Evaluation of the Integrated Services Project for Clients with Challenging Behaviour: Mid -Term Report

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Abbreviations

ABI	Acquired Brain Injury
ABS	Australian Bureau of Statistics
CALD	Culturally and Linguistically Diverse
DADHC	Department of Ageing, Disability and Home Care NSW
DCS	Department of Corrective Services NSW
DJJ	Department of Juvenile Justice NSW
DoH	Department of Housing NSW
DSARC	Disability Studies and Research Centre (formerly Disability Studies and Research Institute – DSaRI)
ED	Emergency Department

Executive Summary

The Integrated Services Project for Clients with Challenging Behaviour (ISP) aims to decrease the adverse impact of challenging behaviour on clients, the community, and the service system. The Project does this by developing intervention and support plans that better respond to the individual needs of clients with challenging behaviour, as well as improving their service access, housing, health and social conditions. The ISP is delivered through the NSW Department of Ageing, Disability and Home Care in cooperation with the NSW Department of Health and Housing NSW.

The average recurrent net cost per quarter of the ongoing Project (expenditure less revenue and set-up costs) is approximately $1,663,808. The cost of direct services to clients (average per quarter $1,332,438) is 80 per cent of total Project expenditure. As of March 2008, the ISP had provided services to 38 clients; the equivalent annualised net recurrent unit cost per client is $194,000 during the ISP. The average cost per client prior to entry to the ISP was $376,000, as reported by the nominating agencies

Analysis of client characteristics shows that ISP clients are a diverse and complex group of people. The gender distribution of ISP clients is 55 per cent men and 45 per cent women. This is almost representative of the community and over-representative of women in client groups of the main nominating agencies, particularly Disability Services and mental health services. Nearly eight per cent of clients identify as being Indigenous Australians and 32 per cent as being from a culturally and linguistically diverse background. Most (86.8 per cent) ISP clients have a mental health diagnosis 18m Tw2.c 0 Tw 3.Tc 0 Tw h0 Trall al hack(-12(na)4(

centred case plans are developed for each client and support plans and guidelines are supplied to residential staff.

Apart from accommodation, the Project provides clinical support to service providers that are involved with the clients nominated for ISP. To build the capacity of the system to better manage such people, the ISP aims to keep agencies that nominated the client involved while the client is in the ISP. The support team also addresses the challenge of involving new service providers if none were previously involved with the client, if the nominator is not the appropriate agency to do this (for example, a criminal justice agency), or if a client moves to an area outside of the jurisdiction of the existing service provider.

2.3 Roles and Responsibilities of ISP Partners

The ISP is led by DADHC in conjunction with NSW Health and Housing NSW (Appendix B). They are each represented on the ISP's Project Management Committee. In addition to these key agencies, the Departments of Corrective Services, Juvenile Justice, Community Services, the Office of the Public Guardian, NSW Police, and the Council for Intellectual Disability are represented on the Interagency Reference Group, which provides a consultative body that informs ISP activities. The ISP is also informed by a Clinical Reference Group, which consists of independent consultants, and senior clinical staff from NSW Health and DADHC. It provides expertise to ISP staff about both the management of current clients and the capacity of the wider service system to support people with specific illnesses and disorders that contribute to the challenging behaviours encountered in the community. An Evaluation Reference Group has also been formed to guide the current evaluation process and includes representatives from a number of the above named organisations and

down and evaluation because these are not comparable to the operational analysis of other health, community and criminal justice service systems. The analysis does not include:

- Costs incurred by other agencies, not allocated to the ISP budget;
- Indirect costs to clients or other stakeholders; and
- Non-financial costs, such as time, stress, and impact on other service providers.

Expenditure is presented as the dollar value at the time of measurement because the analysis is a relative comparison of simultaneous service provision over a short evaluation period. In the final analysis we will assume all other costs for ISP clients do not rise relative to other clients, except the financial cost of ISP (e.g. housing, criminal justice, drug and alcohol management and mental health services).

The average recurrent net cost per quarter of the ongoing project (expenditure less revenue and set-up costs)tia1MC 21(ex)-14(pe)-4(nc(ev)-14(enuuev)-1y)37(heur)-5(1)(1,663,808(.)Tj ( )T
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3.2 Effectiveness

In the final cost effectiveness analysis, ongoing cost per client will be analysed against outcome data derived from the data collection used in the management of the project. This will also be supplemented with qualitative data from interviews. Comparative data on population norms and people with challenging behaviour population norms will be analysed by the evaluators. Table 3.3 summarises the expected outcomes and preliminary findings.

Table 3.3: Expected Outcome Data for Final Cost Effectiveness Analysis

Outcome	Comparison groups	Explanation	Preliminary data
Challenging behaviour	Before and after, ISP clients who leave	Percentage change in Overt Behaviour Scale and incident rate compared to before ISP	Reduced challenging behaviour. Supported by evidence of decrease in contact with the justice system
Stable housing	Before and after, ISP clients who leave	Change in length of tenancy (months) compared to before ISP	Increased stability in ISP and successful exits into stable housing
Reduced hospitalisation	Before and after, ISP clients who leave	Financial savings from relative change in hospitalisation (occasions and days) compared to before ISP	Reduced emergency and inpatient admissions
Imprisonment	Before and after, ISP clients who leave	Change in imprisonment (occasions and months) compared to before ISP	Decreased imprisonment (Corrective Services) for most clients
Personal Well-being Index (PWI)	Before and after, ISP clients who leave, Population norm, HASI evaluation results		

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In summary, the evidence shows an ongoing cost per client of approximately $200,000 per year. The average cost per client prior to entry into ISP was $376,000, as reported by the nominating agencies. For most clients the preliminary evidence shows returns in terms of:

- Reduced levels and severity of challenging behaviour; supported by evidence of a decrease in contact with criminal justice services, particularly Corrective Services;
- Increased housing stability while they are in the ISP and some successful exits into stable housing;
- Reduced use of emergency services and reduced length of stay in inpatient hospital services;
- Decreased imprisonment in Corrective Services;
- Personal wellbeing approaching population norms in satisfaction with future security and feeling part of the community and better than the HASI baseline on this latter measure;
- Similar distribution on self-assessed health to population norm;
- Increased independence in domestic and community skills;
- Increased participation in education and labour market; and
- Increased social contact with family and friends.

It is not yet clear if these improvements will be sustained. Evidence from the longitudinal evaluation will be applied to this question. The remainder of the report describes the analysis to arrive at this preliminary evidence.

Age and gender

The gender representation in ISP is 55 per cent men (21) and 45 per cent women (17). This is almost representative of the community and over-representative of women in client groups of the main nominating agencies, particularly Corrective Services and mental health services.

The average age of clients is 36 years (median 34 years) (Figure 4.1). The predominance of younger clients is consistent with the

Cultural background

The cultural background of ISP clients is diverse compared to the general population (Table 4.1). Nearly eight per cent of clients identify as being Indigenous Australian and 32 per cent as being from a culturally and linguistically diverse background. Clients with an Indigenous background might be over-represented in ISP compared to the general population, although the number of people is too small to draw conclusions. These characteristics may have implications for recruitment and service planning within ISP. These implications will be explored in future analysis.

Table 4.1: Cultural Background of ISP Clients, March 2008 (n=38)

Ethnicity	Number of clients	Per cent
Indigenous Australian	3	7.9
CALD	12	31.6
Other	23	60.5
Total	38	100.0

4.2 Presenting problems and disorders on entry to the ISP

Clients differ in the presenting problems that resulted in their nomination to the Project and the impact of these problems on core activity restrictions. The presenting problems are categorised into the following groups:

- Mental illness or disorder (including personality disorder);
- Intellectual disability;
- Drug and alcohol disorder;
- Acquired brain injury; and
- Physical disability.

Clients in the ISP have a complex mix of presenting problems on entering the Project. Most ISP clients have a mix of mental health, intellectual disability and other disabilities and disorders. Of the 38 ISP clients, people had an average of three to four presenting problems each (Figure 4.2); only eight people had less than three presenting problems.

Figure 4.3: Presenting Problems on Entry to

Table 4.3: Core Activity Restriction by Presenting Problem, March 2008 (n=38)

Restriction	Mental disorder	Physical disability	Intellectual disability	Drug and alcohol disorder	Acquired brain injury	Other
Mild	3	3	6	3	2	0
Moderate	5	7	11	4	3	4
Severe	22	3	8	11	8	0
Profound	3	1	1	4	2	1
Total	33	14	26	22	15	5
Average degree of restriction[1]	2.8	2.1	2.2	2.7	2.7	2.4

Note: 1. The average degree of restriction is a weighted average per person with that reason. Mild=1, Moderate=2, Severe=3, Profound=4.

Figure 4.5: Core Activity Restriction by Presenting Problem, March 2008 (n=38)

Legal capacity

The extent to which ISP services can minimise the impact of a person's challenging behaviour may depend on the client's legal status. Only 11 of the 38 (29 per cent) ISP clients did not have an appointed guardian before they entered ISP; eight of these people gained a guardian whilst in ISP. As of March 2008, only two clients (5 per cent) did not have a guardian. It will be worthwhile in future reports to explore the extent to which legal guardianship encouraged people to engage with ISP services.

5 Client Outcomes

This section reports on initial outcomes which have been experienced by clients since participating in the ISP. Although client outcomes will be systematically investigated in future reports, current analysis has uncovered promising early trends. It is important to note that ISP clients are a small, diverse group of people, making generalisations difficult; refer to Appendix A for a full discussion of the methodology and its limitations.

- Clients have experienced a decrease in the level and severity of challenging behaviour during their involvement with ISP.
- The number of presentations to emergency departments has decreased
- The number of days admitted to hospital has decreased
- The number of days of imprisonment has decreased
- Ratings of self-assessed personal well being are below the Australian norm and are comparable to baseline scores from a similar program.
- 76.7 per cent of ISP clients rate their health as excellent, good or very good
- 83 per cent believe their health is much better or somewhat better than one year ago.
- The majority of ISP clients do not require support more than half the time with self care skills; most, however, need help more than half the time with completing domestic and community skills.
- 60.5 per cent of ISP clients have reconnected with family and friends or made new friends since being involved in ISP.
- 52.6 per cent of ISP clients have become involved in social activities such as church, sporting activities, art classes since being an ISP client.

5.1 Challenging Behaviours

A primary aim of ISP is to reduce clients' challenging behaviours. Overt Behaviour Scale (OBS) was used to measure changes in challenging behaviour (Kelly et al, 2006). This validated instrument quantifies the frequency and severity of a range of challenging behaviours, including: verbal aggression; physical aggression against objects; physical aggression against self; physical aggression against other people; inappropriate sexual behaviour; perseveration or repetitive behaviour; absconding; inappropriate social behaviour; and lack of initiation. (Appendix A describes the scoring method)

OBS data were available for 24 clients still in ISP and five people who have left the Project, allowing for comparisons of challenging behaviours before, during and after ISP. Analysis showed a decrease in both the level and severity of challenging behaviours (Table 5.1). The level of challenging behaviour for people in ISP decreased by 4.8 per cent and, for people who have left ISP, by 36.3 per cent. The severity of challenging behaviours decreased by 6.44 per cent for people still in ISP and by 42.36 per cent for people who successfully exited ISP.

Table 5.1: Measure of Challenging Behaviours Level and Severity (Overt Behaviour Scale – OBS) during ISP, March 2008 (n=24)

	OBS level			OBS severity		
	Pre ISP	During ISP	Per cent change	Pre ISP	During ISP	Per cent change
Average	12.5	11.9	-4.8	29	27.1	-6.4
Minimum	3	3	0	9	6	-33.3
Maximum	23	21	-8.7	55	50	-9.1
Standard deviation	5.31	4.97	-6.4	12.89	12.76	-1.0

Despite the small sample size, these numbers indicate that clients have experienced a decrease in challenging behaviours whilst they have been in the ISP. Changes in challenging behaviour will be measured and analysed more fully in future reports, including further comparisons of OBS scores, types of challenging behaviours and analysis of incident reports.

5.2 Personal Wellbeing

One of the client outcome measures for the evaluation is assessed personal wellbeing. This was measured using the Personal Wellbeing Index (PWI), an internationally validated instrument which measures subjective wellbeing (IWG, 2006).[3] The results are standardised to a scale of 1-100 and compared to the Australian population (Cummins, 2005) and a similar population group, the Mental Health Housing and Accommodation Support Initiative (HASI) clients (Muir et al, 2007: 20).[4]

ISP clients are most satisfied with their safety and feeling part of the community (Table 5.2; Figure 5.1). Although ISP clients are less satisfied with all aspects of their wellbeing than the general population, the scores are similar to the baseline scores for the HASI clients. Compared to HASI clients, they are more satisfied with their health and with feeling a part of the community. These are positive results that are consistent with the goals of ISP. We would expect the scores to increase in some dimensions during the evaluation

[3] These data were collected in March 2008 and therefore do not represent a baseline measurement

[4] Researcher interview scores for three clients were slightly different to the scores collected by ISP staff, illustrating the difficulty of taking self-assessment measurements with this client group.

5.3 Health

ISP staff asked clients how they rate their health, using the standard ABS self-assessed health question (ABS, 2006). Most ISP clients (76.7 per cent) rate their health as excellent, very good or good (Figure 5.2). Although slightly less positive than the mean scores for the Australian population, the distribution of scores is similar. Possible explanations for the

Figure 5.4: Social Networks during ISP, March 2008 (n=35)

While over half of these 35 clients see their parents, siblings, and friends more than once a year, just over one third of clients (34-37 per cent) still have no contact at all with these social networks (no information was available for the one client who died and another two who are still in prison) (Figure 5.4). In addition to increased contact with family, 20 of 38 (52.6 per cent) people have become involved in social activities such as church, sporting activities, art classes since being an ISP client. Some clients are also engaging in economic and educational activities since being in ISP. Six clients (three of whom have exited ISP) are now working at an average of 12.7 hours per week (Table 5.7). All jobs are casual or temporary positions. Three clients are doing some type of volunteer work and another five clients are participating in some sort of educational activity for an average of five hours per week.

Table 5.7: Education and Work Participation during ISP, March 2008 (n=38)

	Number of clients	Per cent[1]	Average hours per week
Working	6	15.8	12.7
Volunteering	3	7.9	4.3
Education	5	13.2	5
No participation	25	65.8	-
N/A or unknown	3	7.9	-

Note: 1. Per cent of all clients (38). Clients might participate in more than one activity so total is greater than 100.

6 Service Use

Table 6.1: Health Services Used in the Community 12 Months before entry and 12 Months after entry into ISP (annualised), March 2008 (n=18)

	Mean pre ISP	SD	Mean ISP	SD	Difference bet. means
Psychologist	12.4	28.3	23.8	50.6	11.4
Psychiatrist	12.1				

services only once a month on average. The change in service use reflects a change in the capacity of the service system to deal with her behaviour through better coordination of alternatives to emergency services.

6.3 Criminal Justice Services

ISP aims to decrease client contact with the criminal justice system. Half of ISP clients (19/38) spent some time in prison in the 12 months before entering the Project (average time in prison was 41.1 months, median 10 months). This section provides analysis of the use of criminal justice services for the 18 clients for whom data were available. As in the previous section, the data have been annualised for the periods before and during ISP.

Contact with criminal justice services reduced greatly for most people once they entered ISP (Table 6.3). The biggest reduction was days in prison, which decreased by an average of 87

7 Conclusion

7.1 Implications of the Preliminary Findings

The ISP serves some of the most complex clients in the service system in Sydney and, for this reason, generalisation across the whole of the ISP client group run the risk of masking significant differences between individuals. The information provided by staff on ISP clients shows that most clients involved in ISP are experiencing improvements in most measures of intended outcomes. Clients involved in this project for over 12 months seem to be improving in many areas of challenging behaviour, which provides benefits to the community and to the service system. These clients have shown a large decrease in their use of hospital and criminal justice services. They have also increased the appropriate use and decreased the inappropriate use of primary and allied health care. The findings will be further explored in future reports when the OBS is compared with incident reports to build a full picture of changes in challenging behaviour

The recurrent cost of ISP is approximately $200,000 per person per year. The average cost per client prior to entry to the ISP was $376,000, as reported by the nominating agencies. The Project has contact with people nominated, entering and exiting the ISP. These multiple points of contact have a broader impact on assisting the nominating and exit agencies to support these clients and others with challenging behaviours.

7.2 Evaluation Progress

The evaluation of the ISP is so far on schedule. Later reports will include further data about

- Nominations to the Project to examine what agencies referred to the project and the criteria for acceptance;
- Service use across the client group;
- Challenging behaviour measures using OBS and incident reports;
- Description of ISP services and accommodation;
- Post-ISP packages; and
- Process and satisfaction with the ISP from workers and key stakeholders

Appendix A: Evaluation Methodology

This preliminary report provides an analysis of the outcome data for 38 clients in ISP. ISP collected the data from April to June 2008. Five sources of data were analysed for this report: ISP client information sheet; client file data; researcher interviews with three case study clients; financial records; and discussions with the ISP management and Evaluation Reference Group. These methods are explained below. All information was given to the researchers in a de-identified format. The interviews were re-identified after they were matched to the secondary data. The full methodology is described in the ISP Evaluation Plan (Fisher & McDermott, 2008).

ISP Client Information Sheet

The researchers developed an ISP client information sheet to collect a set of standard qualitative and quantitative questions for all clients. ISP staff who work with the clients collected the information. The client information sheet includes questions on: demographics; reasons for entry to ISP; mental health and disability; and number of health care and criminal justice services used before, during and, if applicable, after ISP. Other questions addressed living skills, social and community participation, relationships and economic participation. The data will be updated for longitudinal analysis in the future evaluation reports.

Some questions on wellbeing and community participation were drawn from validated instruments so that comparison can be made to other research, such as the Cummins (2005), Kelly et al (2006), Stancliffe et al (2007) and the Robertson et al (2004) study of support for people with challenging behaviour. In addition, qualitative questions were included in the client information sheet to allow ISP staff to provide descriptive accounts of clients' progression through the Project.

Staff collected information on client's challenging behaviours using the Overt Behaviour Scale (OBS). This measure will be used to measure changes in challenging behaviour over time. The OBS measures behaviours in the following categories:

- Verbal aggression;
- Physical aggression against objects;
- Physical aggression against self;
- Physical aggression against other people;
- Inappropriate sexual behaviour;
- Perseveration or repetitive behaviour;
- Absconding;
- Inappropriate social behaviour; and
- Lack of initiation.

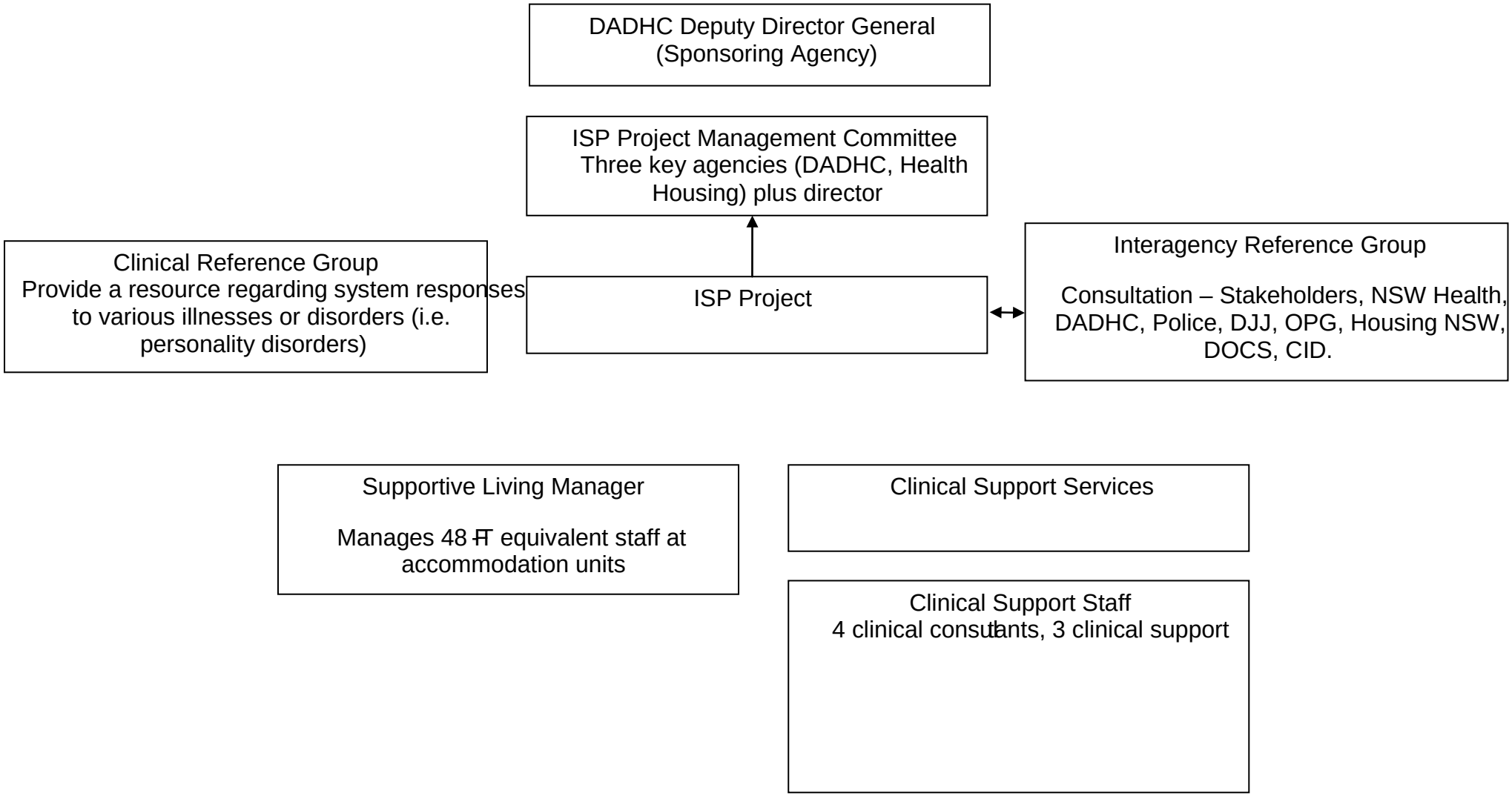
the evaluation. It is possible that later costs will include wind-down costs, which are not typical of an ongoing project.

Discussions with ISP Management and Evaluation Reference Group

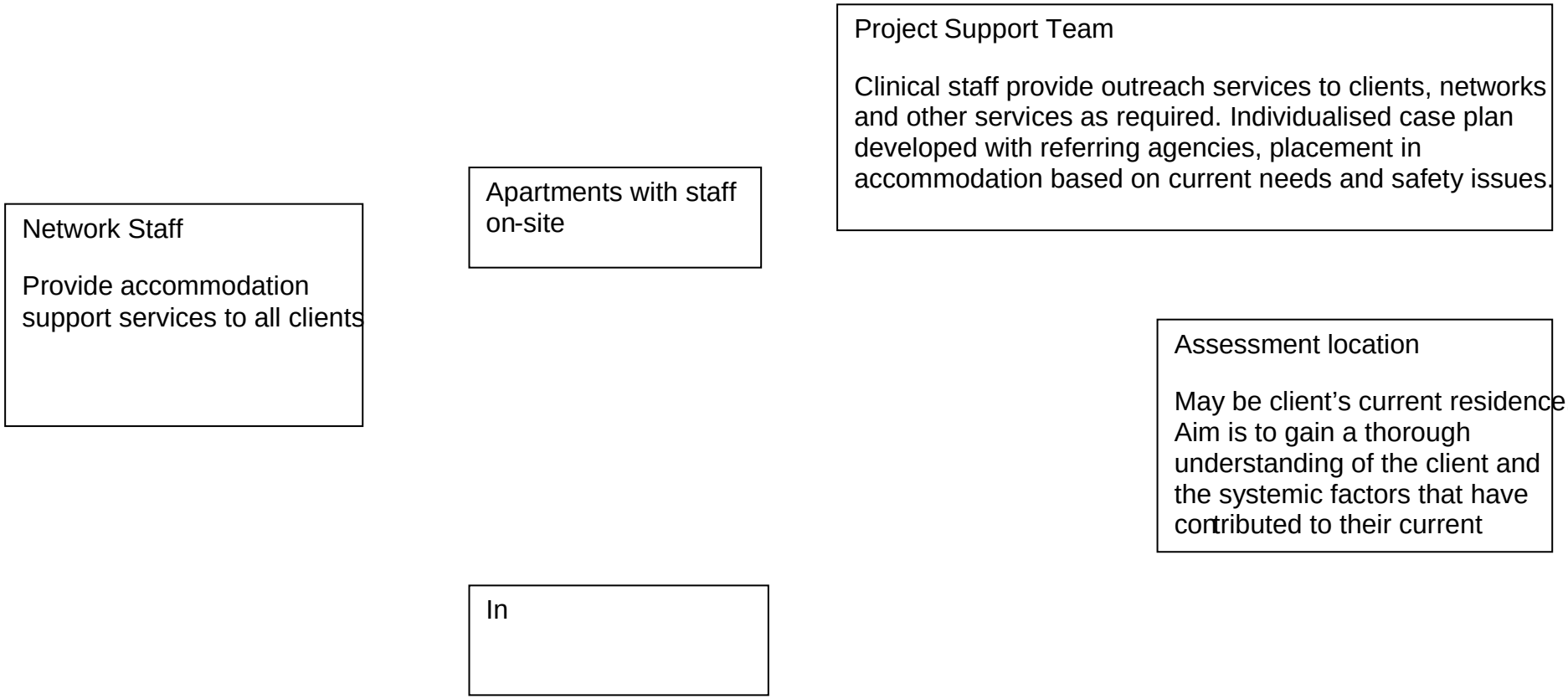
The researchers communicated with ISP management and Evaluation Reference Group members from February to June 2008 about data collection, transfer and quality questions. These meetings also informed the researchers about the establishment, management and operation of ISP. The data were used to inform the preliminary analysis in this report. Comprehensive interviews with ISP management and staff will be conducted in September 2008 for analysis in the next report.

Appendix B: ISP Responsibility Matrix

(See section: Roles and Responsibilities of ISP Partners)



Appendix C: Model of ISP Accommodation and Support Services



Appendix D: Cost Data

Table D. 1: ISP Expenditure and Revenue per Quarter April 2005 to March 2008 to Calculate Recurrent Net Cost Requirement

Significant changes	Funding allocated	Assessment unit closed	Readjustment post-assessment unit	Ongoing project	Ongoing ISP average per quarter (average

Appendix E Case Study Summaries

This section of the report focuses on three of the four clients who will participate in the longitudinal element of the ISP evaluation. The section provides a short summary of the history of these three clients from their files and provides brief analysis of the baseline interviews conducted in April and May 2008. The interviews will be compared with the longitudinal aspects of the evaluation to take place in September 2008 and again in September 2009. The names used in this report are pseudonyms.

Anne

Anne is a 29 year old Anglo-Australian woman. She was born in NSW and moved with her family to Adelaide shortly thereafter. She is the third of nine children who were brought up in an emotionally dysfunctional home – she describes being physically, sexually and emotionally abused by her father. Anne was taken into foster care at the age of nine in Adelaide and maintains regular contact with this family via phone.

When she was 18, Anne was admitted to psychiatric hospital in South Australia for treatment of hypomania and severe depression, which led to debilitating anorexia nervosa, self-harm and suicidal ideation. She lived at the hospital for six years. In 2003, Anne was released from the hospital and lived independently in the community for two years with community-mental health support. In October 2004 at age 25, Anne returned to NSW and was admitted to Nepean Hospital for treatment of an ectopic pregnancy. Following that incident, she was admitted to five psychiatric hospitals in NSW interspersed by short stays in the community.

More recently, Anne was accommodated at Mulawa Prison where she was serving a four year prison sentence, with a non tthie1u[(t)-6k of aonthet wnf- Tcg04 T2oe-2(t)--b 0.004 Tw(Td [)-

John

John is a 34 year-old male with schizophrenia, a mild intellectual disability and an acquired brain injury (ABI). He is described by ISP staff as likable and easy-going character that has had it rough. John has an extensive forensic history as indicated by his 113 convictions mainly for theft, property damage and drug possession, as of July 2005. He has a history of polysubstance abuse and has been a large user of heroin, marijuana, and amphetamines. When not in prison, John experienced periods of homelessness, and has had little coordinated support from services. John's extreme drug seeking and self-harming behaviours are the primary reasons for previous breakdowns in his accommodation and support.

It is reported that John's biological parents both had psychiatric disorders; it is believed that John was neglected and became a ward of the state at 14 months of age. At the age of 13, John was forced to leave his foster home due to allegations that he had made inappropriate sexual advances to a younger child in the home. He has since had limited involvement with his foster family except to contact them from time to time to request money. John's brother, who was a significant source of social support, died of a drug overdose in 2006.

John transitioned into the ISP in December 2007 from gaol

Rebecca has made contact with her brother and sister since being involved in ISP. She had not talked to them since she was ten years old but now they talk on the phone frequently. Rebecca now also sees her children every week. She participates in the community through gardening, window shopping, and shopping at second hand shops. She tries to save her money for her children. She is currently volunteering at the Salvation Army but she would eventually like to work for them. She would like to study but she is scared people would think her to be dumb because she does not know how to read and write.

She sometimes feels like she and the other ISP clients are spoilt with all of the services they receive from the project and feels that other residents can sometimes take advantage of the generosity of the staff. At the end of the interview, she talked about how she was ill and cold when she was homeless and, “that’s why I really appreciate being warm and in a place like this”.