the decision making responsibilities within each site and across the three sites.

2.11 Causal Processes and Outcomes

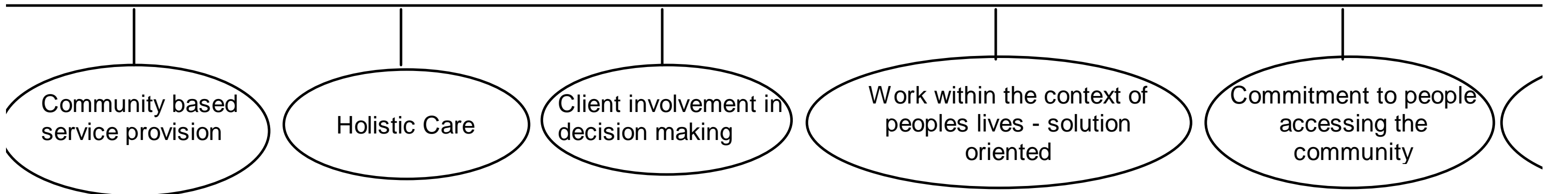
Two other major elements of program theory are causal processes and outcomes. These can be most easily seen and understood within the context of the other program elements discussed above, and summarised in Figure 3. In this figure the first row is the philosophy and principles of LIAISE. The second row are the major external activities of the program. The next row, with items such as client's development of specific independent living skills, increased self knowledge and increased confidence are the hoped for and expected 'immediate' outcomes. The fourth row contains what could be described as 'intermediate' outcomes and includes such things as increased levels of independent living, increased self esteem and increased ability to make choices. The fifth row contains the longer-term and more global outcomes such as the client's increased participation in community life, and increased opportunities.

These different levels have important implications for both the evaluation and the operation of LIAISE. Regarding the first purpose of the evaluation - to clarify the objectives, principles and theory of the LIAISE Program and to ensure that it is appropriately focused - the program theory approach was particularly useful for examining the 'workability' of LIAISE, and to move towards answering questions such as: Are the principles, resources and activities of LIAISE such that the immediate or long term desired outcomes can be achieved? How well do all the elements of the LIAISE Program work/fit together?

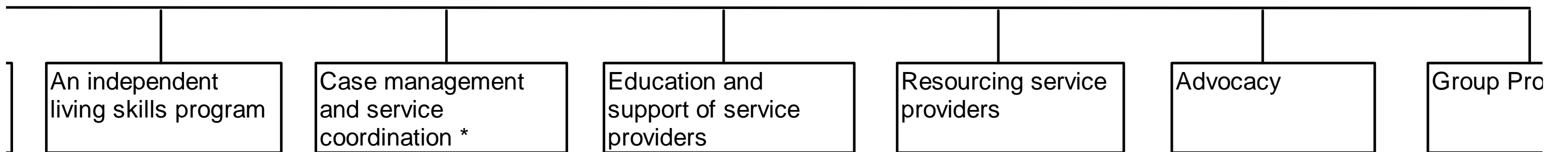
Because of the difficulties associated with measuring the outcomes (immediate, intermediate and long-term/global) of complex interventions such as LIAISE, the emphasis in this evaluation is on the soundness of the philosophy and principles, and the activities of LIAISE. Evidence regarding some immediate and intermediate outcomes was collected as part of the case studies and is presented later (see also Appendix B**).** However, it is difficult to attribute any particular outcomes solely to a client's involvement in LIAISE, as this is only one small part of their lives. Also, many of the most important outcomes may occur after the client's involvement in LIAISE ceases, and well outside the time-frame of this evaluation.

PEOPLE WITH ACQUIRED BRAIN INJURY AND THEIR CARERS

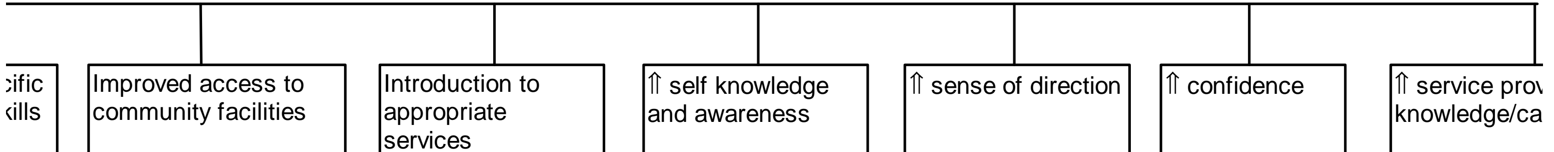
Receive Services Guided by the Following Principles



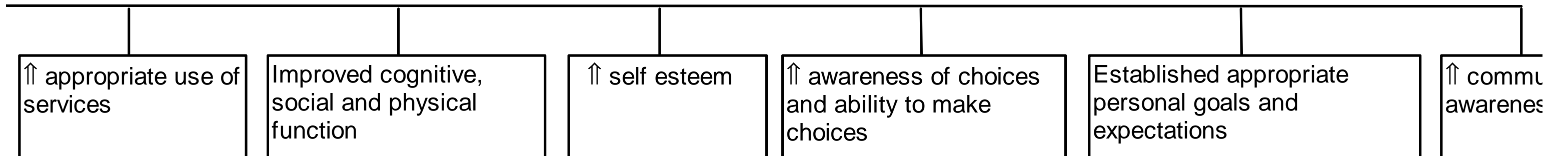
Which include



With aims including the following inter-related causal processes



With the following outcomes



That ultimately contribute to

ution / improvement icular problems of n	Increased participation in the community and increased opportunities	Increased satisfaction with level of functioning and life opportunities	Improved self esteem and acceptance	A change in community attitudes and practices

Fulfilling: - the need for enhanced quality of life for clients
- the goal of maximising valued social roles

CHAPTER 3

Literature Review

3.1 Introduction

The LIAISE Program was conceived to meet local needs and, as part of its development, available models of best practice were examined for their relevance. The model having the most influence on LIAISE is the 'Whatever It Takes' model of service delivery to people with ABI developed by Willer and Corrigan (1994), in Buffalo, New York. The whatever-it-takes model has won widespread support from both providers and consumers because of the flexible, client focused and pragmatic approach it espouses. Fundamental to the whatever-it-takes approach is the abandonment of rigid categories of service delivery that hinder flexible problem solving.

This literature review uses the traditional service categories of 'independent living skills training', 'community integration' and 'case management' to describe and assess models of service delivery. At the same time it recognises the need to move beyond these categories. The final section of the review seeks to assess the extent to which LIAISE developed in accordance with the principles of sound and effective practice discussed in the literature.

3.2 Independent Living Skills Training

Nosek, Zhu and Howland (1992) did a detailed review of the philosophy and history of independent living programs as they have emerged in the US. Independent living programs were pioneered by people with severe disabilities in the early 1970s. These early programs sought to help others with disabilities to live independently and to promote a more accessible society. In 1977 there were 52 Independent living programs receiving US federal funding; by 1992 there were more than 400. More modest growth has occurred in the UK (Chamberlain and Gallop, 1988).

Nosek et al surveyed all US federally funded Independent living programs in 1977, 1984, 1986 and 1988. They considered that the minimum services that constitute an Independent Living *Program* are peer counselling, information and referral, independent living skills training, and advocacy (1992, p175). Providers offering less than this are called Independent Living *Projects*. Many providers offer a much greater range of services (eg housing services, legal aid, health education, equipment maintenance, vocational counselling, social-recreational services, and many more). More important in defining independent living skills programs however is an ethos or philosophy that seeks consumer participation in the direction and delivery of services and the establishment of goals.

In support of this view Nosek, Fuhrer, Hughes (1991) conducted a study in which counsellors with and without disabilities were rated by 71 people with disabilities in terms of experience, expertness, interest, understanding and ability. Counsellors with disabilities were rated more favourably particularly when they were portrayed as non-professional (ie peer counsellors).

3.2.1 General Literature and Intellectual Disability Literature

In Australia one of the earliest groups of people for whom large scale movement from institutional care to community care was attempted was people with intellectual disabilities. This has shaped much of the way in which community services for people with disabilities are organised and delivered. The move from institutional care has had negative as well as positive effects. Wolfensberger (1986) described how the movement towards ‘normalisation’ was hijacked by those with a cost cutting agenda so that the community services necessary to support deinstitutionalisation were never put in place. A survey conducted by Barlow and Kirby (1993) found that people with an intellectual disability living in the community were more satisfied with their personal autonomy than those living in institutions but significantly less satisfied with their social life. Both quantitative and qualitative studies with a variety of groups have revealed that increased social isolation has been a cost of the move to community based care.

The problem of social isolation highlights the difference between the ‘independent living movement’ which, with its individualistic focus, has been widely adopted in developed countries, and the approach to ‘community based rehabilitation’ adopted in many developing countries (Lysack and Kaufert, 1994). Independent living programs were developed to empower individuals in their dealings with a professionally dominated service system. The community based rehabilitation approach seeks to empower local communities to both prevent disability and to adequately care for those with disabilities. In 1979 DeJong analysed the independent living movement noting that the movement mainly attracted mobility-impaired individuals with relatively stable daily routines. He also noted that it did not attract people from marginalised or relatively powerless social groups (see also Doyle et al, 1994). Since that time a broader view of independent living has developed, recognising many of the community development needs and strategies highlighted in the community based rehabilitation approach.

The inadequacy of an approach based solely on enhancing individual capacities is particularly relevant to people with ABI and to the development of the LIAISE program. As mentioned, the program was initially focused primarily on independent living skills training and community integration, both individualistic approaches. LIAISE staff quickly realised that a broader approach was necessary if the program was to have the flexibility necessary to meet the needs of its clients. This included more emphasis on activities such as providing emotional support and working with other family members when appropriate. Although the need for community development and community education are well recognised within LIAISE and provision was made for this in the original LIAISE proposal, limitations of funding and an emphasis on direct client services by the Human Services Department has resulted in LIAISE undertaking almost no work in this area. The exceptions have been when particular community development/education work has been undertaken to meet the needs of an individual LIAISE client.

3.2.2 ABI Literature

A key issue in independent living skills training relates to the distinction between 'therapy' aimed at enhancing an individual's capacity to do tasks in their pre-morbid way, and compensatory approaches aimed at the development of strategies to successfully complete tasks using whatever aids are available (Kreutzer et al, 1989). Evidence for the generalisability of 'therapy' approaches to improving cognitive and independent living skills is scant. Approaches aimed at enhancing the individuals' capacities (without providing new strategies) can produce improvements in neuropsychological tests and in performance in predictable and routine circumstances. They are limited in their ability to help people cope with unexpected events or to modify tasks to suit new circumstances.

This evidence suggests that a combination of specific skills practice and compensatory techniques is likely to be valuable, particularly where skills practice is conducted in the clients home or normal environment. Skills practice can be useful for such tasks as meal preparation, shopping, domestic ADL and other tasks that can be built into a routine. Dealing with variable events and tasks can be enhanced by using compensatory strategies such as diaries, checklists, computers, budgets, contingency plans, reminder or messaging services and so on. More complicated tasks may always require assistance from others and it is an important aspect of an independent living service to make sure this assistance is available when required.

A similar debate rages about the desirability of pursuing 'independence' as a goal rather than quality of life. Independence is an important aspect of quality of life and can contribute to many aspects of quality of life. There is concern however, that for those with more severe disabilities, striving for independence may be a misapplication of energy and resources that would be better spent providing assistance to individuals to engage in meaningful relationships and activities. There is a concern that an excessive focus on independence may in fact be destructive to a person's quality of life and emotional well-being (Batterham 1995a; Corbett, 1989). Others have noted that the pursuit of independence in some tasks for some

individuals is simply inappropriate as they are not tasks the person would have done in any case. (Case notes from LIAISE indicated several examples of clients who had no desire to pursue domestic ADL tasks.) This distinction is recognised by LIAISE in part by the range of services they offer (socialisation, community linking, case management) and by selection criteria that explicitly exclude those without the potential for improvements in ‘independent living’.

This illustrates a more general principle regarding skills training. Skills must be taught at a time and to a level that they will actually be used in the client’s day to day life (Gee et al, 1995). Skills that make a difference to someone’s lifestyle will be used and will improve. Skills that are not useful will be lost (Berg, 1995). Therefore there is a need for both careful selection of skills to be trained and a need to ensure that a sufficient level of skill is achieved to make the task implementable under routine circumstances.

Two further problems complicate the ability of providers and clients to identify independent living skills tasks to work on, particularly for clients with ABI. The first relates to the client’s ability to recognise that they have a problem with a task. Some clients with an ABI simply cannot recognise that they have difficulties with tasks such as cooking, shopping or managing money. Help that is offered to deal with these problems is likely to be rejected. The second problem relates to motivation, or more precisely the ability to see enough meaning and satisfaction in life to make daily tasks non-trivial. The most common approach to rehabilitation is to focus on capacities for routine tasks and to leave the big picture, ‘meaning of life’, issues to take care of themselves. For many clients, including those with ABI, this order does not work. They need to know and experience that life can bring rewards and satisfaction before they find the routine tasks of life worthwhile. For some people with ABI, experiences of positive relationships, pleasurable activities, self-determination and of being valued need to occur before they can set precise skill-goals for themselves (Willer and Corrigan, 1994). Similarly striving to meet one’s goals in the real world can produce insight about the realities of the world and one’s capacity to engage it (Webster, 1994). Overcoming social isolation is as much a pre-condition as it is a result of improved functional skills. This raises the necessity to work on many levels and fronts simultaneously or cyclically rather than in some arbitrary and pre-defined manner (Batterham, 1995a and b, Batterham, 1996). Such a model of independent living skills training brings it very close to what is often meant by ‘community integration’ (Huber and Edelberg, 1993), and in general terms this is the approach used in LIAISE.

3.3 Community Integration

Community integration is an issue that has been discussed more in the context of intellectual and psychiatric disability than physical disability (which has had more of a skills focus). In recent years however the emphasis on community integration for people with complex disabling conditions has increased markedly, particularly as regards ABI. In the intellectual disability and mental health literature community integration is often linked with deinstitutionalisation, although Carling (1990) suggests that the discourse surrounding ‘community integration’ has become much

richer. The initial movement was 'from an era of institutional and facility-based thinking to a transitional period in which people were seen principally as service recipients needing a professional support system,' but has more recently moved 'to a world view in which people are seen as citizens with a potential for, and a right to, full community participation' (Carling 1990: 969). It is this richer view of community integration that makes it an important and powerful principle to guide service delivery to people with ABI. The critical issues for deinstitutionalisation are the availability of appropriate housing and supports to meet daily care needs. The critical issues for community participation are the ability of people with disabilities to select and direct services in order to meet their chosen ends, and the establishment of a strong and varied social network.

Two major strategies to achieve these ends are case management or brokerage, which, if it adopts a model where the case manager is the client's agent, can substantially improve access to services; and peer support groups which can perform a variety of functions. One survey of 74 independent living centres across the US which sponsored support groups obtained the following list of functions and importance ratings (Suarez de Balcazar et al, 1989, p 156):

Table 1: Functions of Support Groups

Group Function	Mean importance
Members are provided with information about community services they may need.	97%
Members discuss their problems (eg family relationships)	95%
Members discuss their feelings	92%
Members show each other how they solved problems on their own.	88%
When members tell about their problems and negative feelings, other members offer positive ways of looking at it.	87%
Members report their progress in meeting goals or solving problems.	80%
Members help each other set personal goals (eg weight reduction)	76%

For young people with ABI the move from the family home to life alone in the community is often a more relevant issue than deinstitutionalisation—it is equally fraught with problems and difficulties. Studies by DeJong (1983) found that for many young people institutional care was a preferable and more empowering option than long-term residence with their parents. This move is very difficult for many people

with ABI to achieve, as much because of their loss of other social networks (a result of both institutionalisation and their friends' and relatives' reaction to their ABI) as because of functional problems (Bergland and Thomas, 1991; Leftoff, 1983). Establishing age and situation appropriate social networks is a critical issue for community integration whichever way it is conceptualised.

Although the concept of community integration is complex it clearly implies a number of principles:

- services are provided in clients homes, workplaces, schools and other natural settings wherever possible;
- the goal of services is to help clients develop and fulfil aspirations which allow them reasonable life satisfaction;
- services are guided primarily by the client bearing in mind issues which may affect the client's ability to set appropriate goals such as depression, lack of insight, learned helplessness and lowering of expectations;
- a key objective is always the strengthening of appropriate social networks. Peer support groups, mentoring or partnering arrangements are important strategies to achieve this;
- the maintenance and development of socially valued roles for people with disabilities.

3.4 Case Management

Case management can be viewed as serving two related yet quite distinct purposes (Bush, 1989). On the one hand its primary function maybe to coordinate services to ensure efficiency and continuity of care (Uomoto and McLean, 1989; Tate, DG et al, 1992). In this case the case manager is an agent of the service system and the smooth operation of the system is their primary concern. At other times, however, the primary function of the case manager is to customise a package of care in accordance with the wishes and aspirations of the client; in this case the case manager is an agent of the client and individual empowerment is their primary concern (Balcazar, 1994). The first model of case management is appropriate to manage major transitions between one system and another (eg acute hospital to rehab hospital to community rehab); the second model is more appropriate to support independent living and community integration for those learning to manage their disability in the real world (O'Hara and Harrell, 1991).

Summers and Segal (1996), in their evaluation of the Melbourne City Mission, concluded that there is an important place for both a central case management service to assist people through the transitions from service to service and eventually back into the community and for local case management services to provide ongoing support to the process of community integration and to 'be there' at times of need. It is appropriate that this local case management service be built around a 'client's agent' model.

As well as the general model a critical issue in determining the effectiveness of case management services is the nature of the relationship that is built up between the

client and the case manager. Many people with ABI have developed scepticism about the ability of services to really meet their needs. The client needs to develop trust, the case-manager needs to develop an understanding of the extent to which the client is able to set their own goals and the extent to which they should be encouraged to look higher or in different directions to find appropriate goals. This is a difficult balance for the case manager to achieve, yet it is only one aspect of the complex interaction of problems and the results of problems that typifies ABI. Because of this complexity many have argued that specialist case management services are required for ABI.

3.5 Summary

As the whatever-it-takes model proposes, this literature review has demonstrated that narrow categories of service provision are artificial and can inappropriately restrict an agency's ability to provide the range of services that are necessary to meet their clients' needs. Skills training does not necessarily precede community integration nor is it necessarily the case that people can be given a set of skills and then left to their own devices. Both the literature and the data from this evaluation demonstrate that social isolation and the need to have someone to 'be there' are critical problems affecting the ability of people with ABI to function in the community. Although precisely targeted, short-term skills training may sometimes be appropriate, more typically skills training, community integration and case management blur into a general commitment to find solutions appropriate for individual clients whatever it takes.

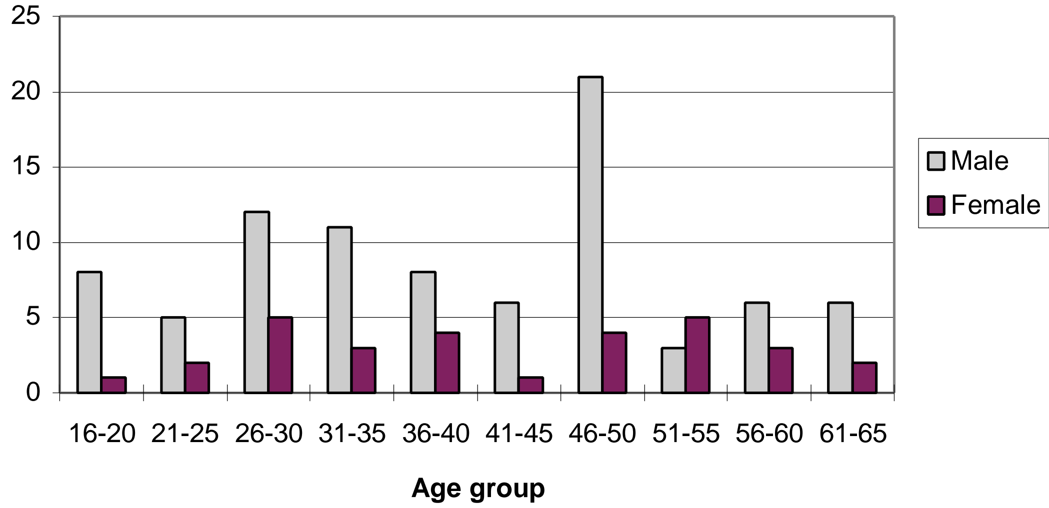
CHAPTER 4

Description of LIAISE Clients

4.1 Age and Gender

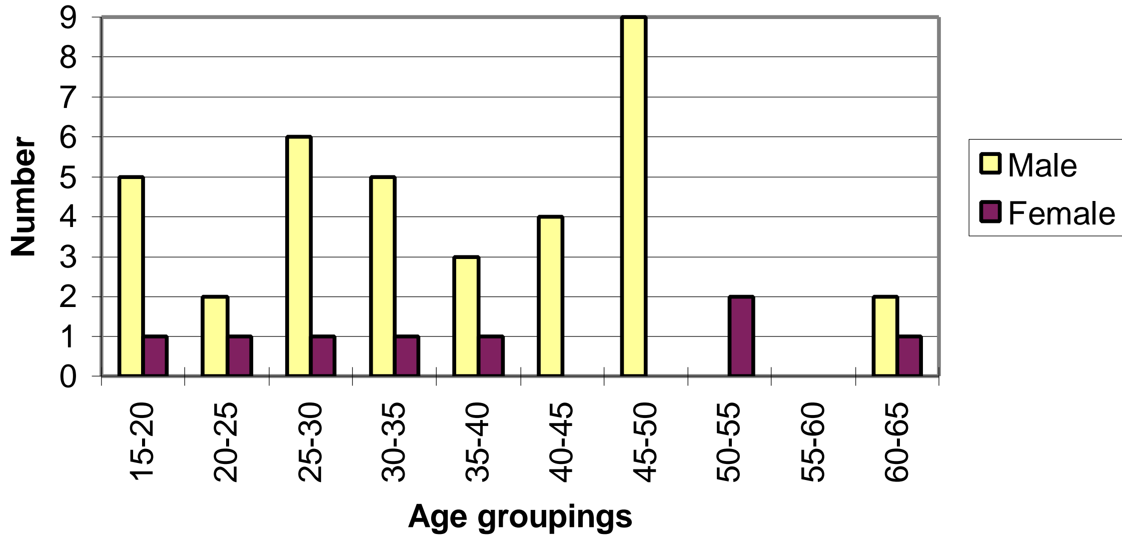
Most discussions of ABI emphasise that it is primarily an issue for young men. For instance the Head Injury Impact Project (1991) noted that in 1987-88, 68% of all public hospital admissions for head injuries were less than 25 years old, and that 71% of them were male. Figures 4 to 9 give a breakdown of LIAISE clients by age and gender for each site and for the program as a whole—they show a different picture to that obtained from the hospital admission data. There are several reasons for this difference. First, the LIAISE client group excludes children (those under the age of 15 account for approximately 40% of public hospital admissions for head injury). Secondly, the LIAISE client group includes people who have had their ABI for many years (see Figure 12). Also, the public hospital admission data would not include a significant number of people whose ABI was not the result of a traumatic injury (see Figure 10). It is important not to be misled by the common idea that ABI is primarily an issue for young men, because clearly this provides a limited and inaccurate picture of who is living in the community with ABI. Note that eligibility criteria for LIAISE excluded people over the age of 65.

Figure 4: LIAISE Clients by Age and Gender



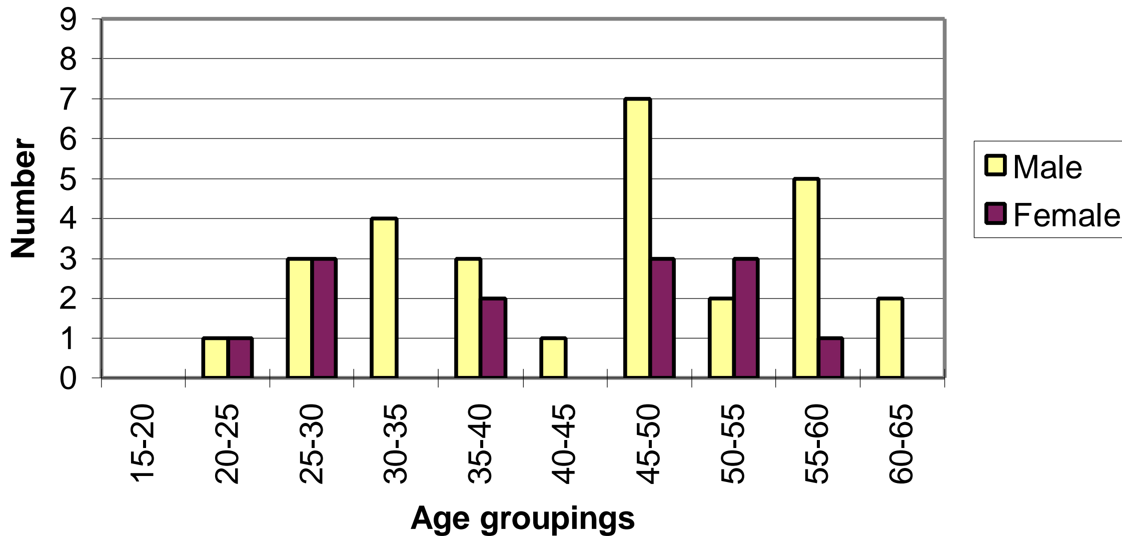
Cranbourne had the greatest proportion of males and also had the youngest client population. As with all sites however the peak is still in the 45-50 year age group

Figure 5: Cranbourne Clients by Age and Gender



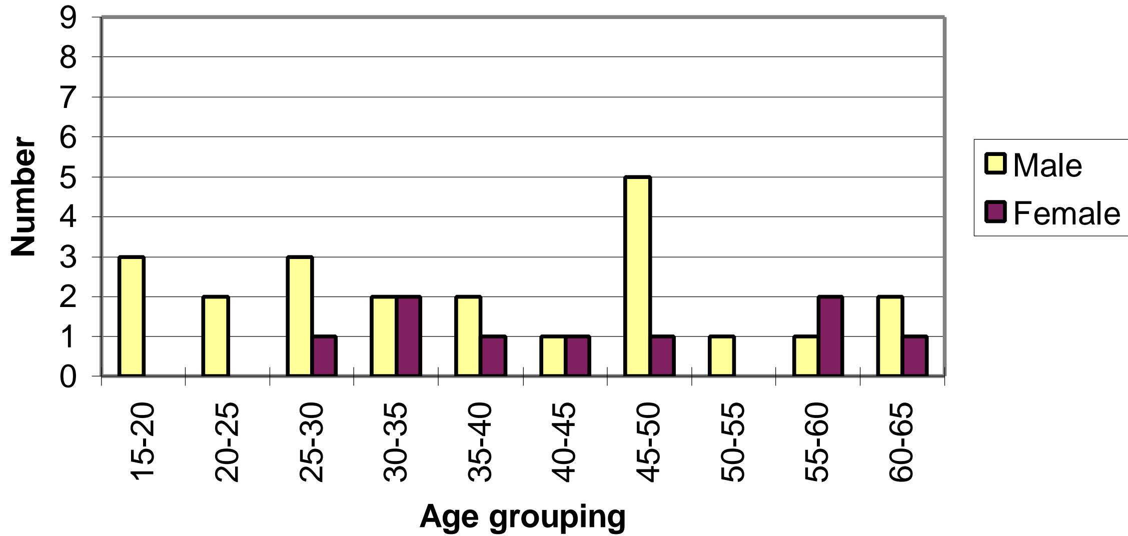
By contrast Bentleigh had the oldest population and a higher proportion of females than the other two sites. This is somewhat surprising given the fact that Bentleigh had more clients whose head injury was of traumatic origin.

Figure 6: Bentleigh Clients by Age and Gender



Mornington had a relatively even spread of clients across all age groups whilst still peaking in the 45-50 group.

Figure 7: Mornington Clients by Age and Gender



Figures 8 and 9 demonstrate more directly that Cranbourne had the youngest population and the lowest proportion of females while having the largest number of clients overall.

Figure 8: Average Age of Clients at Each Site

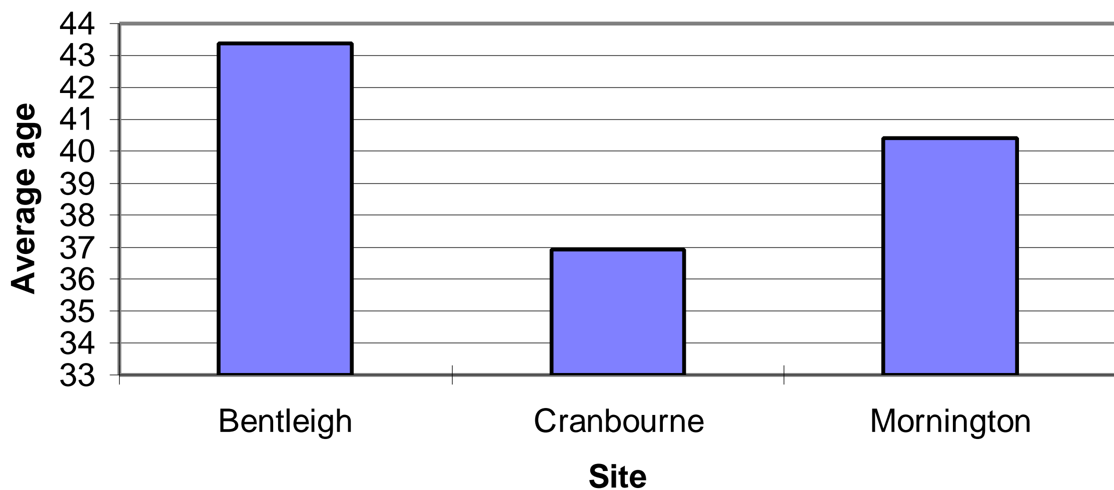
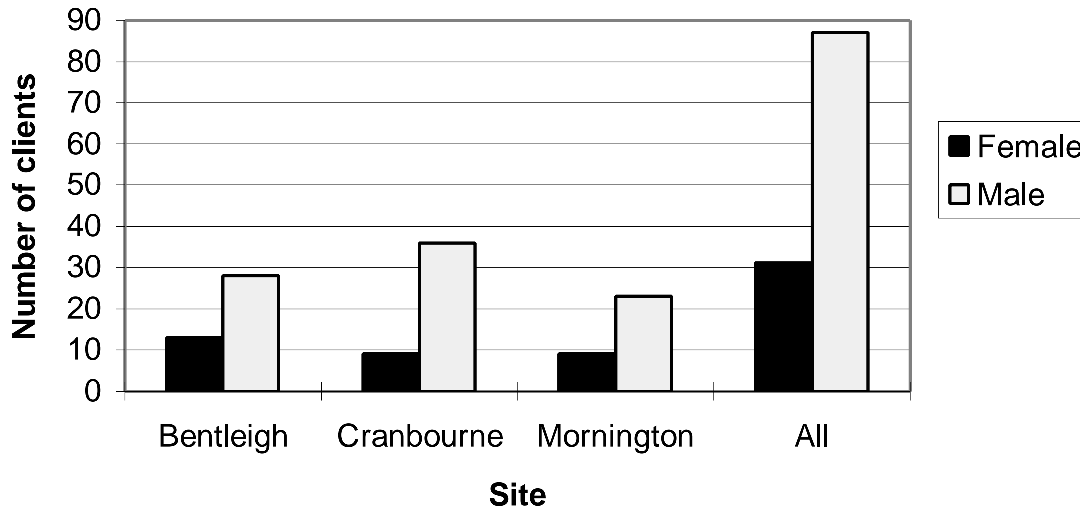


Figure 9: Gender by Site



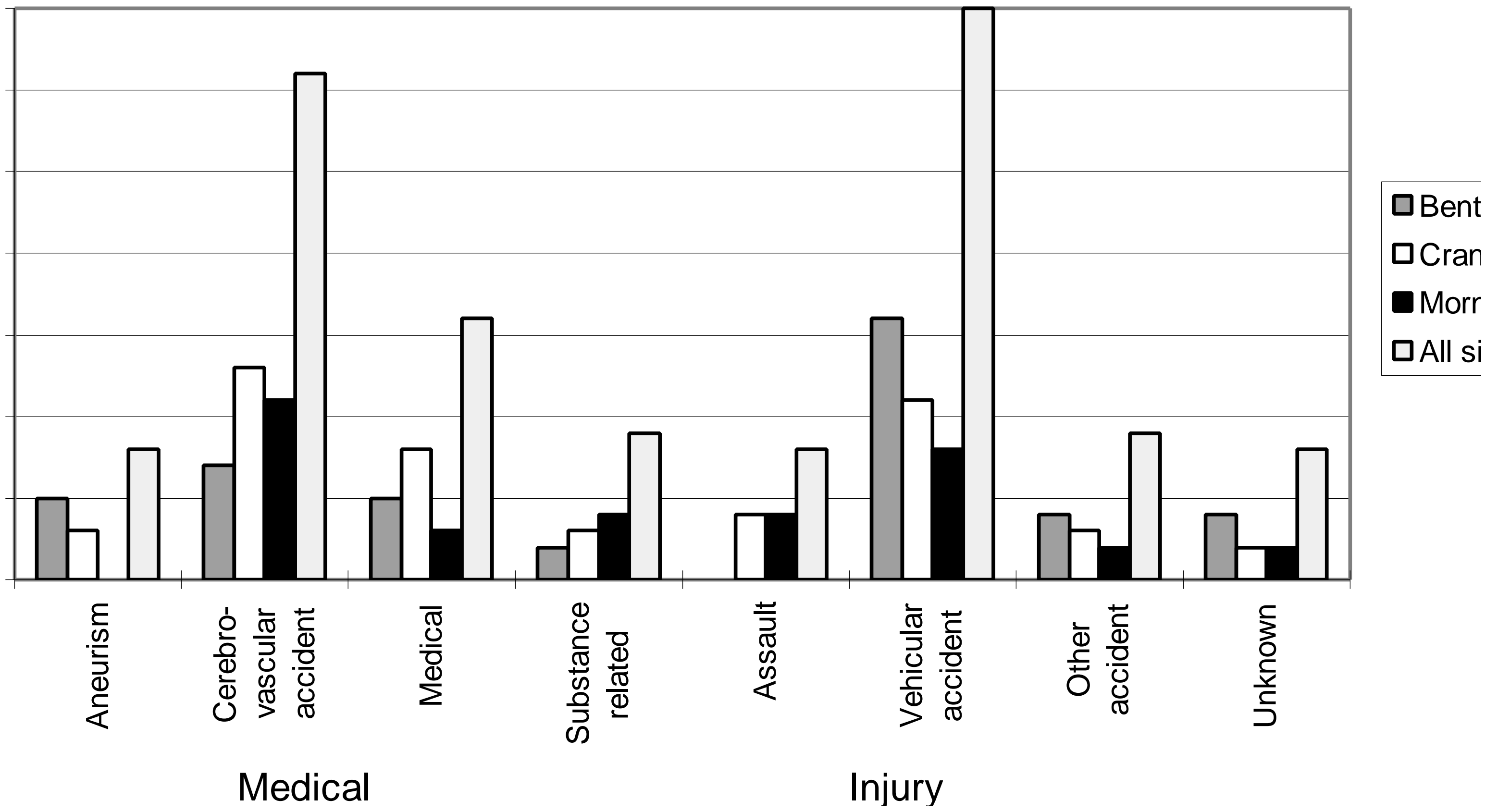
4.2 Cause of ABI

Although other studies have emphasised that the source of a client's ABI is of quite limited importance when working with clients in the community (see Summers & Segal 1996), it is of interest in understanding how ABI occurs and what might be done to prevent it. Figure 10 shows the causes of ABI for clients at each site. Several interesting issues arise from this data. Surprisingly, given the age and gender distributions, Cranbourne has the highest proportion of clients whose ABI arose from medical causes (aneurism, CVA, other medical) whereas Bentleigh has the highest number whose ABI was of traumatic origin (assault, vehicular accident and other accidents). Mornington had a relatively even spread of causes.

Cases of medical origin (54%) slightly exceed those of traumatic origin (46%) as a proportion of known causes of ABI for LIAISE clients. This in part explains the fact that there were more older LIAISE clients than would be predicted from hospital data on trauma admissions.

This figure also illustrates the relatively high number of people LIAISE is working with whose ABI was the result of a vehicular accident. None of these people are currently receiving compensation for their ABI. Some of these people, like those in other categories, may receive compensation in the future through civil action undertaken through the courts, or through administrative appeals processes. A number of people had received compensation many years ago, often quite a small amount. Others have been injured inter-state and are not eligible for compensation. And a few were injured in off-road vehicle accidents and are not eligible for compensation.

Causes of ABI

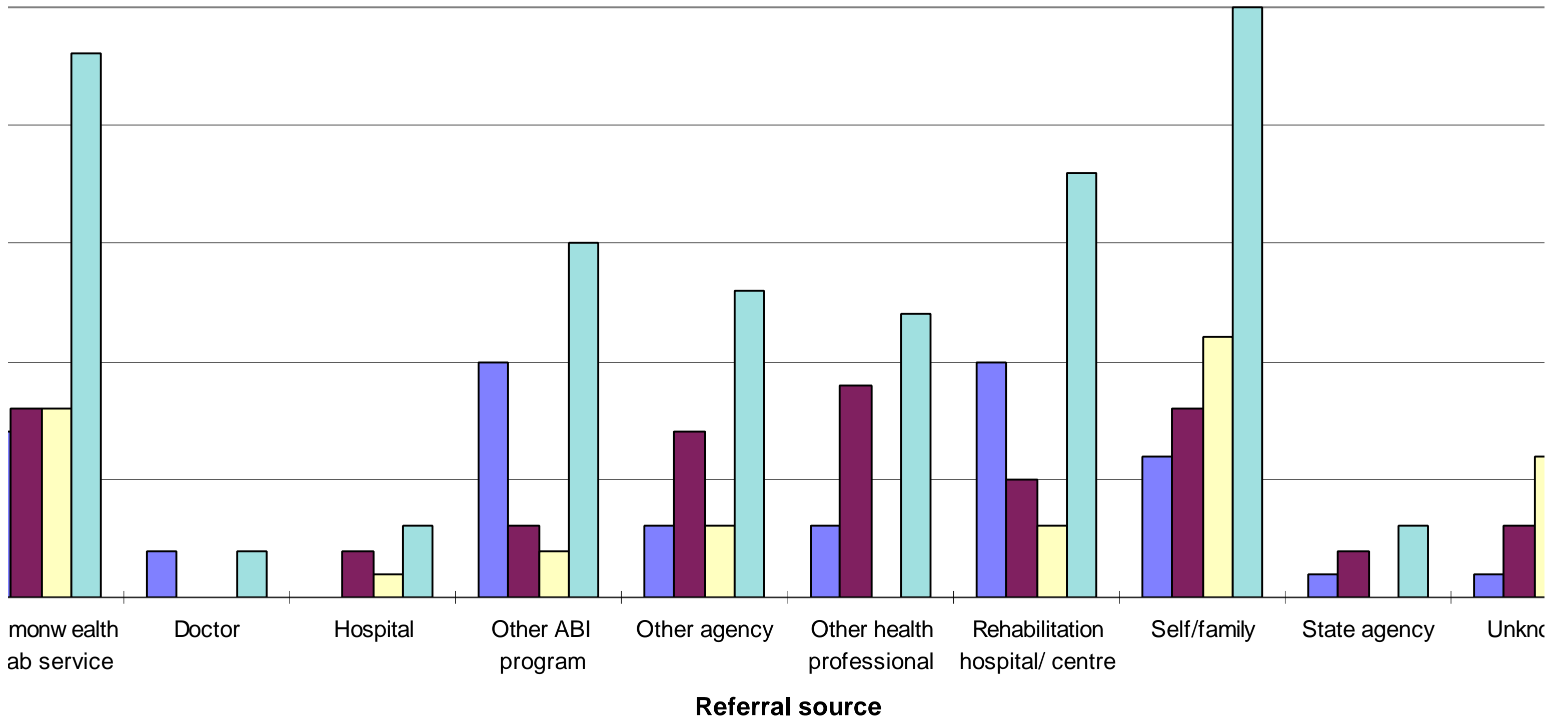


4.3 Referral Sources

Figure 11 summarises the sources of referrals for each site. The wide range of referral sources is a good indication that LIAISE is reasonably well known. In particular, the high number of self and family referrals suggests that the marketing strategy is reaching people in the community with ABI, and the variety of organisations making referrals suggests that LIAISE is reasonably well known amongst service providers working with people with ABI. Other less frequent sources of referrals also suggest that LIAISE is widely known. These included community-based agencies, day hospitals, local councils, public (non-rehabilitation) hospitals, and the Department of Human Services. However, in the interviews with service providers and LIAISE staff there were numerous comments to suggest that LIAISE is not as well known as it might be. It may be that this is reflection of how difficult it is to attain and maintain a high profile. Marketing is time and resource intensive, and it is unlikely that LIAISE can spare more resources for this.

Once again there are some noteworthy variations. The overall majority of referrals came from the Commonwealth Rehabilitation Service or from the client or their family. However, nearly all of the referrals from rehabilitation hospitals and other ABI services occurred at Bentleigh. This may just indicate that their are more services available in the Bentleigh catchment but it is noteworthy that existing ABI services felt that what LIAISE is offering is sufficiently distinctive to make cross referral worthwhile. In particular, there were concerns early in the establishment of LIAISE that LIAISE might be duplicating other available services. The relatively high number of referrals from services that are working with some people with ABI (eg Commonwealth Rehabilitation Service), and the comments made by other service providers and clients/families when interviewed for this evaluation, provide convincing evidence that LIAISE is filling a large and previously unfilled gap.

Referral Sources for Each Site and the Program as a Whole



4.4 Complicating Factors and Concurrent Diagnoses

Data was collected on a range of coexisting conditions and complicating problems. This information indicates the complexity of working with people with ABI who typically have functional deficits in more than one major area (physical, intellectual, emotional, behavioural, social) and frequently have other diagnoses which either pre-existed the injury or have arisen independent of the injury (eg asthma, arthritis, atherosclerosis) or have arisen as a result of the injury (eg epilepsy). No quantitative summary is given here as the categories coded in the reporting sheet and their definitions appear arbitrary and ill defined and in most cases the collected data probably represent substantial underestimates. As noted in the literature review the complexity of ABI is often taken to indicate a need for specialised ABI services.

Many LIAISE clients have serious medical issues that make working with them that much more important and that much more difficult. One of the LIAISE sites estimates that approximately one-half of their clients have major substance abuse and/or psychiatric issues.

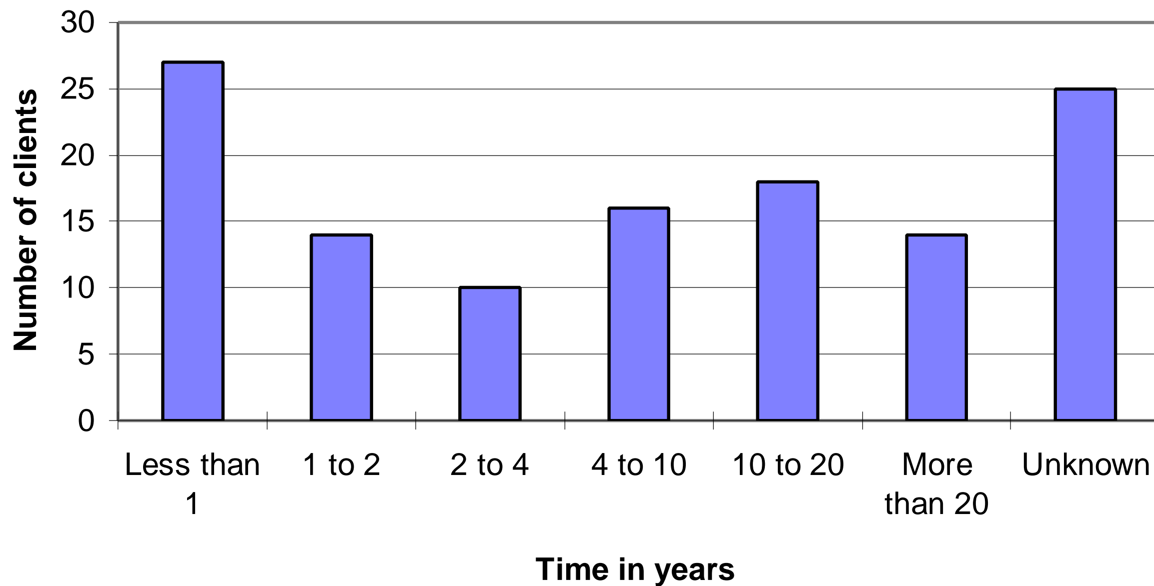
4.5 Preferred Language

It is important to note that there were six LIAISE clients whose preferred language is not English. Other preferred languages were Arabic, Russian, German, Thai, Cambodian and Polish. Also there is one client who uses a communication board. Clients from non-English speaking backgrounds whose preferred language is English were not identified. However, the relatively low proportion of people whose preferred language was not English suggests that LIAISE has not adequately reached local NESB communities with its marketing strategy. In its first year LIAISE worked with ADEC (Action on Disabilities within Ethnic Communities) to improve its capacity to reach and provide services to people from non-English speaking backgrounds - not just in regards to language issues, but also in relation to being sensitive to other cultures and what this means for particular clients. This is an issue that requires more attention from LIAISE and the adoption of appropriate strategies for improvement in this area. It is also an issue of resources, reaching and working with people from non-English speaking backgrounds requires a higher level of resourcing/funding than does working with other population groups.

4.6 Time Since ABI

Figure 12 summarises the number of years that people have had their ABI before becoming LIAISE clients. Most of the people who have had their ABI for one or two years have come to LIAISE directly from acute care or rehabilitation hospitals. Most of the clients who have had their ABI for four or more years have been living in the community for some time. The large number of people whose ABI occurred many years ago emphasises the level of unmet need and the need that many people with ABI have for life-long assistance (either intermittent or in some instances ongoing).

Figure 12: Time Elapsed from Injury Till LIAISE Program Commencement



CHAPTER 5

Description of Liaise Services

5.1 Throughput

Figure 13 shows the number of admissions, discharges and the number of people currently active in the program for each month since the start of 1995. The total number of clients joining LIAISE from its inception to the end of October 1996 has been 88. It can be clearly seen that the number of clients increased after the establishment of LIAISE over a period of about 6 months, and the number of clients has been a more or less steady since July 1995. Since July 1995 the program has had an average of 40 clients at any one time. This average falls just short of the 1995-96 service agreement targets of servicing 15 clients per site at any one time.

LIAISE has achieved a regular rate of discharge averaging approximately four per month since July 1995 and allowing an equivalent number of new admissions to the program.

5.2 Length of Stay

In Figure 14 the average (mean) length of stay for clients are presented. The length of stay is important because as it increases there is less client turn-over and therefore fewer opportunities for new clients to access LIAISE. For instance, Cranbourne's average is slightly lower, and the number of clients it has worked with is higher. Note that the date used to calculate current client length of stay was 15 Nov 96.

Table 2 : Average and Range for the Number of Months in the Program

Site	Measure	Months
Bentleigh	Average of months in program	6.7
	Minimum	0.8
	Maximum	25.1
Cranbourne	Average of months in program	7.5
	Minimum	1.4
	Maximum	21.9
Mornington	Average of months in program	10.1
	Minimum	0.3
	Maximum	20.7

Commencements, Discharges, Number in Program Per Month for All Sites

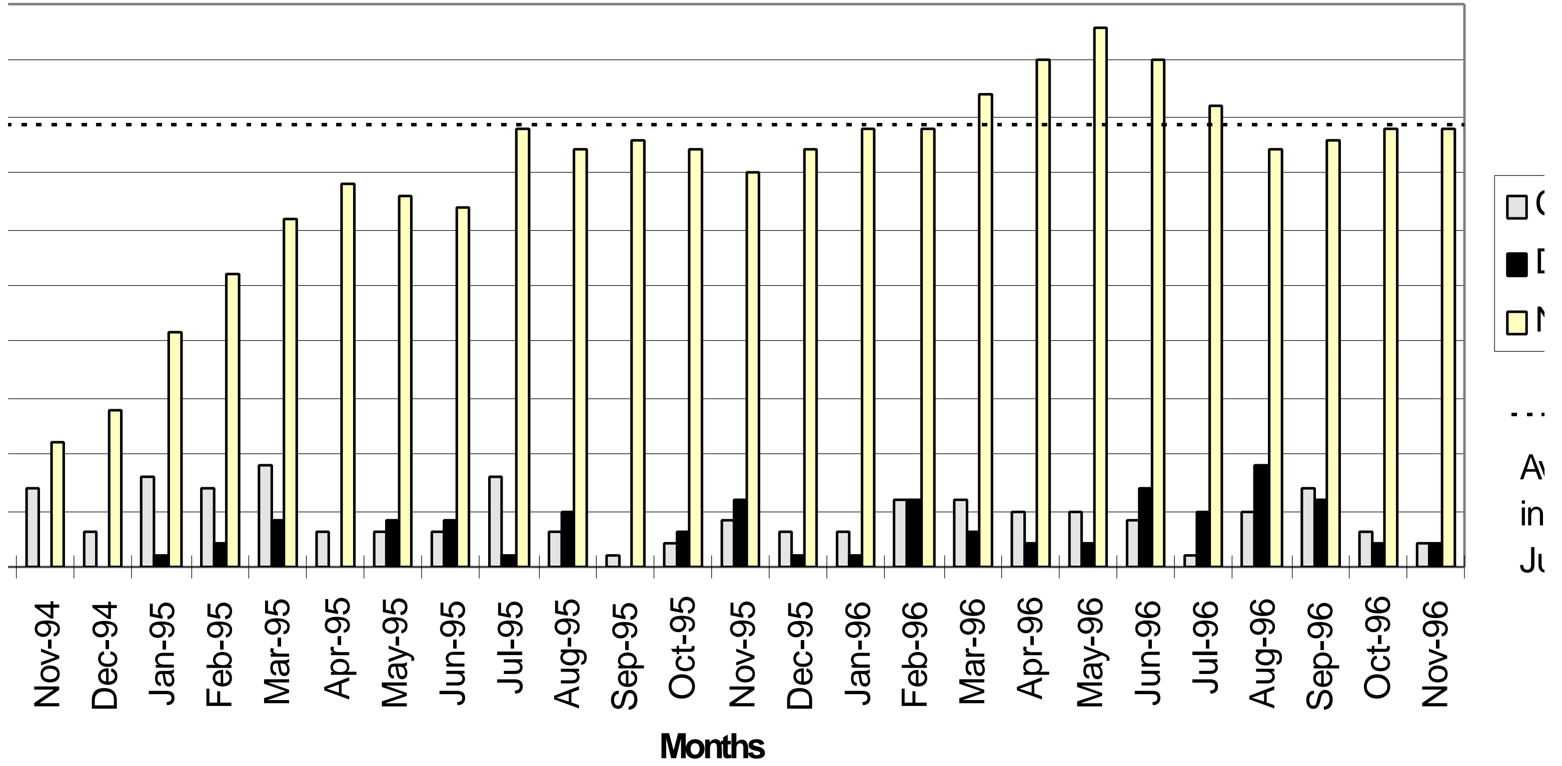
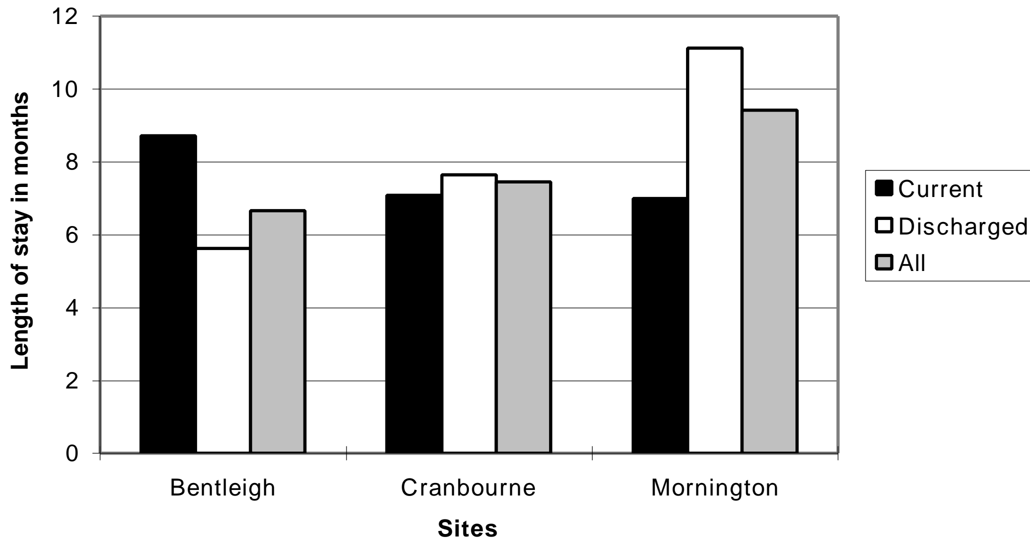


Figure 14: Average Time in the Program for Discharged and Current Clients



5.3 Assessment Period

The average length of time of the assessment period (the time between when clients were referred to LIAISE and when they were actually accepted as clients) is summarised in Table 3. The figures are somewhat inflated by a number of individuals who clearly were inappropriate at the time of the initial referral but developed a need for LIAISE services later. Three of these outliers have been excluded from Bentleigh's average although one or two longer assessment period clients remain. The underlying figure for the assessment of clients who are accepted into the program on the occasion of their first referral is probably about 30 to 35 days. Work that is done during this time includes meeting the client and family/carers (if relevant); completing a relatively detailed assessment; obtaining documents from hospitals and other organisations, and determining the clients eligibility and interest in the program. One month for the completion of this range of tasks seems reasonable.

Reasons for longer assessment periods and delays in assessment include: clients remaining in or being admitted to hospital; clients unsure about whether they want/need LIAISE; difficulties and delays in talking to potential clients and arranging meetings for assessment such as clients going on holidays interstate or not returning telephone calls; the time needed to arrange and access client records and information held by other organisations such as hospitals; and occasionally the non-availability of a coordinator to do the assessment (on leave or other LIAISE commitments - including other assessments). It should be noted that there is a short waiting list at Cranbourne (although these figures suggest that this is not causing excessive waits as Cranbourne's average and maximum are lower than the other sites).

__Table 3: Time in Days for Assessment Period__

Centre	Data	No Days
Bentleigh (average excludes 3 outliers above 290)	Average Minimum Maximum	50 7 190
Cranbourne	Average Minimum Maximum	37 0 87
Mornington	Average Minimum Maximum	38 6 146
Overall	Average	43.6

CHAPTER 6

Description of Liaise Activities

This section contains two sets of figures that show the breakdown of how LIAISE staff have spent their time in a twelve month period from 1 November 1995 to 31 October 1996. This period was chosen because by this stage the program was in a relatively settled state and many of the 'set-up' activities were complete. The first set of figures (15-20) is based on all three sites combined. The three subsequent figures (21-23) show a breakdown of all recorded time usage, but for the individual sites rather than the program as a whole.

6.1 All Service Activities

The most notable features of Figure 15a are the high proportion of both non-client time and travel time and the low proportion of direct client contact.

The proportion of time spent on travel is high but this should probably be interpreted as a positive finding consistent with the high proportion of service delivery that occurs in people's own homes. As demonstrated in the case study of Charles (see section 7.2.2), travel time can sometimes be a very significant issue. Although there is considerable variation across the three sites, the differences are consistent with the size of the catchments for each site and the relative number of clients at each site.

Table 4: Mileage by Site for Three Month Period

SITE	KILOMETRES
Bentleigh	2030
Cranbourne	6089
Mornington	3692
TOTAL	11811

The low proportion of direct client contact time (defined as time actually spent with a client face-to-face or on the telephone) is a concern both in terms of the efficiency of the service and its viability under unit costing. These issues are discussed in detail in a separate section of the analysis. It is recognised also that the evaluation itself placed demands on program staff which may have inflated the amount of time spent on non-client related activities.

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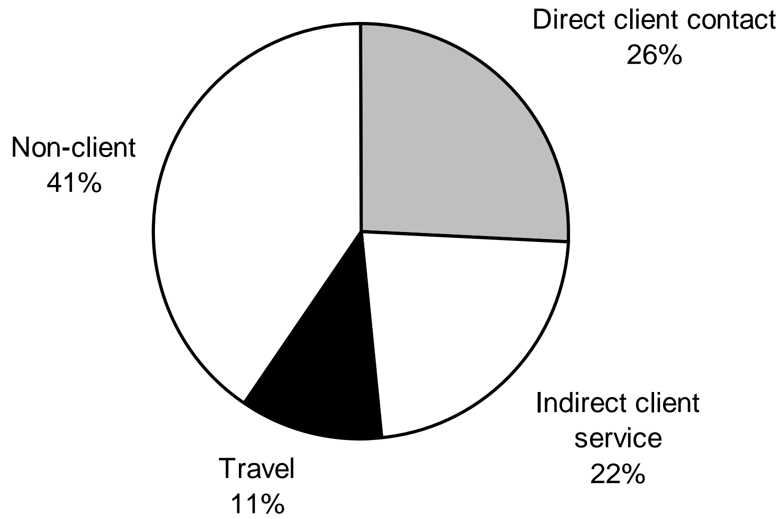
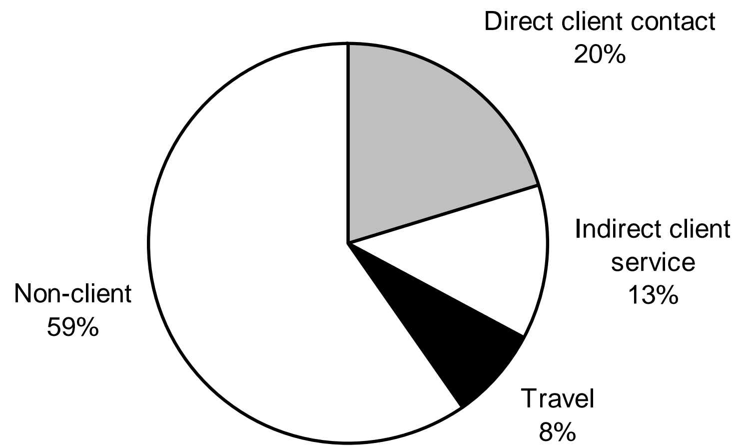
Figure 15: Time Utilisation Across All Sites from Nov 95 to Oct 96

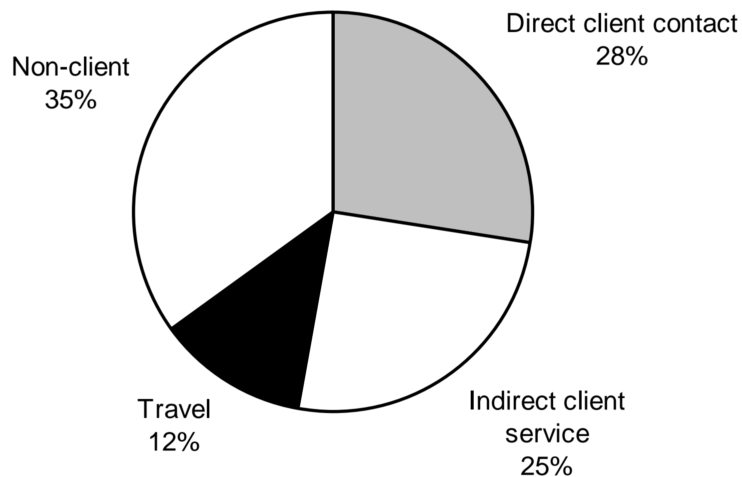
a. Total time usage by all staff



b. Total time usage by coordinators



c. Total time usage by community support workers



6.2 Direct Client Contact Activities

Figure 16 and Figure 18 give a more detailed breakdown of the sectors of Figure 15. Details of the use of non-client time are given in Table 5.

Figure 16 shows a more detailed breakdown of direct client services. The categories included on this chart are the most detailed that the evaluators felt could be reliably identified from the data. By far the greatest proportion of time was spent on skills training, and Figure 17 gives a detailed breakdown of this. However, as indicated in the case studies, this time was frequently used to achieve a number of objectives including emotional support, monitoring and community integration. Therefore the times shown for other activities probably do not accurately reflect the extent to which these activities actually occurred. Counselling (which means informal and semi-formal support, problem solving and information provision rather than formal psychological counselling) occupies a significant and increasing proportion of time but still probably substantially underestimates the amount of counselling that occurs.

Individual program resourcing (14%) includes some activities undertaken to implement individual client program, for instance, the time spent identifying possible recreation or education options available and appropriate for a particular client, and assisting other service providers to work with particular clients. At a broader level these activities are part of the program's case management role.

Figure 16: Time on Direct Client Service Activities from Nov 95 to Oct 96

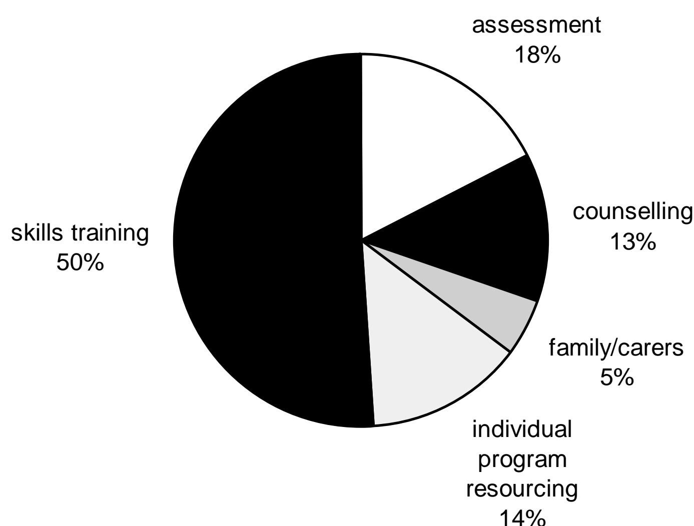
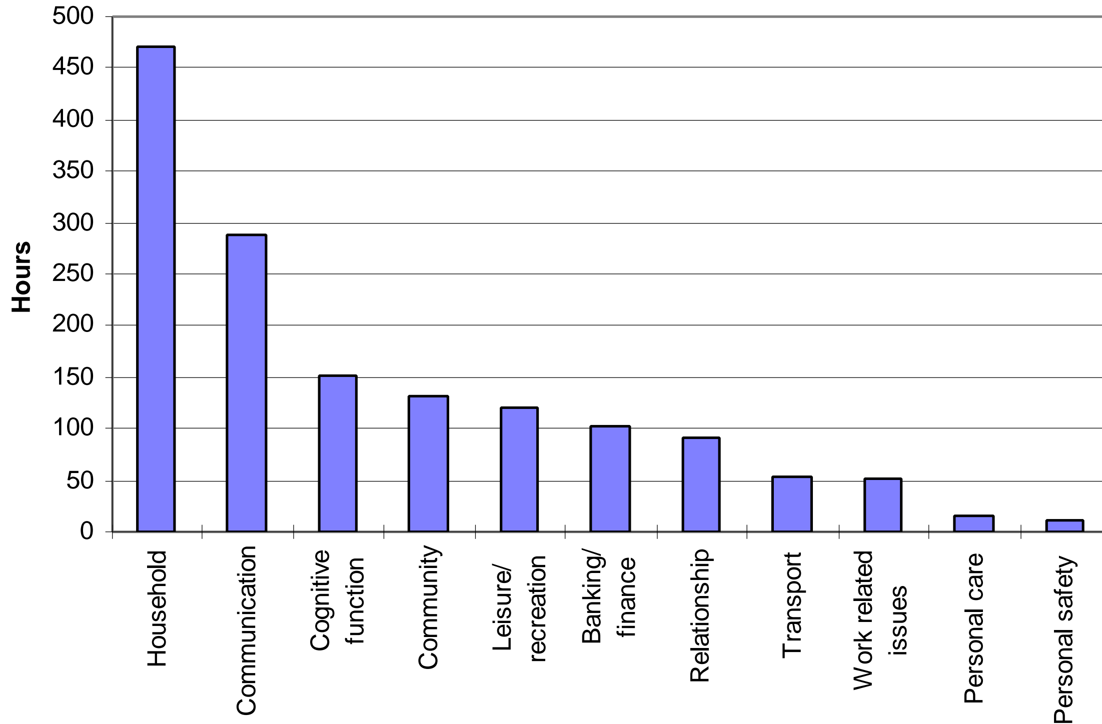


Figure 17: Breakdown of Skills Training by Type of Skill (Hours)



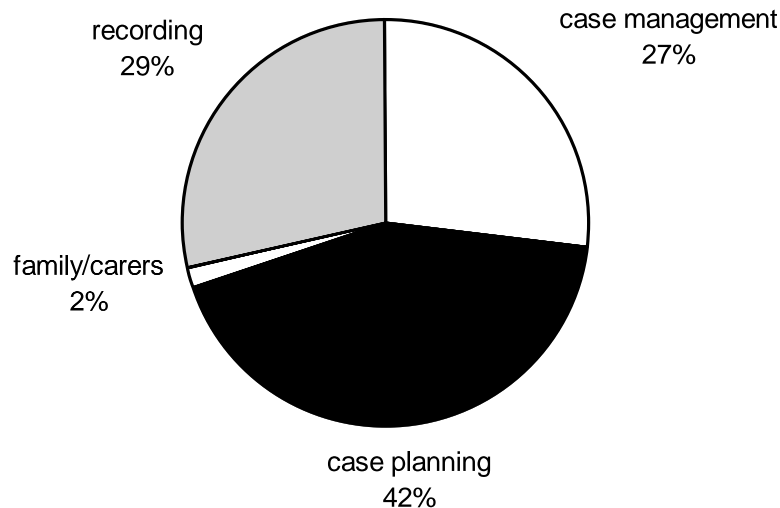
6.3 Indirect Client-Related Activities

Figure 18 gives a breakdown of time spent on activities on behalf of individual clients which don't involve working directly with the client. The bulk of this time is taken up with planning and preparation, and with recording. This may reflect the level of supervision required in the planning process. Although recording appears on this chart to occupy a large proportion of time it only occupies 6.6% of overall time. This is probably still a little high—files examined as part of the case studies were generally thorough but often contained considerable repetition which could be reduced.

Case planning (42%) includes activities such as planning client programs, preparation for client contact and case review.

The high proportion of time spent on indirect client services overall may represent the extent to which the service has taken on a case management function and is involved with networking on the client's behalf. As discussed in the literature review this may well be an appropriate use of time. For example, much of the community integration work may be recorded as indirect time.

Figure 18: Time Spent on Indirect Client Activities from Nov 95 to Oct 96



6.4 Overall Time Spent On Client Related Activities

Figure 19 illustrates several critical issues. The graph plots client related activities in the groups direct time, indirect time and client related travel as well as total client related time for each month of the program's existence.

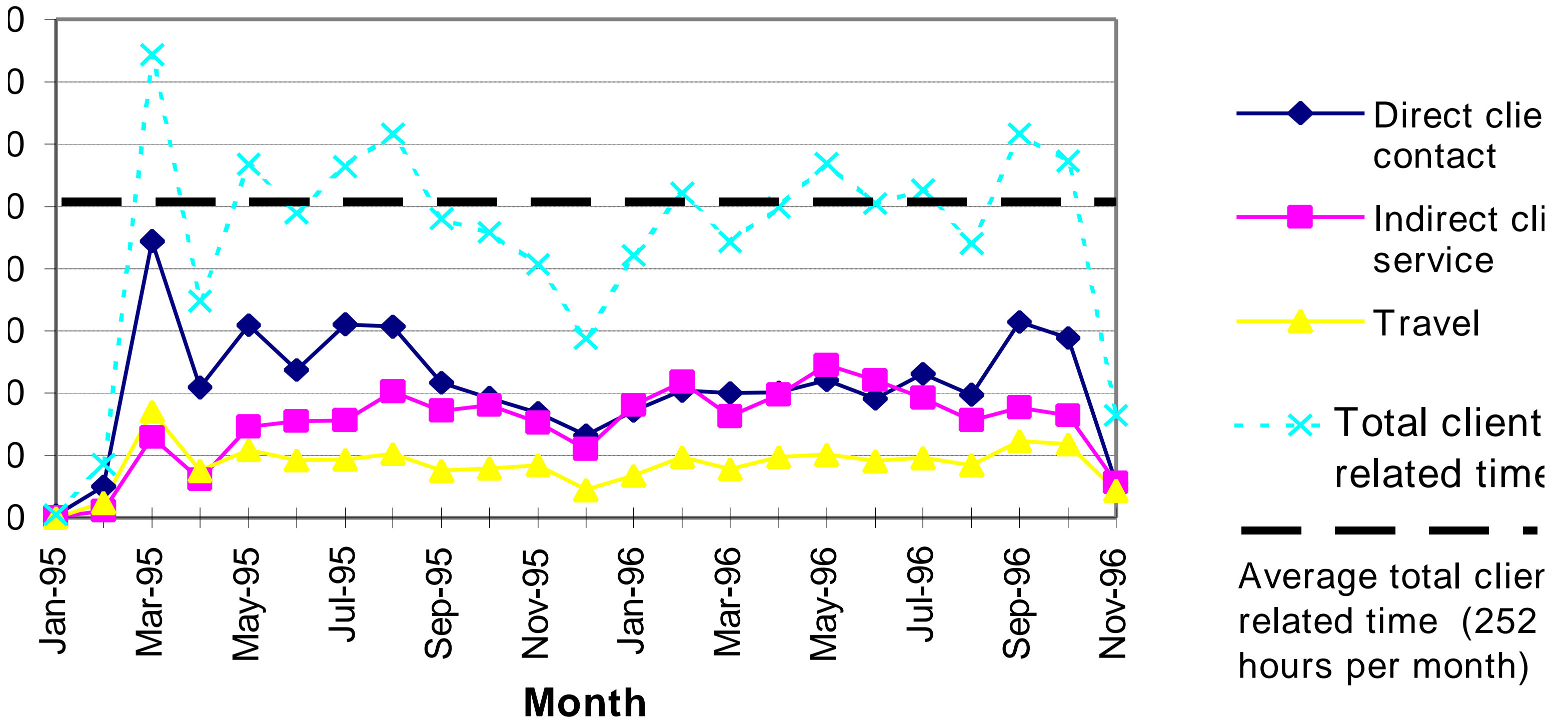
Although the figures took several months to stabilise, from May 95 onwards the figures are relatively regular. Notably the figures for the three groups tend to rise and fall together maintaining fairly constant proportions. What variability in proportions does occur, occurs between direct and indirect care. The regularity of these proportions suggests that they may well be appropriate for this client population or at least for matching the current staffing formula to the needs of clients.

The graph also enables us to explore the issue of what should be included in any unit funding formula for this program. Current unit costing formulas for independent living skills training have been developed for centre-based work with people with intellectual disabilities. Under this formula payment is based on the number of direct client hours services provide, with an allowance of 12-15% for indirect client-related activities including such things as writing assessments, preparation for therapy session with a client, travel to and from client, and phone calls to other professionals regarding a client. Typical unit costing for ILT services is $22.80 per hour (the rate for 'Community Support - Client Support Services' established by Department of Human Services, objectives for this unit cost are maximising independence, community participation, personal organisation etc., and it includes a 15% allowance for indirect activities). Under this formula the current LIAISE program would not be viable: it does not provide enough direct service to clients and the hourly rate is

inadequate. Under this unit costing rate with the current number of direct client hours provided, LIAISE would receive approximately half of its current level of funding.

A similar service working in the Northern and Eastern Regions, Community Access Service, did a 'snapshot' audit over a two week period in December 1996 of how the workers spent their time. This audit found that they spent 33% of their time in direct contact with clients or undertaking case management activities (such as contacting other service providers and helping clients gain access to other services) on behalf of clients. This compares with LIAISE's 32% (26% direct time plus 6% case management). This comparison suggests that this proportion of direct and case management time may be appropriate, especially as both services are working to a similar 'whatever-it-takes' model and providing a mix of independent living skills training and case management services. This, in addition to the evidence that LIAISE is meeting clients' needs suggests that the appropriate mix of services is being provided. Therefore, it is essential that an appropriate unit cost rate, or unit cost formula, be which recognises and funds this mix of services is established to make LIAISE viable under unit-based costing arrangements. These issues are considered further in the Analysis and Conclusion section and the Recommendation section of this report.

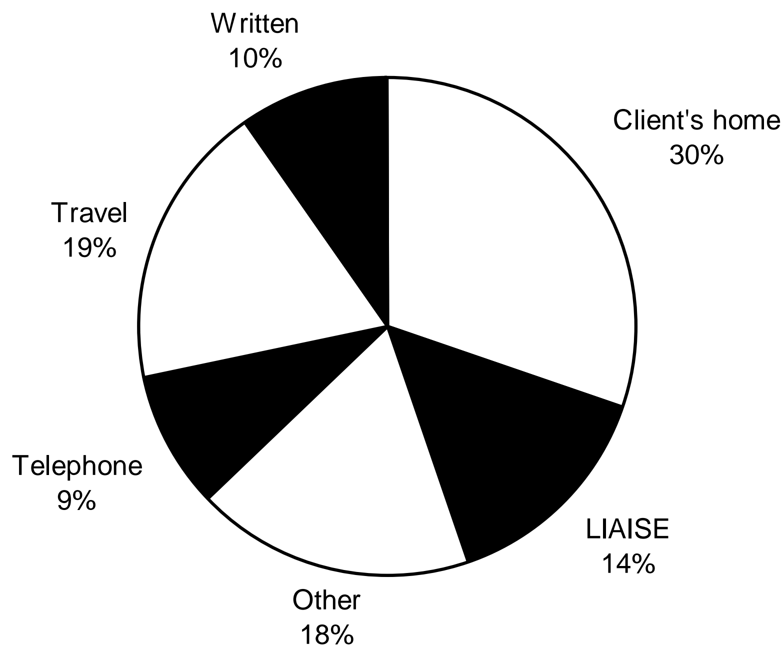
Client Related Time Utilisation for All Sites



6.5 *Place of Service Delivery for Direct and Indirect Client Services*

Figure 20 shows the proportion of time for client-related activities (direct and indirect) which occurred in different places (client's home or LIAISE offices)and through different mediums (such as written or by telephone). Note that in most instances both written and telephone activities were usually undertaken at the LIAISE offices. The high proportions of travel and time in clients homes are a result of the program's emphasis on working with people in their own homes as much as possible. This emphasis seems appropriate given the mandate of the service to work with people in their everyday circumstances in order to develop sustainable solutions to clients' problems.

Figure 20: Location of Direct and Non-direct Client Service Delivery from Nov 95 to Oct 96



6.6 *Time Usage At Each Site*

Figures 21, 22 and 23 give the breakdown of overall time for each site. Mornington has substantially less time noted as non-client time this may however reflect differences in recording conventions as noted in the discussion of Table 5. Mornington and Bentleigh have the same proportion of time spent on direct client services. Travel is almost exactly the same at all three sites which suggests that 10-12% travel time is probably an inevitable feature of this model of service delivery.

Figure 21: Time Utilisation at Bentleigh from Nov 95 to Oct 96

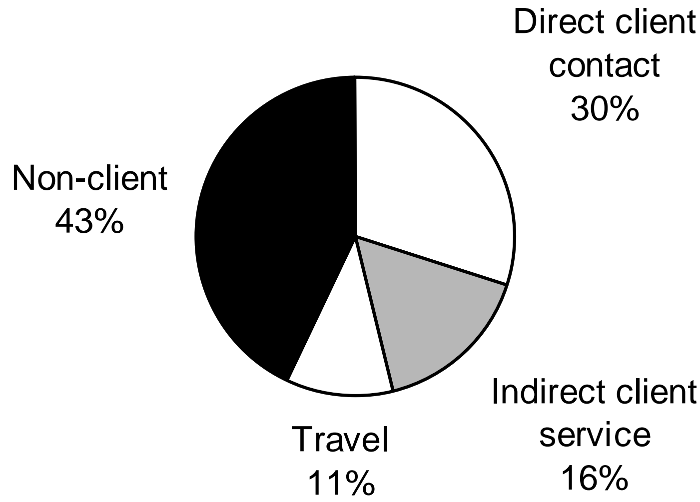


Figure 22: Time Utilisation at Mornington from Nov 95 to Oct 96

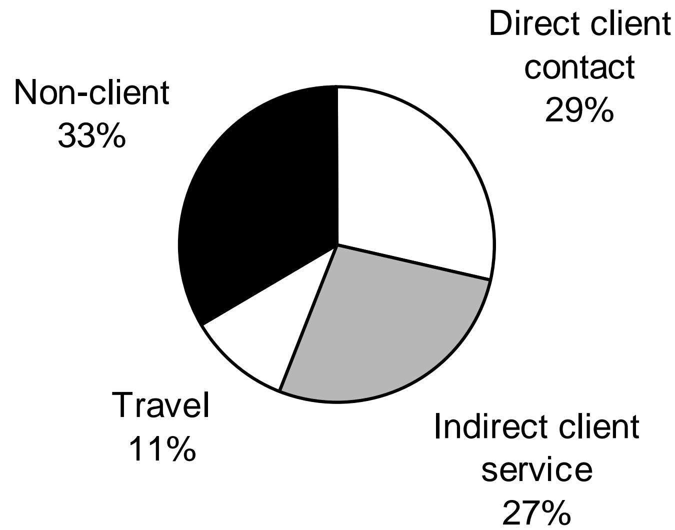
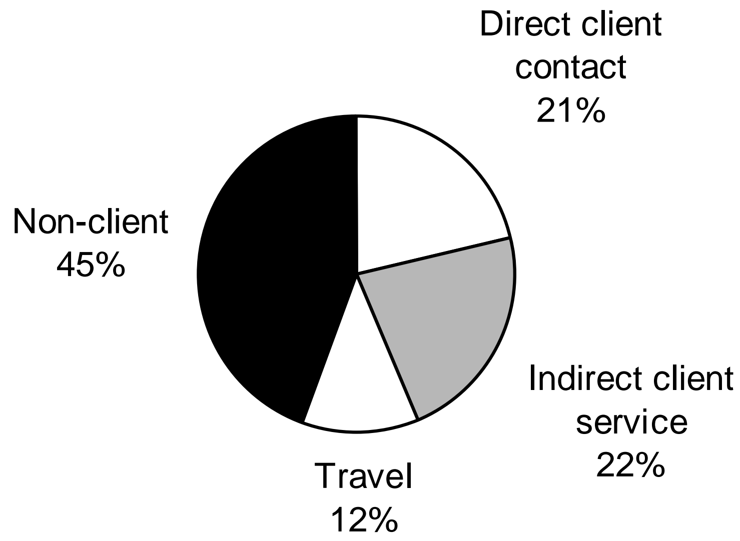


Figure 23: Time Utilisation at Cranbourne from Nov 95 to Oct 96



6.7 Non-Client Related Time

Table 5 shows the main categories of non-client related time across the three sites. The table lists activities in the order of the amount of time they occupied.

The most time consuming category relates to program development and includes activities related to the development of the program as a whole such as policy and protocol development and some aspects of the evaluation. The fact that this has continued to occupy a large amount of time in part reflects the fact that the program has demonstrated ongoing evolution and change in response to the perceived needs of people with ABI in the community. Over time the need for program development should gradually reduce, but will always be a significant activity in any program which constantly strives to make quality and efficiency gains. The figures for Cranbourne are high which may reflect the fact that Cranbourne did some significant development work on behalf of all the sites (eg data collection and recording systems).

Managers of the auspicing agencies developed guidelines for training and marketing in July 1995. These guidelines stipulated that the time to be spent on general promotion during 1995-96 should not exceed 64 hours per site and that other local promotion should not exceed 26 hours. Time spent on marketing was well within these guidelines although it is possible that much of the 'networking' time was primarily for promotional reasons.

Staff training occupied 246 hours which is approximately 1/2 hour per week for each staff member. This does not seem to be unreasonable given the cost savings gained by employing staff at low rates of pay. Also, ongoing staff training levels are likely to be lower than this because this period includes the implementation of LIAISE's training plan funded by the Non-government Disability Training Unit. Funding for the first year under this plan is significantly higher than subsequent years.

Differences in definitions probably account for the some of the differences between sites. For example some of Bentleigh's 'written administration' and 'correspondence' may be equivalent to Cranbourne's 'program development'. The differences in definition may even extend across the client/non-client boundary; for example at Mornington a lot of supervision occurs as case related discussion and planning and therefore is included as indirect client related time. This may explain some of the variations in time allocation noted earlier.

Table 5: Non-client Related Activities by Hours at the Three Sites from Nov 95 to Oct 96

Activity	Bentleigh	Cranbourne	Mornington	All sites
Training	109.3	97.2	39.3	245.8
Program development	26.2	80.8	86.3	193.3
Travel - Non client related	49.8	67.0	56.0	172.8
Staff meeting - Auspicing agency	25.8	74.3	54.0	154.1
Networking	47.6	51.6	42.0	141.1
Supervision	25.9	84.2	19.5	129.6
Written administration	31.5	37.8	42.0	111.3
Marketing	12.2	11.8	54.6	78.5
Staff meeting - Location LIAISE	21.3	15.0	41.0	77.3
Staff meeting - Full LIAISE team	18.5	33.0	17.0	68.5
Correspondence	27.2	22.2	17.0	66.3
Student supervision	6.3	46.0	9.9	62.3
Recording & collating statistics	26.3	13.7	2.8	42.8
Supporting self help groups	0.0	8.4	31.6	40.0
Other	47.9	88.4	22.9	159.2
Not recorded	47.1	116.9	64.1	228.1
Total:	**523.0**	**848.1**	**599.9**	**1970.9**

Meetings with the auspicing agencies have occupied a considerable amount of time some of which is probably developmental and some of which may be important in order to organise extra services for clients.

The above category 'other' includes activities such as financial management, other meetings, participation in the evaluation and special training. It is unclear whether the overall administrative burden could be rationalised by either restructuring the LIAISE program to operate from one site or by redistributing responsibilities between LIAISE and the auspicing agency.

CHAPTER 7

Case Studies

There were twelve case studies undertaken, four from each site. Each case study involved an interview with the client; interview with one (or more) family members if relevant; interview with the client's community support worker; audit of the client's LIAISE file; and examining information related to the client on the LIAISE data base. The following section is in two parts. The first part presents an overview of the results of all the case studies (detailed comments from clients/family members and issues from each of the twelve case studies are presented in Appendix B). The second part presents individual summaries of four case studies. These four individual case studies were chosen to illustrate the range of clients' needs and situations, and the different ways that LIAISE has worked with different clients. For these individual case studies the clients' names have been changed; each client has given their permission for their stories to be included in this report; and both the client and the community support worker were given copies of drafts to correct any mistakes in fact or in emphasis/tone (this also allowed clients to make informed decisions about whether or not they wanted their stories published).

7.1 Overview of Case Studies

With only one exception, every client and family member/carer interviewed to date stated quite strongly that they would recommend LIAISE to anyone in a similar situation. Outlined below are some of the other key points they made in relation to:

- independent living skills training;
- emotional support;
- information;
- accessing other services;
- aids and strategies for daily living;
- social isolation.

The most common activities that LIAISE has undertaken with clients and their families have already been described. The case studies provided the opportunity to understand what clients and families gained from these activities and what was most important to them. What emerges from these twelve case studies are numerous accounts emphasising not so much the independent living skills that have been gained, but rather how working towards these have helped clients and families to feel that things can move forward. This in turn appears to help generate a sense of accomplishment and increase the confidence clients have in themselves.

Also figuring prominently in most case studies is the importance that emotional support and informal counselling in assisting clients and their families in being able to cope with daily life after an ABI. Intrinsic to this was a pervasive feeling that the community support workers and the coordinators were 'there for them'. Just knowing that some help was available - even if they did not need it - helped to make them feel more secure. Clients and families often felt very much alone and ill-equipped to work through the many issues that come with having an ABI. Implicit in much of this was also the idea that because someone is there to help them, they are valued and important members of society. This was an important issue, particularly for many people who have been coping with their ABI for many years with little or no assistance.

In most case studies LIAISE was also an important source of information on ABI and on the services available to people with ABI and their families. In several instances clients and families commented that although the ABI occurred many years ago this was the first time that anybody had sat down with them and explained some of the details about what this really meant. In these cases both families and clients clearly gained some relief and some insight into a wide range of problems and issues that they had been grappling with for many years, and usually some valuable strategies for change. Also, LIAISE frequently arranged for various assessments to be undertaken for clients including neurophsychological, visual and hearing assessments. These often provided not only technical information to facilitate the development of a client's program, but also often provided clients and families with information to help them understand and recognise the client's needs and abilities. In regards to information about available services and programs many families and clients cited instances of where LIAISE had been able to identify relevant programs quickly and apparently quite easily, after families had spent many fruitless hours (often over many months) trying to do the same. As one mother commented: 'They know what families can't [know].'

Clients and families also emphasised the importance of LIAISE in not only identifying a wide range of other services, but also assisting them to choose and access appropriate services. The most commonly requested activities and services were social, recreational and leisure. Many clients and families commented that it was difficult for them to find out about other services, and that they greatly valued LIAISE's expertise in this area. It should also be noted that in the case study interviews with the community support workers it was apparent that considerable time and effort went into identifying appropriate services, helping clients gain access, and monitoring/coordinating the various services working with individual clients. Because most of this work is not done in the presence of clients and

families, few of them appeared to be aware of how much time and effort was involved, but they did clearly appreciate and value the end result.

In most case studies a number of simple and practical aids and strategies were either introduced or further developed to help clients overcome memory and organisational problems they were experiencing. Most often this involved using aids such as diaries, note pads by the telephone and weekly planners. One indicator of the success of using diaries was that only one client that I went to interview for the evaluation had 'forgotten' about the appointment. It was also apparent in many interviews that having such tools gave clients a sense of mastery and control over their lives that was previously lacking.

Social isolation was a major issue for every case study client (with one exception). Given the level of need for assistance to reduce their isolation, and the importance of this in relation to facilitating other improvements for clients (eg reduced isolation can generate increased interest and motivation for achieving goals related to activities of daily living) this is a legitimate and essential activity for LIAISE. LIAISE used a number of strategies, often in combination, to help clients with this. These included trying to identify work, recreation, leisure, education and self-help group options that might interest a particular client. Often clients were not interested, or after trying something once or twice stopped going. However, in some instances it did work out and the clients gained much valued opportunities to be with other people - even if it was short-term. Additionally community support workers often assisted clients in developing essential skills for social interaction, particularly communication skills. Social isolation is a difficult issue to resolve, and it is unrealistic to expect that any single program will be able to totally solve this problem for its clients. Consequently there were very few instances in which it could be said that LIAISE was completely successful in helping a client. However, it was evident that many clients had made some gains in this area.

7.1.1 Problems Identified Through the Case Studies

Throughout the case studies we also looked for any major problems with the structure or operation of the LIAISE Program. With one exception none of the clients or families involved in the case studies alluded to any serious problems or dissatisfaction with LIAISE. The one exception was a client who had been told that if he wanted to access a particular ABI accommodation option that he had to become a client. He expressed considerable anger at having 'someone stick their nose into [his] business'. After a relatively short period the accommodation proved inappropriate, he moved and LIAISE withdrew - much to his relief.

There were two other issues identified through the case studies that warrant mention. First, although generally subtle there were numerous small pieces of evidence which suggest a pervasive emphasis on independent living skills training sometimes in spite of the fact that this was not what a particular client expressly stated that he/she needed or wanted. Usually their expressed needs were met, however, the emphasis on independent living skills was not always appropriate.

Second, there were a number of occasions in which community support workers spent too much time working on inappropriate or fruitless activities with some clients. To a degree this is unavoidable - after all you cannot always know something is inappropriate or fruitless before it has been tried. However there were several instances in which these activities (usually independent living skills training) appeared to be pursued for too long. In most cases these were picked up by the coordinators who suggested to the community support worker more appropriate activities. There was nothing to suggest that the community support workers were not doing an excellent job given their level of experience with ABI and qualifications, in fact the evidence suggests quite the opposite. However, this problem does emphasise the difficulties and complexities of working with people with ABI and the value of experience - more experienced workers made few, if any, of these errors.

In the interviews with clients and families they were asked if they thought anything could be done to improve LIAISE. The major comments were:

- ability to see clients outside normal working hours;
- wish they had known about LIAISE earlier;
- wish they could access it for more than 18 months, the ABI is not going to go away and will occasionally need assistance throughout life;
- need more than LIAISE itself can provide: respite care, speech therapy, social support.

7.2 Individual Case Studies

7.2.1 Tara

In 1992, when Tara was 19 years old, an aneurism burst. After leaving hospital she spent three months in a rehabilitation centre. She was referred to LIAISE by Headway. When LIAISE began working with Tara in May 1996, her major goal was to be able to move out of the family home and live independently.

The other major issue was social isolation. As the support worker noted when she first started working with Tara: ‘A once active individual, she now reports being socially isolated. Friends have dropped away, with reduced social contacts and activities. Depends heavily on Mother for emotional support. Mother still very emotional about situation with daughter. Is no longer able to continue nursing studies.’ However, she has maintained her relationship with her boyfriend.

A number of related needs and issues were subsequently identified by LIAISE and Tara. These included:

- lack of confidence/self esteem;
- need to cook a range of meals;
- need for recreational, leisure and educational opportunities/activities, and/or part-time work.

Initially LIAISE worked fairly intensively with Tara, sometimes visiting twice a week. In the last four or five months the LIAISE community support worker has been

visiting Tara approximately once a week. The total amount of time the support worker spends with Tara and undertaking other relevant activities now averages between eight and nine hours each month. The main activities undertaken by the support worker with/for Tara to date have been:

- cooking skills;
- travel training and budgeting (relatively little time needed to be spent on these);
- identifying leisure and educational opportunities;
- assistance in improving range of social and cognitive skills;
- talking and informal counselling/emotional support.

While the community support worker was assisting Tara with cooking skills, this time was also used to by Tara to talk about what was going on in her life, her feelings, her problems and her successes. In addition, the worker also used cooking to help increase Tara's overall cognitive functioning, and to create opportunities for Tara to monitor her own increasing skills thereby helping her to gain confidence in her own abilities. Informal counselling and 'being a friend' also helped the community support worker to provide the support that has enabled Tara to make considerable gains in her view of herself and her abilities to cope with and enjoy life. Tara was interviewed twice for this evaluation - first when she started working with LIAISE and again four months later. Her increased confidence was readily apparent in the second interview.

In both interviews the process by which decisions are made (relative to LIAISE) was discussed. Tara emphasised the point that she felt she was in control of the decisions made, and also stated that the support worker was a valuable source of information and advice - but that the decisions were hers to make. In discussing this with the support worker, the support worker observed that this was one of the key parts of LIAISE's overall strategy to assist clients to increase the amount of control they have over their lives with the view that this would also help clients to increase their decision making skills, motivation and self confidence. Tara's comments would suggest that this approach worked well for her. In discussing what had been important about having a LIAISE community support worker, Tara stated that:

'She has been important in helping me to get myself ready for the future.'

'Most important is [the community support worker's] understanding. I'm able to talk to her and get my feelings out...I would have been lost without a shoulder to cry on.'

'They've been a life saver. Taught me how to rebuild my life....'

Tara and her mother also observed that in the four years since Tara's ABI, this is the first time that anybody has ever really been there to help them. Tara's mother observed that: 'We've been in a boat, rowing with no oars. They are an advocate, I don't feel all alone....Someone to lean on.' Both Tara and her mother said that in many ways LIAISE made an increasingly difficult family situation sustainable. One of the results of this is that although Tara is still planning on living independently one

day in the not-too-distant future, there is no longer the pressure to make this move as urgently as there was when LIAISE first started working with her.

Tara recently completed a TAFE course, and when last interviewed was about to begin working as a volunteer with other people in situations similar to hers. To assist her in finding work as a volunteer the support worker provided encouragement and also found out who Tara should contact in a number of hospitals about doing volunteer work. Tara then organised the rest, with some support from the worker.

School and volunteer work are important to: provide Tara with meaningful daily activities; help her develop skills and confidence; and be with other people. The community support worker also undertook a range of activities to help Tara become less isolated. This included contacting numerous organisations in the local area to identify recreational and leisure opportunities to pass onto Tara. Probably the most successful action was arranging for Tara to meet someone else, a woman about her age, in a similar situation, and they quickly became friends.

Tara and her mother also emphasised two other issues that were very important to them. The first was the ‘caring attitude’ of all the LIAISE staff with whom they had come into contact. The second point was the importance of LIAISE as information providers - ‘They know what families can’t know’. This information was both about ABI and about possible options (work, recreation, education etc) for now and the future.

7.2.2 Charles

Charles had a brain haemorrhage in October 1994 while living in Cairns, he was 28. He spent four weeks in hospital at Townsville, and this was immediately followed by five weeks in a major Melbourne hospital. On discharge from hospital, Charles then spent six months in a Victorian rehabilitation centre. Charles came back to the Melbourne area because this is where his parents live. At this point it was suggested that he go to a nursing home as his rehabilitation progress to date had been limited and the expectations for the future were not hopeful: after 6 months he still could not find his own room at the rehabilitation centre. After looking at several possible nursing homes his parents decided that this was inappropriate (Charles was 30 years old at the time), and they decided that they wanted to bring him home. To do this they would need support and the rehabilitation centre made a referral to LIAISE for this support. LIAISE began working actively with Charles when he left the rehabilitation centre and moved into his parents’ home at the end of May 1995. LIAISE stopped working with him in November 1996 after he began a part-time work-placement program.

Charles had been living away from his parents home for nine years before his brain haemorrhage. When Charles moved back home after his time in the rehabilitation centre, his parents were living in the outer suburbs of Melbourne and his father was travelling much of the time with his work. For a number of reasons, including the need to be home more, Charles’ father left his job and bought a share in an agricultural enterprise and they all moved to a relatively isolated rural area. Part of

the plan was the hope that at some time in the future Charles would be willing and able to work in the agricultural business they had bought into.

When LIAISE began working with Charles they found that he had significant short-term memory problems but that he could learn skills and information over time with significant assistance and prompting in the early stages. They also found that he was socially isolated and had little insight into his ABI.

The major activities that the community support worker undertook with Charles were:

- shopping skills;
- navigation and map reading skills;
- cognitive skills;
- employment-related referrals.

The community support worker spent approximately ten weeks (17 direct hours) working with Charles on his shopping skills. While these skills were seen as important to increasing his independence they were also an important method for improving his overall organisational, planning and problem solving abilities. When people at the rehabilitation centre were informed of his achievements, such as being able to find all the items on a shopping list in the grocery store, they were very surprised.

Considerable time (21 direct hours) was also spent with Charles learning to find his way around in his new rural environment through map reading and navigating in the car. Eventually this was abandoned after the worker found that although Charles often had trouble finding the most direct route he could usually get where he wanted to go and felt more comfortable and confident going the way that he already knew (previously he had driven trucks in the area and in a general sense knew his way around). Navigation was seen as important because for Charles his most important goal was to regain his driver's license - which he has done. LIAISE did not work with him directly in getting his license. Initially Charles was tested by a qualified Road Traffic Authority tester at the rehabilitation centre where he was an inpatient and outpatient. He failed this first test, took four driving lessons and passed a second test six week later.

The work done on Charles' cognitive skills included activities such as helping him to improve the way he used his diary, and other memory and organisational strategies.

Charles' road to employment has been a long one. It began with a Commonwealth Employment Service Review Panel to work out what he should do. This led to a referral to the Commonwealth Rehabilitation Service. However, they found they could not do much for him as he was not 'work ready' and did not know what he wanted to do. In March 1996 the LIAISE community support worker accompanied Charles to an initial interview at Dandenong Valley Job Support where it was suggested that he attend a more geographically accessible program - LaTrobe Personnel. This was done and eventually (4 months later) a work placement was found for him working in a gardening business half-time. In this job he does things such as mow lawns. He cannot work more than half-time as he gets very tired.

While these were the core activities of the LIAISE program for Charles, other activities were also undertaken including: in-home respite care (unavailable after family moved to rural area); enrolment in a memory course (ceased after 2 sessions when Charles began his work-placement); cooking (Charles hates cooking); worked briefly - only a few sessions - as a volunteer in a local meals-on-wheels programs; and recreational activities occasionally through the Kookaburras (a day activity group run by a community health centre).

In addition to the direct work with Charles, there were also some benefits to his family - particularly his mother. The time that the worker spent with Charles provided his mother with some respite. Also when interviewed, Charles' mother commented that after his ABI there was a lot that she 'had to come to terms with' and the LIAISE helped with this. In particular the community support worker tried to link her up to a counsellor but she was not interested, however she did attend a carers support group run by the local community health centre and commented that that had been very helpful (it was set up to only run for six weeks). Although the worker spent most of her time working directly with Charles, his mother felt that 'help was there if I needed it' and that it was valuable to her to know 'that someone was around that we could turn to - no one else out there'. She also noted that because she and her husband are migrants, and English is their second language that it was important to have someone available who could explain things and who understood the health and community services systems. The progress Charles has made has given his parents some hope for his future (and theirs) and the encouragement necessary to make them feel that having him at home - as hard as that might be at times - was the right decision.

When asked if Charles had received what he needed/wanted from LIAISE, his mother responded that he 'got more out of LIAISE than got anywhere else'. But she also observed that it would have been good if the community support worker had been able to spend more time with Charles more often, because he would have made more progress more quickly. The support worker also made a similar comment about her work with Charles, but noted that given the amount of travel time, 45 minutes each way to their house, this was not possible. Over the course of Charles' involvement with LIAISE the community support worker spent approximately 51 hours with him, and 55 hours travelling to and from his home.

When Charles and his parents were asked if a 'plan' had been developed for the work LIAISE would do which them, they said they did not know. In reading the LIAISE file on Charles it was found that a range of formal written program goals and strategies had been developed. In discussing this with the community support worker she made a number of comments. She felt that it would have been of little value to Charles to go over the plan formally. She did however think that by having a written plan it helped to give her work with him a focus and helped identify the appropriate sequence of activities. Also she used ongoing assessments/reviews to help track what she was doing and what needed to be done. In particular she noted that the value of program plans was that often she knew what to do unconsciously, but that having to write it down gave it more direction and also functioned as a summary of the work she had done.

7.2.3 Samuel

Samuel was involved in a car crash in 1968 in NSW. His ABI was not diagnosed until some time later, and he worked as a fitter and turner until 1991. Samuel was 54 when LIAISE began working with him, and lives alone in his own house in a small rural town. He read about LIAISE in a local newspaper and contacted LIAISE in November 1994. LIAISE began working with him in March 1995. He wanted help from LIAISE because he was not coping well on his own, he was depressed and lonely. Later Samuel also expressed dissatisfaction with his capacity to undertake a range of daily living tasks such as cleaning the house and personal hygiene. As a result of his ABI Samuel has problems with his short term memory, reduced motivation, and gets frustrated and anxious. He has some contact with his ex-wife and his son visits him occasionally.

With Samuel the LIAISE community support worker developed a program to address his range of needs. Major work undertaken by LIAISE included:

- household skills;
- communication skills;
- informal counselling and emotional support;
- information and assistance in accessing a range of local services and programs.

The support worker spent 22 hours working directly with Samuel on household tasks. This involved a wide range of activities such as explaining which cleaning agent to use when, cooking skills, shopping skills, and working with Samuel to develop and monitor a weekly planner outlining one cleaning task to be undertaken each day. Samuel was in the middle of doing some gardening and there was a basket of clean laundry on the table when I arrived to interview him, and he commented that having the weekly planner and the LIAISE support worker helped him to remember to do these things and be motivated enough to do them (although it was also apparent that he really has to work at keeping it up - it does not come easily to him to do these things).

Eighteen hours were spent working on Samuel's communication skills. Much of this activity took place within communication skills group conducted by LIAISE at the community health centre which ran for eight weeks. The main issues were his ability to initiate a topic and follow it through, finding the right words, completing sentences and motivation.

The largest single amount of direct contact time with the support worker (36 hours) was spent on informal counselling and emotional support. Samuel also sees two psychiatrists, and the LIAISE worker organised for him to see the community health centre counsellor. When asked what was the most important thing the community support worker did for him, Samuel replied: 'Her physically being here - other things were a bonus...Comfortable with [community support worker], she's older and I could talk more about personal things with less apprehension - such as sexual issues.' He

also said that ‘Sometimes she [the community support worker] will just sit and talk with me when I’m down. Human contact...I function better with human contact.’

Although the community support worker only spent a few hours helping Samuel to access other local services and programs, this was an important aspect of the work undertaken. Some of the programs/services Samuel has accessed since being involved in LIAISE included:

- a local self-help gardening group run by someone with an ABI (Samuel commented that he hated gardening, but that it was good for social contact and ‘I don’t have to cover up my ABI there as I do elsewhere’);
- a cooking program at a community health centre;
- a relaxation program at a community health centre;
- a Transport Accident Commission rehabilitation support group;
- a Stroke Support Group (although he has not had a stroke they have similar needs/problems);
- ABI communication group (see above);
- counsellor at community health centre (see above);
- ABI Support Group;
- Peninsula Employment Access Program (linked to this by the Commonwealth Rehabilitation Service), it is a service for people with disabilities to help them become ‘job ready’.

A number of other points were made by Samuel when he was interviewed that warrant mention here. In regards to how decisions in relation to LIAISE were made he commented that the community support worker often provided him with information and advice: ‘She makes me aware of it. But I make the decisions. Let’s me know what she thinks, if its a good idea.’ When this was discussed with the support worker she commented that the decisions were his, but that sometimes it was necessary to draw his attention to things that needed work such as various housekeeping tasks that were not getting done.

When LIAISE began working with Samuel face-to-face contact was quite frequent, at least once a week and sometimes twice a week. This became once a week and then once a fortnight. Samuel commented that this ‘was all she could do, more would not have helped’. Samuel has had to ring the worker for assistance on a few occasions, usually for crisis, ie water heater, or when he didn’t understand something. If she was not available he noted that she always rang him back promptly.

When asked if he thought LIAISE had met his needs and if he would recommend it to other people in his situation, Samuel stated: ‘I am my own worse enemy. I don’t believe in myself. People can only do so much for you and I need to stand on my own two feet.’ ‘I think it is highly recommendable...I never have to feel ashamed to ask her anything...I mistrust most people...If all of them are of the standard of [his community support worker], I hope that it will be continued, for other people to benefit.’

7.2.4 Elizabeth

Elizabeth sustained a hypoxic brain injury after an accidental overdose in October 1994. She spent eight days in an acute care hospital, followed by six weeks in a rehabilitation hospital. On discharge from the rehabilitation hospital she went home to her family (husband and two teenage children), and was referred to the Commonwealth Rehabilitation Service. CRS found that her needs were too intensive for them and made a referral to LIAISE in March 1995. In April LIAISE began working with Elizabeth, and stopped working with her in July 1996.

With LIAISE Elizabeth identified a number of needs and goals. Many of these related to daily household tasks such as cooking, cleaning and shopping. Most of the problems with these arose from her lack of motivation, difficulties in getting organised and problems in remembering what needed to be done. Other major issues identified were communication problems (particularly conversational skills), lack of recreational/leisure activities, and the need for counselling and emotional support. Working together Elizabeth and LIAISE developed and implemented a program plan to meet these needs.

The support worker spent 16 hours working directly with Elizabeth on household skills. Some of this involved assistance with practical skills such as drawing up a grocery shopping list, but most of it was trying to develop strategies to help Elizabeth organise her time, be motivated and monitor her own progress. A plan of tasks for each day of the week was developed and posted on the refrigerator, and the worker helped Elizabeth to monitor her success in following the plan. Elizabeth commented that she thought this did not work, and that it is the prompting of her husband that really helps her to get things done - she kept forgetting to use the planner. Notes from the LIAISE file on Elizabeth suggest that the support worker believed the planner had been effective to some degree. Elizabeth did very little of the household tasks before LIAISE became involved, her husband did most of it (which was possible because he has been unemployed much of the time since she came home from hospital). When I spoke to Elizabeth and her husband after LIAISE had finished working with them it was evident that she was doing more than she had previously.

To assist with her communications problems Elizabeth joined the ABI communication group that LIAISE ran at the community health centre, and the worker also provided one-to-one assistance (one of the LIAISE workers was a qualified speech therapist). LIAISE spent 15 hours working with Elizabeth on her communication skills. Assessments done by this worker before and after the eight weeks of the communication group suggested significant improvements in Elizabeth’s conversational skills. These improvements were also noted by Elizabeth and her husband. He commented that previously her conversation consisted mostly of ‘yes’ or ‘no’, and that now they could talk about things, and this in turn had helped improve the quality of their relationship. Another communication issue was Elizabeth’s literacy. When the LIAISE assessment was done it was noted that her literacy skills were below what Elizabeth wanted them to be. The support worker

identified a number of options such as adult literacy courses and in-home tutors, but Elizabeth did not elect to participate in these.

Informal counselling and emotional support were important to Elizabeth. For instance, she commented that: 'I like having [the community support worker] around to talk to and have a cup of coffee. It cheered me up and got me on the right path...After I finished with LIAISE what I really missed were the conversations.' She also made the point that 'LIAISE made the difference in the way I think about people and look at life. It made me aware of just how many people, ordinary people like me, have head injuries...and LIAISE has helped my husband and kids understand ABI.' Elizabeth commented that she sometimes got quite depressed because she knew she would never be the person she was before her ABI. The community support worker spent 14 hours providing informal counselling and emotional support to Elizabeth, and a referral to the community health centre counsellor was made and eventually acted upon by Elizabeth. Also, the worker spent some time talking to other family members, particularly Elizabeth's husband. In addition to issues related to Elizabeth's ABI there were other serious family problems and one of the daughters is also receiving counselling.

Together with Elizabeth the community support worker helped to identify a number of leisure and recreation options. Elizabeth made some steps towards acting on a number of these, but in the end she felt that there were other priorities (mainly domestic ones). The community support worker commented that perhaps if she had pushed Elizabeth she may have become more involved in some of these activities, but that it was difficult to know how much of the lack of follow through was Elizabeth expressing her own desires and how much was the motivational problems arising from her ABI.

Elizabeth felt like she was in control of the decisions being made. Often the support worker provided suggestions, information and advice but the decisions were made by Elizabeth. For instance the support worker told Elizabeth about the ABI self help group auspiced by the community health centre, and in Elizabeth's words: 'I thought it was a great idea and found it very helpful'.

Elizabeth's husband also noted that having LIAISE involved took some of the pressure off of him, and that LIAISE was able to do things for her that he did not know how to do.

CHAPTER 8

Interviews

This section describes the results of two major sets of interviews and discussions that were undertaken as part of the evaluation. Twenty-two interviews were undertaken with eighteen service providers and policy makers (several people were interviewed more than once). See Appendix A for a list of people interviewed. Interviews and meetings were also undertaken with the LIAISE staff and the managers at each of the three sites. In particular staff members were formally interviewed on two different occasions approximately six months apart.

8.1 Service Providers and Policy Makers

The key issues from the service provider and policy maker interviews include the following:

- LIAISE is filling a big gap in service provision for people with ABI;
- good that LIAISE is based in local communities, provides better access for clients and better understanding of local services/opportunities;
- working with people in their homes/the community is vital to ensure that skills training is relevant and appropriate, and to ensure that other community integration issues are identified and addressed at an individual level;
- there is a general understanding that LIAISE is providing primarily ILS training and links to social and recreational services/opportunities, but there are some who do not have a clear understanding of what LIAISE does;
- LIAISE staff are generally seen as professional and thorough, with a good understanding of ABI issues and skills in working with people with ABI, which generates confidence in the service and facilitates making referrals to LIAISE;
- the process of referring people to LIAISE is generally working well, but a number of service providers would like feed-back about what has happened to client;

- the part-time nature of LIAISE means that sometimes staff are hard to contact, but generally this is not a major problem - even with full-time staff as an outreach service staff would often be unavailable;
- perception that LIAISE is not well enough known, and that it would be good if LIAISE was more involved in various networks/committees etc;
- LIAISE has responded positively to some criticisms in the past, and LIAISE has improved over time - an inevitable part of setting up a new service;
- it would be good if there was a widely distributed map which showed the LIAISE catchment area, and the catchment for each LIAISE site;
- there is some uncertainty/unease about the capacity and/or willingness of LIAISE to work with families of people with ABI (this was only expressed by two people interviewed, but expressed quite strongly).

8.2 LIAISE Staff

Outlined below are some of the key issues and comments that were made by staff. There were numerous conversations and discussions between the LIAISE staff and the evaluators during the evaluation, in addition there were two rounds of formal interviews conducted with staff.

Referral and Assessment Processes

I. maybe you can do an initial client assessment in 3 hours, but assessment is generally an ongoing process: client needs and issues emerge as trust and relationship gets stronger;
II. not getting referrals from a broad enough range of sources;
III. accept most referrals, about 80%. Reasons for not accepting clients include:

    A. client not interested, did not ask for or want referral;
    B. major issues in other areas, especially psychiatric or drug/alcohol dependency;
    C. outside catchment or age group.

Major Activities with Clients and Families/Carers

- what we do depends on what clients want or need;
- some independent living training (for domestic tasks; social skills; planning and organisational skills or aids); demand is not primarily for ILT; many clients do not want or need ILT;
- helping clients to access other services, clients don’t know what’s out there or how to access other services (main assistance with social/recreational services) - this is seen by most staff as the most important and common (and often very difficult) task they undertake, this often involves elements of case management/case coordination;
- people often ask for social/recreational activities because they are socially isolated and want to have friends;

- help client see themselves, and be seen by others, in a positive way: help clients build self-esteem, self confidence and decision making abilities;
- social and emotional support, but not formal counselling;
- help with crisis, ie. family breakdown, losing house, criminal charges;
- listen to clients;
- building relationships with clients/families/carers;
- assist with establishing/running client and carer support groups.

Program Plans

- useful to do but sometimes difficult;
- could be done in a simpler form;
- helps to clarify what needs to be done and what has been done;
- do not work that well for clients that mainly need linkages to other services and case management;
- useful for community support workers but not always for clients.

Case Management

- some clients do not need any case management, for others it is 90% of what we do;
- only in the last 6 months have we felt that it was 'OK' to do case management;
- for some clients case management is the most important thing we can do for them.

Barriers to Meeting Clients' Needs

- lack of low-level funding (ie. $25 per client) prevents purchase of aids such as diaries for some clients;
- transportation: public transport limited in many areas; clients' inability to pay for transportation and lack of voluntary transport service restricts clients' access to other services and social/recreational opportunities;
- limited recreation and leisure opportunities in many areas, many clients don't 'fit' into existing programs which are often for older people or people with intellectual disabilities, or run at times when transportation and/or other assistance is difficult to organise;
- for some clients lack of access to a community friend/volunteer buddy, or attendant care restricts their ability to access recreation and leisure opportunities;
- many clients on limited incomes, ie. disability pensions, and cannot afford many otherwise available options such as a TAFE short-course or bowling;
- no or little success in accessing funding programs - especially In Home Accommodation Support Scheme and the Regional Disability Support Initiative - for clients;
- lack of affordable and appropriate accommodation for clients;

- office too crowded & need privacy occasionally when clients come in.

Advantages of the Current LIAISE Structure

- being locally based results in access for clients, less travel time for staff, knowledge of local services;
- nine staff, three at each site, means access to a good range of skills and knowledge, and capacity to support each other;
- across three sites having single identity helps with marketing/referrals;
- being based in other organisation provides access to other skills, networks, and resources (including infrastructure such as cars);
- one of the reasons LIAISE is up and running reasonably well has been the support and commitment of the auspice agencies at each of the three sites;
- community support workers often rely on coordinator's experience and find it useful that the coordinator knows all of the clients.

Disadvantages of the Current LIAISE Structure

It should be noted that most of the disadvantages listed below have been addressed. In particular there are new policies in place which clarify lines of communication and responsibility, and each site is functioning more independently so there is less need for coordination and meetings across the three sites. Also the activities associated with establishing the program required more coordination across the three sites than is necessary for its ongoing operation. The most recent interviews and discussions with staff and managers suggest that the program is running much more smoothly than it had previously. Recommendations about the need for clear lines of responsibility and communication were made in the Interim Evaluation Report, and these have been acted on with the development and implementation of several new policies.

I. lines of communication and decision making were too complex (with too much potential for conflict) with three coordinators and three managers; and there were not clear delineation regarding responsibilities and decision making;
II. too much duplication across three sites:
    A. 3 sets of policies
    B. 3 marketing strategies/activities
    C. 3 coordinators going to meetings;
III. difficult for all staff to get together - part time and across three sites;
IV. too much time was spent coordinating the activities of the three sites.

8.3 Meetings with Managers

Throughout the course of the evaluation meetings were held between the evaluators and the three managers of the auspicing organisations. Outlined below are the key points made by the managers about LIAISE:

- the way the program was established created a problem in that staff working in the LIAISE program identified with and had loyalty primarily to LIAISE rather than to the auspicing organisation. This is gradually changing as the sites become more autonomous and integrated with the auspicing organisation;
- the original attempt to have a single LIAISE program that was consistent across all three sites did work against tailoring the program to local needs, but that recent changes to more autonomous sites overcome this;
- the Department of Human Service's interpretation of what LIAISE should do was very narrow and constrained the development of the program;
- there were very few best practice models in ABI which could be used to inform the establishment and development of LIAISE;
- the current level of resourcing of LIAISE is inadequate and requires cross subsidising from other programs to make LIAISE viable (one site estimated that they subsidised LIAISE at a cost of $11,000 for a six month period). This raises questions for the sustainability of LIAISE;
- locating LIAISE in other organisations made it viable through access to such things as cars, administration, payroll services, people from other disciplines and physical facilities;
- locating LIAISE in other organisations also helped to legitimise LIAISE by associating it with other well respected organisations already known to the community.

CHAPTER 9

Analysis and Conclusions

This section of the report draws together evidence related to the major issues raised in previous sections. In particular it examines: the effectiveness of LIAISE in meeting the needs of its clients; the gradual evolution of LIAISE; issues related to how LIAISE staff spend their time including the appropriateness of the current ‘mix’ and implications regarding unit costing; and the appropriateness of the current target group for LIAISE.

9.1 The Effectiveness of LIAISE

As a first step in determining the effectiveness of LIAISE in meeting the needs of its clients it is essential to examine what is meant by effectiveness and how this can be measured. In general, there are considerable difficulties in measuring the effectiveness of complex interventions like LIAISE in terms of simple short-term outcomes for clients. Consequently effectiveness has been largely measured by examining the elements that are generally considered to be essential for the effectiveness of services like LIAISE. Several sources of information have been used to identify these essential elements, including examining the theory of the LIAISE program; a literature review; client case studies and interviews with service providers and policy makers. Detailed discussions of each of these are presented above.

The key elements of an effective program for this client group are presented below. In particular an effective program requires flexibility in delivering a range of core services including:

- independent living skills training;
- emotional support/informal counselling to clients and their families/carers;
- information - on ABI and available services/options for clients and families/carers;
- development, training in the use of and provision of aids and strategies for clients/families for daily living;
- provision of skills training and assistance with access to services and other options to help ameliorate social isolation;
- assistance to clients and families in accessing other services/case management;
- community development/community education activities in the general community and with service providers to increase understanding of ABI and thereby increase access, acceptance and participation in community life.

The way in which these core services are delivered is a critical element in relation to effectiveness. Major issues include:

- clients having control over decisions that affect their lives - clients have the right and the need to make their own 'mistakes';
- work with clients must be sensitive to the client's beliefs, values and culture;
- a good knowledge of ABI (including its impact on individuals and families and strategies for working with people with ABI) is essential to working effectively with people with ABI;
- the quality of the relationship between staff and clients is a major determinant of the programs effectiveness;
- natural supports last longer than professional interventions and must therefore be acknowledged and supported;
- flexibility is paramount to ensure that the program delivers what the client needs thereby maximising the potential for effectiveness, rather than delivering what the program is 'able' to deliver ('able' in the sense of available skills and resources): basing the capacities of the service on the needs of the client rather than determining the needs of the client based on the capacities of the service.

According to the evidence gathered throughout this evaluation, the LIAISE program has consistently met the above criteria for effectiveness. The only major exception has been their limited capacity to deliver community development/community education services, and this has been primarily the result of their funding limitations rather than a lack of skills or interest. Some work has been undertaken around the needs of specific clients, but there has been no capacity to engage in community development/education activities more broadly. Additionally there have been some problems in recruiting community support workers that have significant experience in working with people with ABI. (One of LIAISE's responses to this has been a strong commitment to attract and work with students on work placements.) This in turn has meant that workers have not always had the knowledge of ABI necessary to work effectively with their clients, but they have gradually developed this expertise on the

job. These recruitment difficulties are in part a consequence of the low salaries paid to the community support workers, and in part a reflection of the general lack of people with experienced in working with people with ABI.

Evidence was gathered regarding outcomes. In relation to the service system one of the major outcomes of the establishment of LIAISE has been the filling of what many service providers described as 'an enormous gap in service provision in the Southern Region'. Service providers consistently emphasised the importance of having a specialised ABI service with the expertise necessary for working with this client group. This was echoed in the case studies by people who had been living with their ABI for several or many years without access to a service such as LIAISE. Examples of this were seen in the above case studies of Tara and Samuel who both reported that they were unable to get the help they needed before LIAISE.

In relation to outcomes for clients, all of the case studies (with one exception) contained evidence that LIAISE had made positive, and often significant, contributions to their lives. Examples of this from the individual case studies described above include:

Tara - increased confidence and self esteem, maintenance of previously precarious living situation, a hopeful and positive attitude about the future, and reduced social isolation.

Charles - significant gains in overall cognitive abilities (much of this is attributable to Charles' and his family's hard work, but the availability of LIAISE in supporting Charles and his family was a vital element in avoiding Charles being place in a nursing home upon discharge from hospital)

Samuel - moderately increased satisfaction with life arising from increased knowledge, skills and ability to organise his time in order to complete activities of daily living such as cleaning the house and doing the laundry to his satisfaction, more understanding of his ABI, improved communication skills and reduced social isolation.

Elizabeth - significantly increased communication skills, moderate increase in confidence, access to counselling and strategies to help deal with depression, a somewhat more positive view of the future based on progress she has made - particularly regarding communication skills, and increased understanding by her family of Elizabeth's ABI and some strategies to help Elizabeth and themselves.

9.2 LIAISE as a Learning Organisation

One of the founding principles in the establishment of LIAISE was the knowledge that the needs of people with ABI are complex, and that a service established to meet those needs would have to learn the most appropriate ways of meeting these needs - not all the solutions could be known beforehand. The LIAISE staff and management clearly succeeded in creating a responsive and learning organisation that has constantly made improvements in all aspects of the program. This was

commented on by a number of other service providers and observed throughout the life of the evaluation. Criticisms, comments and suggestions from service providers, policy makers and the evaluators were consistently responded to by positive changes in program policies. Additionally, staff within the program consistently examined their own practices and sought improvements.

One of the results of this has been a gradual shift in the focus of the program from an initial concern primarily with the provision of independent living skills training to a more flexible and holistic approach. This gradual change was driven primarily by the staff of LIAISE as they gradually found out what was necessary to fulfil the primary goals of LIAISE: to assist clients to increase their quality of life by facilitating client independence, increasing participation in community life, and improving self-esteem and confidence. This shift would have occurred more quickly and comprehensively if there was not a perception within LIAISE that it was essential to keep independent living skills training as the central and major activity of the service in order to help secure its future funding. This perception was generated by the Department of Human Service's initially narrow view of what LIAISE should be doing, this view has since broadened. That the shift towards providing a more broadly based and more appropriate range of services has occurred in spite of this belief is evidence of the strong commitment that staff have to meeting clients' needs whatever it takes.

9.3 The Current Activity Mix

The program currently has high levels of non-client and indirect client related time. This is not viable under current unit costing proposals for LIAISE, particularly if the unit costing system values hands-on independent-living-skills training above other services. Increasing the viability of LIAISE as an ongoing program will require changes in the current unit costing proposals (to bring them into line with what is the appropriate mix of services that such a program should be delivering), and to make some modest increases in the time LIAISE spends working directly with clients.

This section first looks at the evidence from the evaluation that suggests that the most of current service mix may be appropriate. It then looks at evidence that suggests areas and directions where the service mix should change. This discussion looks at possible areas for change and the likely benefits of change. Finally the section suggests criteria that any funding arrangements for the program needs to meet.

9.3.1 Appropriateness of the Current Activity Mix

There is evidence from a number of sources that the current mix of activities is approximately right. First, there was overwhelming evidence from the case studies that LIAISE is meeting the needs of clients. This was not a mere passive assent; both clients and families made it clear that LIAISE had provided them with information and help that was of great value and that no other program had been able to provide. Second, the things that clients said were of most importance included more than independent living skills training. In particular they emphasised

the importance of having informed support available as needed and the increased confidence that getting the opportunity to try things out afforded.

The statistical information indicates that the relative proportion of time spent on direct and indirect client service and on travel was remarkably constant over time (see Figure 19). Although this may reflect some inappropriate (but consistent) activities, the regularity of the proportions suggests that this mix may actually reflect what this population group needs in terms of service provision. Certainly the literature suggests that an approach that involves much more than one-to-one skills training is required, and that often this will involve networking with a wide variety of groups on behalf of the client. It seems probable that a high proportion of indirect client-related time is an inevitable aspect of meeting the needs of this client group.

The proportion of time spent on non-client related activities is of more concern. Nonetheless a breakdown of the various coded activities indicates that much of the time was probably appropriately spent. The absolute time devoted to marketing and to networking activities to educate the community and other agencies about ABI was small relative to the need in this area. However it occupied a substantial proportion of staff time because of the low staffing levels. Training and supervision occupy a substantial proportion of time but the community support workers employed in a diverse and difficult job at very low salaries (Class 1 salary is $536.50/40 hr week). Salary cost savings gained from employing staff at this level must be supported by adequate amounts of training and supervision. Indeed there is some evidence from the case studies that supervision should be increased to prevent time being spent pursuing inappropriate goals (this should probably be in the form of 'case-review' that can be classified as indirect client related time).

9.3.2 The Need for Change in the Activity Mix

Although there is evidence that much of the current activity mix is appropriate there is also evidence of specific areas where changes may be needed or where efficiency could be improved. Some of the changes are changes at the margins which may lead to small but useful improvements in overall efficiency. Large improvements, particularly as regards non-client time, may require significant structural reorganisation.

The case studies, the interviews with staff and the statistical data also indicate that time savings could be made in recording both client file notes and work statistics, and probably in the time spent in meetings.

Changes of this sort are changes at the margins but cumulatively may be able to release 5-10% of staff time to be spent on direct client services. This is nowhere near enough to make the service financially viable under the proposed unit costing arrangements. As indicated on page 38, current performance, even with the most favourable assumptions, would only attract an annual budget of $26,430 per site. Attaining financial viability will require changes to be considered in one or all of the following areas:

- staffing arrangements;
- organisational structure;
- funding arrangements.

The evaluators believe that from top to bottom the items on this list increase in importance.

9.4 Staffing Arrangements

Two issues need to be considered in looking at options for staffing arrangements. These are the use of part-time staff and the relative proportions of coordinators and community support workers.

Having a completely part-time work force involves inefficiencies: returns on training and supervision would both be greater with full-time staff. On the other hand the current part-time staff bring with them expertise and the benefits of training from their other jobs and having more part-time staff increases the range of skills available to the program. Although the current arrangement - all part-time staff - is working well, if the size of the program at any site was increased, it may be appropriate to move towards employing one full-time staff member. It is recognised that it may not be possible to find suitably experienced staff willing to work in a low salaried position full-time.

Although it may be that clinically qualified staff could be expected to work more efficiently and with less supervision and training than non-clinically qualified staff, this comes at a greater cost. The evaluation has shown that suitably experienced non-clinically qualified staff can work very effectively with people with ABI providing that adequate supervision and support is available. Furthermore some clients would prefer to relate to a program that is not dominated by therapists.

LIAISE has made extensive use of students placed with the program and of some volunteers drawn from the ranks of clients. There may be opportunities to increase the use of volunteers provided that a mechanism is established for funding their supervision and training.

9.5 Organisational Structure

LIAISE staff and the auspicing agencies have long recognised the difficulties with having one small program located at three sites. As previously noted the program has moved away from being a single program located at three sties to three semi-autonomous programs. This shift was largely driven by the need to reduce time consuming and expensive administrative and management activities necessary to support the original model. Additionally this shift was more easily and appropriately done after the core work of establishing the program had been completed.

The current arrangements have reserved a few core activities to be done in co-operation across the three sites such as staff training, program promotion and funding negotiations with Human Services, but these are minimal and generally activities that are more efficiently done at this level.

There are basically two possible directions for the future of the organisational structure of LIAISE. The first is to continue with the current model, the second would be to move to a centralised model with the program operating out of a single location. There are costs and benefits to each of these approaches.

Advantages of the current model include:

- more localised so more familiar with local services (knowledge of local services often important for finding services for which local clients are eligible);
- spread across a number of agencies gives those agencies an increased interest and capacity in working with people with ABI;
- the program at each site can be tailored to local conditions and different client demographics;
- being closer to clients reduces travel time and costs.

Disadvantages of the Current Model:

- duplication of management (three managers & three coordinators);
- reduced flexibility in employing staff;
- potentially high supervision costs because all staff are part-time;
- time (although greatly reduced from previous levels) spent coordinating some activities across three sites.

Advantages of a Single-Site Model:

- no duplication of management or time spent coordinating across three sites;
- increased flexibility in employing staff;
- greater potential for staff to support each other;
- small efficiency gains in administrative activities.

Disadvantages of a Single-Site Model:

- more travel;
- potentially more difficult to be familiar with local areas and service providers;
- only one auspice organisation would gain the benefits of having an ABI program;
- the change to a single site would incur significant costs including potential loss of skilled staff.

9.6 Funding Arrangements

The evaluators strongly believe that **it is not possible to run a program that effectively meets the needs of clients with ABI using unit based funding focused primarily on direct client contact activities**. The literature and this evaluation clearly indicates that other aspects of service delivery are critical, and these need to be recognised and reimbursed appropriately. The following activities must be specifically recognised and funded if the funding arrangements are to be a reasonable match with clients' needs:

- one to one client assessment, independent living skills training, counselling, personal support;
- counselling and information provision to carers, family and friends;
- supervision that involves case review of individual clients (unless the option of employing all clinically qualified staff is chosen);
- travel to a client's home, workplace, school, recreational facilities etc;
- making arrangements with other service providers or organisations on behalf of individual clients;
- purchasing or making devices required by individual clients to enhance their function;
- recording notes that are not day to day case notes such as assessments and reviews;
- correspondence on behalf of individual clients;
- phone calls to monitor clients;
- helping to establish and support groups of clients/families working either on specific activities such as communication skills, or as self-help groups;
- community development and community education for the community generally and service providers specifically.

Although some allowances are made for the provision of some of these activities under current arrangements, failure to recognise and fund all of these activities adequately can only work to inhibit the development and operation of a program flexible enough to meet the wide range of clients' needs.

In addition, funding mechanisms should provide positive incentives for the development of group programs and the use of students and volunteers where this is appropriate. As previously noted, group work fulfils several very useful purposes: more time can be spent with clients using fewer resources; it helps to alleviate one of the most common problems for people with ABI - social isolation; individuals learn that they are not alone, many of their problems are common problems and solutions can be shared; and assists clients to develop communication and social skills.

It is our view that a capitation payment system can more appropriately meet these requirements than a unit costing system (see 9.6.2 below).

9.6.1 Adequate Funding

Another important issue is the availability of resources - particularly funding - to support the LIAISE program. It is our view that the current funding of LIAISE is inadequate. The program has been sustainable to date largely for two reasons. The first has been the willingness of staff to accept relatively low wages for difficult and complex work. The second has been the willingness of all three LIAISE auspicing agencies to subsidise the program both in terms of direct funding, in the use of organisational vehicles and the uncosted time and energy that the agencies managers have contributed to the program. While it is appropriate for program budgets to be lean, it is important that they are not so lean that they threaten both the viability and the quality of the program itself.

Some small savings at the margins of the program such as reduced duplication in file notes and a less onerous data collection system would help make better use of current funding levels. Additionally, the possibility of LIAISE working with fee paying clients needs to be put back on the agenda. The economies of scale of working with more clients, and the ability to generate its own income may have the potential to make LIAISE more economically viable.

9.6.2 Proposed funding formula

If a capitation payment system were adopted efficiencies achieved through more extensive use of groups and other mechanisms may offset the need for increases in the total budget. The cost per client of the program to date has been approximately $3,250. An effective funding formula, involving equivalent per capita costs, could be $20,000 per year per site for infrastructure support and $2,250 per client. Such a system would need to be supported by appropriate service monitoring and performance indicators and would need to allow some adjustment for out-liers (eg people who stayed with the program for more than a year).

9.7 Statistical Reporting

It is imperative that a statistical reporting system be developed that facilitates accurate recording of all fundable time. The evaluators are concerned that the emphasis on detail in the current data collection system has produced both confusion and a considerable loss of accuracy, and is time consuming. This may have led to substantial underestimates of the time staff spent on client related activities. Certainly the total amount of time accounted for by all of the statistical data falls far short of the total amount of time worked by LIAISE staff. It is recommended that a substantially simplified statistical system be developed for routine use and that the detailed instruments currently in use be reserved for periodic audits for quality assurance purposes or in order to answer specific questions that may arise.

9.8 Target Population

The eligibility requirements for LIAISE (see section 2.2) were appropriate for a program focused primarily on independent living skills training. A broadening of the eligibility criteria should now be considered given that (a) LIAISE has moved quite appropriately beyond this narrow focus in terms of the services it is providing, and (b) that these eligibility criteria exclude many people with more severe ABI who do not generally have access to other specialist local ABI services and could benefit from LIAISE. Moving away from a primary emphasis on independent living skills training work to legitimise the work LIAISE is already doing (particularly case management and emotional support to clients). Having a broader client base (for instance including people with more severe disabilities or children) would make better use of the specialised ABI skills of the LIAISE staff. Broadening the client base would increase the demand for participation in the LIAISE program, and meeting this increased need would have staffing implications in terms of quantity of clients, overall volume of work, and qualifications/experience. Consequently, if eligibility requirements were broadened this would necessitate some overall funding increases.

9.9 Viability of Replicating This LIAISE Elsewhere

Given LIAISE's overall success in meeting the needs of its clients in the Southern Metropolitan Region, it appears desirable and possible to replicate the model in other regions. There are several important issues that need to be considered in replicating LIAISE elsewhere.

First, the problems with the current funding arrangements (both in terms of appropriate unit costing rates/mix and overall level of funding) need to be resolved. In particular the potential success of other LIAISE programs would be enhanced by funding arrangements that support a broad based and flexible range of program activities. Additionally, extra allowances need to be made in funding new programs to cover infrastructure and start-up costs (such as marketing the program).

Second, one of the reasons for LIAISE's success has been the commitment of its auspicing organisations and staff to the program itself and its overall philosophy of shaping the service to meet the needs of clients. The initial ability of the program to recruit a few people with experience in working with people with ABI was also important. These are essential pre-conditions for success and need to be present in any new locations.

Finally, the organisational structure of the program should not be copied dogmatically. There is a core structure that should be retained. This includes:

- the principles of the program (see section 2.6);
- skilled staff working as a team;
- a flexible and wide range of services offered tailored to the needs of people with ABI;
- a time limit of 18 months per client, with the capacity to re-enter the program as necessary;
- location within an existing community-based organisation.

In other locations careful thought should be given to whether a semi-autonomous set of multiple sites should be established or a single central site. Making this decision should include consideration of the characteristics of the region, the availability of auspicing agencies, the availability of qualified and experienced staff and the needs of people with ABI in the region.

CHAPTER 10

Recommendations

The following recommendations arise from the analysis and conclusions presented in the previous section. The detailed rationale for these recommendations forms part of that discussion. The following lists recommendations with regard to the continuation and replication of the program including funding as well as some recommendations for program organisation and improvement.

10.1 Continuation of the Program

10.1.1 There is a need for the program in all of the locations it is currently operating and the program should be continued at the same or an increased level of funding.

10.1.2 The program is not viable if it is to be purely an independent living skills training program. Continuation will require formal recognition of the broader scope that the program has adopted.

10.2 The Scope of the Program

10.2.1 Case management, emotional support and group programs should all be formally recognised and accepted as important functions of the program that should be specifically funded and probably expanded.

10.2.2 The program should actively seek to define, and where appropriate meet the needs of people of non-English speaking background. It should be noted that this would increase the overall cost of the program.

10.2.3 The program should actively seek to define, and where appropriate meet the needs of people with more severe disabilities. These people frequently require the same sorts of socialisation, emotional support and case management services as those who are less disabled. It should be noted that this would increase the overall cost of the program.

10.2.4 The program should expand its role in community education either on its own or by strengthening its relationships with Headway Victoria. Appropriate funding mechanisms to support these activities should be identified.

10.3 Funding Mechanisms

10.3.1 If the program is to be funded under a unit costing system great care must be taken to ensure that the funding system supports flexible involvement in the full range of activities necessary to meet a client's needs. (This includes a range of activities which are currently considered to be 'indirect' client services. Furthermore, mechanisms need to be developed to encourage group activities, community education and the use of students and volunteers.)

10.3.2 Consideration should be given to alternative funding mechanisms. In particular a system where the client is the unit rather than hours (ie a capitation payment system) should be considered. Combinations of capitation and unit payment systems are possible and should be investigated. (For example an infrastructure grant of $20,00 per site and a capped payment of $2250 per client plus $800 per year for clients staying with the program for more than one year would approximately maintain the current funding levels.)

10.3.3 A much less detailed statistical recording system that allows staff to accurately account for all of their time should be developed and implemented. This system must reflect the funding definitions agreed with the Department of Health and Community Services.

10.4 Organisational Structure and Staffing

10.4.1 LIAISE should probably be incorporated as one of the activities of the auspicing agencies rather than as a free-standing program. Mechanisms for sharing information, tools and experience between the ABI programs at each site should be maintained.

10.4.2 Having said the above, ABI is a sufficiently specialised area that it warrants a team of specialised staff and a particular commitment of resources: the program should not disappear into the routine activities of the auspicing agency.

10.4.3 Standards should be developed to protect the funding allocated to ABI. These standards should address at a minimum, required staff expertise and the range of services to be provided as well as service targets.

10.5 Improving the Program

10.5.1 Procedures by which coordinators review cases should be formalised and made uniform. This should be considered part of the client service time as it allows LIAISE to function effectively using very lowly paid staff.

10.5.2 Mechanisms to allow clients to access the program at any time during the working week and where necessary out of hours should be established (eg. for those who work).

10.5.3 A source of petty cash should be established to allow the purchase of simple items for clients. A capitation payment system would resolve this and other problems.

10.5.4 There should be a continued expansion of group activities. In particular the establishment of peer support groups and other peer support mechanisms (partnering, mentoring) should be encouraged and financially supported.

10.6 Improving Efficiency

10.6.1 The recording (client notes) and statistical systems should be streamlined. Together these activities should occupy less than 5% of total staff time.

10.6.2 Time spent in meetings other than case review should be reviewed. Some meetings fulfil particular service functions (eg community education) and should be funded appropriately

10.6.3 Further efficiencies may be able to be achieved by closer integration of the LIAISE program into the activities of the auspicing agency.

10.6.4 At best the proposed reforms may release 5-10% of staff time from non-client related activities for direct client service. These improvements should be made but cannot compensate for the need for an appropriate funding system.

10.7 Replication of the LIAISE Model at Other Sites

10.7.1 The LIAISE model is appropriate for implementation at other sites providing that auspicing agencies that are sufficiently supportive can be found. There are advantages in locating the program within Community Health centres in areas that are not well served by other agencies.

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APPENDIX A

Service Providers and Policy Makers Interviewed

Alan Blackwood
Headway Victoria
609 Bridge Road
Richmond VIC 3121

Ms Jenny Boulton
Melbourne City Mission
ABI Case Management
Plenty Road
Preston VIC 3072

Ms Barbara Buchner
Speech Therapist
Frankston Community
Rehabilitation Centre
125 Golf Links Road
Frankston VIC 3199

Ms Ruth Clark
Social Worker
Royal Talbot Campus
Austin Hospital
Heidelberg VIC 3081

Ms Cathy Clay
Frankston Community
Rehabilitation Centre
125 Golf Links Road
Frankston VIC 3199

Mr Alan Dayman
Project Officer Disability Services
Dept Human Services
122 Thomas Street
Dandenong VIC 3175

Ms Kath Gibson
Melbourne City Mission
ABI Case Management
Plenty Road
Preston VIC 3072

Ms Stephanie Gottleib
ARBIAS
226 Gertrude Street
Fitzroy VIC 3065

Ms Cath Harmer
Headway
609 Bridge Road
Richmond VIC 3121

Ms Diana McLauchlan
Positive Approaches to Challenging Situations
Parkville Centre
35 Poplar Road,
Parkville VIC 3052

Ms Maree Mealor
Commonwealth Rehab Service
3 Stawell Street
Cranbourne VIC 3977

Ms Jenny Morris
Linkages Case Management
Davey Street
Civic Centre
Frankston VIC 3199

Ms Kate Rickard
Hampton Rehabilitation Hospital
15 Beach Road
Hampton VIC 3188

Mr Peter Ryan
CAS & Community Friend
35 Lynch Street
Hawthorne VIC 3122

Ms Fiona Sheehan
Caulfield General Medical Centre
260-294 Kooyong Road
Caulfield VIC 3162

Ms Sue Summers
Cranbourne & District Community
Health Care Centre
3 Mundaring Drive
Cranbourne VIC 3977

Ms Ann Truscott
Caulfield General Medical Centre
260-294 Kooyong Road
Caulfield VIC 3162

Mr Michael White
Leisure Link-up
7a Bragge Street
Frankston VIC 3199

APPENDIX B

Summary of Case Study Interviews with Clients and Families/Carers

This appendix provides a summary of the analysis of the interviews with clients and their families/carers done for the 12 case studies. Please note that causes of ABI and referral sources have been excluded to help protect client confidentiality.

WHAT DID LIAISE DO?

Client A

ADLS: house cleaning, cooking, transport training, washing machine

Information: explained abi & memory issues/performance with abi/family expectations, info on services, pamphlets (Headway kit?)

Emotional support: yes informal counselling, with referral for counselling

Access to services: Counselling (stress management, original suicide attempt, family issues-has son, relationship with ex, etc), tinnitus, assist with disability pension, memory group

Client B

Major need: speech therapy. When support worker was qualified speech therapist he got considerable assistance with speech. Also provided some help with comprehension and memory. Needed this from LIAISE because not available elsewhere - Rosebud Day Hospital therapist left and not replaced. Client also very active in church (bible studies & fellowship), golf, stroke support group

Client C

ADLS: household tasks (the lot, cooking, cleaning), main problems motivation and organisation...could do tasks but not remember to do them...tried various things ended up with board to write things on.

Information: Headway kit

Emotional support: a huge issue, provided some strategies for dealing with emotional stuff (depression, never going to be who she once was): also referral for counselling, and problems with daughter who was also referred elsewhere for counselling...there were serious family problems before/without her ABI.

Access to other services: Communication skills group (conversation/communication were identified as one of her key needs), also When support worker was there got some speech therapy also, interested in recreation options but never followed any through - other priorities...worker noted that some of these might have worked out if the LIAISE worker had pushed harder...but not always clear when to push/not to.

Literacy also an issue, and while the support worker made suggestions to XXXX, XXXX has taken no step to date to resolve this issue - perhaps she has other priorities.

Husband stated that when in rehab hosp she started using diary, LIAISE initially said to keep doing it, but she has gotten out of the habit. LIAISE got her to write things down. He thought shopping work LIAISE did with her was inappropriate...he never took too much notice of LIAISE, but believes that they did help her with her conversational skills....LIAISE 'woke her up a bit, got her to take more responsibility'

...worker would come around an monitor how she was going with the weekly planner of activities...tried lots of different prompts/strategies to find ones that worked.

Client D

ADLS: schedule/weekly planner on fridge, cooking, recipes, shopping, tricks like keeping diary by telephone (suggested to him to CRS), folders for bills, cleaning - what product to use when

Information: from Headway and Headway Kit

Emotional support: hrs & hrs of counselling/emot support, esp regarding relationships with girlfriends & ex wife, 'Sometimes just sit and talk with me when I'm down. Human contact.'

Access to services: LIAISE Cranbourne, gardening program-doesn't like gardening but good for social, and 'I don't have to cover up my ABI when I'm there, but I do elsewhere' (person running program has ABI); LIAISE Cranbourne cooking program, Mornington relaxation program; Counselling at PCHS-Mornington, ABI

communications group PCHC & Cranbourne CHS, TAC rehab support group; stroke support group; Peninsula Employment Access Program (PEAP) link by CRS.

Client E

ADLS: not much, generally pretty capable with daily stuff, exception was some budgeting, memory and organising the next week-using the diary for both past and future events, started out with severe memory problems, but much better now. Also moved house recently and helped with the move...didn't do a lot but provided important support.

Information: not really

Emotional support: problems coming to terms with ABI, telling everyone her life story, poker machines, 'She's a link to the outside world.' , took her out to lunch a few times...lonely.

Access to other services: Neighbourhood house, social & craft group for 6 months-stopped when started working...Worker organised Work Focus (gets people with disabilities back to work), also CRS working with her, has a work placement now.

When LIAISE started working with her it was not at all clear just what they could/should do for her.

Setting tasks for her weekly, ie bake cake, catch train - often things she hadn't done since abi, helped to get her going and build confidence

Client F

'NOTHING' his involvement was not voluntary.

ADLS: attempted cooking & budgeting but got nowhere

Information and support: no

Access to other services: tried to link him into local programs, but he had little/no interest, helped him find new accommodation when first arrangement didn't work out, looked into possible TAFE courses for him - not interested, provided some support to paid carer who was working with client for a short time to support move to independent accom (funded by RDSI via Melb City Mission)

Client G

ADLS: cooking (helps to develop skills/pride/confidence/satisfaction), public transport

Information: esp to go to school, have knowledge family didn't-re abi?

Emotional support: some...seems more than she was admitting esp via cooking training spent lots of time talking, issues about moving out with boyfriend etc, didn't have much direction, now she is up and running, finding her own solutions/opportunities. In second interview stated 'She'll be my counsellor as well as my helper. She's great. She sits there and she listens.' More confident because of Worker, can cry tell her what's upsetting me....

Access to other services: introduced to someone else young with aneurism, goes to support group (not organised by LIAISE), volunteer work..not yet but working on it

Wants to live independently/with friend not ready yet but is getting there, wants LIAISE around for support when she does make the move.

Really needed LIAISE 3-4 years earlier when it all began...mother 'would have had less tears and less gallivanting. They would have guided us.'

Client H

ADLS: Budgeting mostly, organisation/time mngmt to get household tasks done - ie shopping, feed dogs, personal hygiene.

Information: Lots of paper given on support groups (but not used), also prior to LIAISE info from Headway on ABI - very useful.

Emotional support: social & emotional support, talking with him, informal counselling, encouraging him, reference point, help him feel he is on track...also sees psychotherapist - some marijuana use issues

Access to other services: assessments (psych & neuropsych), support groups (only went once)

Client I

ADLS: Travail training, shopping, use diary (improved use), also tried cooking but he hates cooking, didn't really know what he wanted to do...so imp just to provide some direction/ideas

Information: None noted, except Carer's Kit

Emotional support: Mostly to mother

Access to other services: Memory course at Cranb - but started work so didn't finish, Latrobe Personnel - after 4 mnths found him work gardening (lawns etc), Kookaburras, Respite/Recreation via HACC, CRS

Client J

ADLS: does need assistance with things like showering, but has lot of dignity and is sorting these out on his own ---NOTE - HE DOES NOT SPEAK, USES SIGN. LIAISE, worked teaching him sign language,...Their success wife- 'Secret of success was that LIAISE came to house' result was very flexible, work on it depending how he was on the day...very unlike hospital rehab in that LIAISE 1-1 work...

Information: Worker/Coordinator have been willing and available to explain things no matter how insignificant

Emotional support: Wife said: 'Never came across 2 such caring people'...most important issue see below, for both of them- he gets very depressed

Access to other services: Assessment: ARBIAS, eye test at Guidedogs, referral to MCM, and recently organised speech pathologist that comes to house

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Client K

ADLS: ironing, cleaning, budgeting-esp planning, cooking, shopping - mostly he can manage, motivation is the main issue---also although he can do many of these things, practicing them gives worker a chance to assess wide range of skills, abilities and to provide support/reinforcement where helpful

Information: about head injury, Headway Kit, about services, not aware of what's out there and LIAISE has helped a lot with this

Access to other services: help with disability support pension, drug & alcohol counselling at CHC, in process of organising ARBIAS Assess & CRS assess...assessments esp important to client for seeing what problems he has related to ABI, help mother to get carers pension, kookaburras he goes sometimes...he also sees psychiatrist (pre-existing), and advice/referral for anger mngmt....initially assessment suggested mostly ADLS, only later did the depth of issues/problems surface. Anger mangmnt referral but hasn't gone yet

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Client L

ADLS: Cooking mainly, using it as vehicle for skills development, memory, organisation etc, building confidence/self esteem, also a good time for talking about things with worker, also goes to the Brashes' Soundhouse (at the Arts Centre in Melbourne) to work on keyboard skills

Information: Explained abi, no one had ever done this before to him in a way that he could understand

Emotional support: most emot benefit via explaining abi to him, and the general work to increase his confidence, etc

Access to other services: Sound house, neuropsych assess & psych assess, referral to dietitian, worked extensively with school to get them to recognise that he has an ABI, no ID and this has changed the way they work with him which has helped him considerably - learning better because more appropriate learning strategies being used, also with school he has an aid (pd for by father from compensation from accident payout) for 8 hrs of school-LIAISE got aid to back-off so he could develop some friendships etc, helped to organise some work part-time at Safeway, help organise DSPension

MOST IMPORTANT THINGS THAT LIAISE DID FOR YOU?

'Giving me the confidence to do things. More confident in everyday life...I didn't want to speak to people before...If it wasn't for her I wouldn't be wanting to go back to cricket.'

client 'making me talk, prompting me, being firm & made me do exercises. Wife: 'made him use his language skills. A third person he would do it for, not me & I get sick of nagging him and so does he. Another person for XXX to meet.'

emotional support made a difference, especially at the beginning couldn't even hold a conversation. 'LIAISE made a difference in the way I think about people and look at life. Made me aware of just how many people, ordinary people like me, have head injuries.'

'LIAISE has helped XXX (husband) and kids to understand ABI and what I need'.

worker: without LIAISE client would have gotten more depressed, as it was she felt more useful,

stopped with LIAISE a while ago - only misses the conversational side of it.

'her physically being here - other things were a bonus' Also, 'had someone younger than this community support worker, but more comfortable with this one. She's older and could talk more about personal things with less apprehensions' ie sexual issues.

social contact, support.

nothing, didn't want anything from LIAISE

'helping to get myself ready for the future'. and mother: 'A friend. I've been in a boat, rowing with no oars. They are an advocate, I don't feel all alone....Someone to lean on.' Didn't get the support and caring that they needed from elsewhere.

caring: example: worker suggested Neighbourhood House as place to go for activities, worker was there waiting for client when she arrived--thought that was great

‘most important, is [community support worker’s] understanding, I’m able to talk to her and get my feelings out.’...’I would have been lost without that shoulder to cry on.’

very supportive ‘They are there’

for him: Driving and travel training, including memory issues - used shopping to develop some of this...

most imp=emotional support: early on they were both at the ‘Why me?’ stage and support was essential...this really helped client be where he is today...

most imp ‘Feeling that there is help & being able to talk about things/hope for the future/ confidence about future / a friend’ his mother said this....also ‘backup from LIAISE workers give me confidence & I feel better about myself...if things get tough we can work it out and get LIAISE involved if necessary....also Marriage broke down and LIAISE helped with this - ref for counselling...help with son helped take some of the load off her, a lot to cope with, also son’s grandfather dying...felt she was getting by mainly because LIAISE was there to help..

most imp -someone explained ABI to him in a way he could understand..lots of emotional support has flowed from this, and has helped him to realise that he can learn at school

UNMET NEEDS

‘no, I’ve got everything’...but worker said: need for privacy, cramped living in crowded house with Aunt, brother etc...

speech therapy now that [community support worker who was qualified speech therapist] gone for LIAISE. ‘We were lucky to have Worker who was a qualified speech pathologist.’ (Wife)

wanted more memory training sessions - but little or nothing seems to be available

no unmet needs

no unmet ends.

nothing, didn’t want anything from LIAISE

no unmet needs

(flatmate) yes - if they don’t see him at intervals of less than fortnightly it just doesn’t work. Needs more regular/frequent monitoring and support - but LIAISE not

available out of hours and client works full time. LIAISE not available out of hours so has really not had enough contact recently to be helpful...first time involved with LIAISE they were more willing/able to work out of hours and that was more helpful.

none noted, except worker felt that recreation a major issue but client/family did not so not much done around this

they said no unmet needs, worker noted that he still doesn't sign outside of house, and they have tried to work on writing via a Canon Communicator/computers

getting what he wants from LIAISE, worker notes that soc support is needed and hard to organise, but that he is spending more time with friends

LIAISE PROGRAM PLANS FOR CLIENTS

developed & he has copy: 'only a few things on it, I didn't really want much.'

yes one was done: wife: 'OK, but bureaucratic bullshit. I understand why it was done, but XXX couldn't comprehend it, so of little value to him.' She has seen it but not sure if they have a copy. Case worker: 'good for clarifying goals. He could comprehend it and helped to clarify LIAISE role. Emphasised that our work was with XXX, not on XXX. XXX had to do the work.' Worker: he should have copy as he signed it...

got copy, but didn't help because she kept forgetting to use it...in reference to organisational plan, not plan for LIAISE's work with her. Worker thought that this organisational plan did work well. Also client noted that what got her to do things was her husband's prompting. (please note above comments under what LIAISE did for her in which she sites monitoring of weekly plan by worker as useful/helpful....)

client can't remember, worker said 'No, not really. Hard to get him going on more than just a daily routine' via weekly planner...

worker: plan but more tokenistic, not that useful but it did have value in setting tasks for her weekly, ie bake cake, catch train - often things she hadn't done since abi, helped to get her going and build confidence

yes, but he never got copy

initially no, later yes, did it with client, plan was useful in that it helped to show that worker cared, but didn't use it in a practical sense, just put it away.

yes - in the form of weekly organiser/planner...but he looses the plot after a while without constant follow-up///follow-up also helps with motivation....Also in the form of a budget which as been very helpful.

yes, but client/family didn't get copy and said they didn't know if one had been done. Worker didn't see the point of going over it with XXXX, but important for worker in creating focus and sequence for activities...way to tie individual activities together, and to track what is being done and needs to be done....Value: Hard to come up with things to write about. Often things you do without being conscious. Writing it down gives it more direction and a summary of what you have/have not done.

yes..fairly structured plan, needs fairly clear

yes, weekly tasks plan done, large plan does not include emotional issues which don't really fit into plans..Yes done, but client not given copy???

he said no, worker said yes

DECISION MAKING PROCESSES

'it's me who decides' she might encourage him, for instance to try memory classes and if didn't like only go once...Worker: most of the time he knows what he wants. Sometimes she needs to explain something a lot...

'the things we worked on were my decision.' Wife: worker would tell wife what they had been doing, wife happy with this.

felt like she had all the control, ie 'going to the self-help group was [worker's] suggestion, but I thought is was a great idea and found it very helpful'

'she makes me aware of it. But I make the decisions. Let's me know what she thinks, if its a good idea.' worker: yes, needed to do some leading, such as pointing out some key ADLS that were weren't getting done.

she can't really remember/answer...worker noted that client often sought advice on major decisions such as buying a new unit, worker would defer comment and ask if she had spoken with her daughter who has regular contact with her

his involvement in program was not voluntary...

she makes the decisions, mother is not involved and that's fine with mother (lives with parents and sister), she felt like she was in control all the time.

relies on LIAISE for information, but decisions are his...supportive but don't nag...suggestions about ways of doing things but always up to him.

worker would suggest things, but decisions were his...Mother-'never pushed him into things'...Worker noted that the three of them mom, client and worker would sit down and decide things, much of it depended on mother's suggestions

decisions made by client and his wife: she said 'We feel we have total control over decisions being made.'

worker is the ABI expert, but decisions are made by client...support worker provides info&suggestions but up to client if he uses any of this...ie 'Do you want to try this....' and if he doesn't want to, he doesn't

he's going to Holmesglen next year, special program for people with disabilities. He resisted, but she convinced him over time, his concern was that it is a special program for people with disabilities and he's tired of being made different....but she convinced him that it wasn't like that...He says he has control over decisions, but that she points him in particular directions.

CONTACT

about 1x week, worker also rings 1xweek/fortnight. Its enough: 'Gives him a push to do things. Not always motivated to do things.'

never tried to ring her

support worker 1x week, less when she left

towards end of support worker's time at LIAISE she was only visiting 1xmonth, but things fell into a heap, afterwards seen more often until got back on track. early on 1xweek, then less and then back to 1xweek

ringing never a problem, the couple of occasions she rang worker there or returned call fairly promptly.

1-2xweek in beginning, then 1xweek, then 1xforthnight. 'It was all she could do, more would not have helped'.

rang worker a few times, usually for crisis, ie water heater, or when he didn't understand something...if not there rang back promptly

began 1xweek, gradually less.

rang a couple of times but always good at ringing back if not there

1-2xweek when organising accommodation, most work with parents/state trustees...not clear that support worker meant contact with him or just working on issues related to him 1-2xweek.

2xweek initially, now 1xweek, enough

ringing-easy to reach, rings back promptly

last visit was March/April (interview in early July!!). Not enough contact...better if 1xweek but that hasn't happened since support worker left...Lots done over telephone while he is at work (according to worker), worker felt this was adequate!!!

most contact by telephone lately, mostly worker contact him - 1xweek, but when he rings there is good prompt response if not there

visit 1xweek mostly, towards end less...Family and worker noted that client would have benefited from more but difficult given that they live in the country and travel time for worker made more frequent contact difficult.

2xweek visits by previous worker, now 1xweek new worker, but speech pathologist also visits regularly so OK.

ringing worker has been ok, able to reach her

early 1-2xweek, now maybe 1-2fortnight. Mother: this is enough to keep on top of things. Girlfriend- less wouldn't be good.

client hasn't rung, but mother has, always rings back fairly quickly if not in, and if it is something urgent she is sure that she could get help quickly. 'If we really need her we can find her. She makes herself available' - mother

1xweek until recently---its enough according to client

only tried to ring 1x that he can remember and he was able to reach her

WHAT HAS LIAISE DONE FOR FAMILY/CARERS?

worker knows family, speaks mostly with Aunty who seems to appreciate the help, Aunty thinks he's less capable than he is.

aunty feels she has things under control and doesn't need personal support

wife: used support worker as a sounding board, but not a major support (got this from friends), Just someone else to talk to who knew the problems, was interested and cared, and could understand wife's difficulties

husb stated it took some pressure off of him...improved conversational skills has helped their relationship (LIAISE assisted in improving her conversation skills)...but he can't say if LIAISE made any difference to keeping the relationship together.

worker spent time talking to husb and daughters about things...work with family always done on basis of client's needs. There were other family issues/problems and referrals were made for counselling for these.

none have met worker-lives alone but 'I think it helped with relationships. She worked with me when I was pretty gloomy. My son comes over and I think he enjoys it.'

client doesn't know, hard to answer...worker: probably not a lot, client keeps life compartmentalised ie kept worker and daughter apart.

he didn't really have an answer, worker said 'yes, it made a difference to them. Helped them to see what was happening with XXX, and trying to get him involved in other things, like TAFE courses. Good talking to his father who got more involved with XXX's life afterwards.' She contacted them.

both mother and client really glad that having LIAISE meant that mom could sept back a bit and they both really needed the space...LIAISE helped make the family situation sustainable. 'Gave her [mother] a break, a rest.'

there is a flatmate - she insisted that either he get help or she would move out...LIAISE involvement allows her to do less mothering...Worker stated that by having LIAISE there it meant that later when flatmate did decide to leave that Client not left stranded/alone - although in fact LIAISE withdrew very shortly after flatmate left!!!

provided emotional support to mother, gave her break via some respite/recreation activity including just taking client shopping, travel training etc...suggested counselling but mother didn't take it up, tried to address issues via attending carers group at Cranb CHC (a course that went for 6 weeks), Respite & counselling referral. Also helped mother with info, someone who understood...'Knowing that someone was around who you could turn to. There is no one else out there.'...

support to wife, very important and very well done

yes mother relies on LIAISE a lot, informal counselling & support, and referral for counselling from the CHC which she has used.

mother 'Originally, I thought 'At last, things are going to get fixed', now I realise that it is not so simple, but things are being done' 'It's made a difference just in coping and not getting too frustrated.'

lives with father (mother killed in the car accident where he got his abi) His comment 'Father doesn't have to cook on Wednesdays', worker noted that both father & client now have better idea of ABI, and helped dad with burden....has talked about accident a bit, informal counselling

WOULD YOU RECOMMEND LIAISE?

‘definitely. Helps you get back into society.’

‘yes I would, it would be good for others to get the help he has, and has suggested it to others.’ (wife of client)

‘yes I have [recommended it to others], even when people have said they don’t know what they want, many people feel left out and forgotten. So LIAISE can be very important for this. People loose self-esteem, slip through the system, and feel neglected and know they need some help but don’t know what.’

‘yes, because I’ve seen it work for other people (even if it didn’t work for me) and stories within the support group. Didn’t work that well for me because my memory is so bad.’

‘I think it is highly recommendable...I never have to feel ashamed to ask her anything...I function better with human contact. I mistrust most people.’ ‘If all of them are of the standard of XXXX, I hope that it will be continued, for other people to benefit.’

went for a long time without LIAISE, the difference as learning strategies to help remember things, and using a diary properly

‘definitely’ ‘It’s a lifeline, and feel that if I needed help I could ring her and if possible she would be here.’

‘not really, they didn’t do anything’

yes ‘fantastic...they’re fabulous friends. They really help you.’ Mother: yes, ‘it’s a friend. Someone to take them beyond rehab. Parents/families not informed enough. I have done the rounds of many services and got nothing.’

yes ‘they’ve been a life-saver. Taught me how to live again and rebuild my life...without it I would have had a nervous breakdown from being unhappy and having to do everything myself.’

yes ‘get direction...help you cope...dirty house, empty bank account, nothing in the fridge’, flatmate: ‘most of what they’ve done are practical solutions’

flatmate: ‘Ian you have learnt that you can do something [tools for planning] the beginnings. And this was not there before LIAISE’

‘got what he needed’ Mother- ‘Got more out of LIAISE than got anywhere else’ Yes ‘Things they have done for him have been good’

client ‘yes’ , wife ‘definitely’ ‘because they know so much about ABI. They are marvellous’

definitely, absolutely. Mother wished they had had something like this years ago. His problems started before haemorrhage, because the aneurism itself created some problems pressing on the brain since childhood. There was no followup at Children's hosp in 1984, only surgical checkups...brushed-off regarding behavioural problems...Just to be told he had an ABI and what that meant was a great relief, it helped many things to make sense....Client thinks they are very helpful and will talk through dramas and get to the bottom of things...reassuring.

'yes, if they can't help you they know who can. They seem to know what's going on. By ourself you don't know where to go.' said by girlfriend

yes 'Because they understand and teach you an easier way to do things.'

SUGGESTIONS FOR IMPROVING LIAISE

'no. Everything has been to my benefit. She's been good.'

need more time, resources and people...main reason LIAISE stopped was community support left and no other LIAISE speech pathologists. Needs to be more diverse. Many people with abi are sitting at home and need more than LIAISE can offer: respite, social company, support for carers....(wife)

'lot of unmet needs in the area. Unless people have money there is very little after you are discharged. Without support and help things go down hill, and it's depressing for everyone involved.'

'LIAISE is not equipped to get people back into the community: there are not the dollars, not specialisation, time, facilities, spiritual need (not in religious sense, but in self) because ABI can be so devastating. Who you are, where you are going the essence of the person. Have to dig for information, found out about Brain Foundation herself, and had never heard about LIAISE until referred there.'

'people at LIAISE are worth more than they get paid.'

more direct help with memory

'I cant think of anything. I got what I asked for, such as cooking & cleaning skills. She can't be here day in and day out. I would like her to be here everyday, but I can't expect that.'

'no, I've had nothing else and this is much better than that.' mother: 'more people should know about LIAISE, CRS, Rehab Centres etc'

'need more follow-through, not just a plan on paper' stated flatmate - don't see him often enough because don't work out of hours, so not that useful to him.

visits not very long, 2xweek visits and everything would have developed quicker, longer visits=more respite but realise that it is not a respite program

maybe more hrs for workers, other services don't know enough about LIAISE.

no, not really...'They are helping with whatever we need', but - mother 'Wish it could go longer than 18 months, wish we could go in and out of it as needed. The head injury will not go away, we may always need a little bit of help.'

OTHER

'worker very nice and caring, spends a fair amount of time with me. I never would have gone to groups otherwise.'

client lack motivation on daily tasks, but is generally keen to learn and try things, husb gets in the way, hard to tell how much of motivation issue is ABI and how much is just who the client is...

'I am my own worse enemy. I don't believe in myself. People can only do so much for you and I need to stand on my own two feet.'

note that this is the one where worker relied a lot on coordinator to identify unproductive activities of worker and suggest other courses of action.

it was especially hard at first, in a daze & don't know what to do....'If community support workers hadn't been there, I wouldn't be here.' When referred to Melb City Mission ABI service client was violent and MCM go psych counselling at Bouverie.