THE UNIVERSITY OF NEW SOUTH WALES

EVALUATION OF THE INTEGRATED SERVICES PROJECT FOR CLIENTS WITH CHALLENGING BEHAVIOUR

EVALUATION PLAN

FOR INTEGRATED SERVICES PROJECT NSW

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Abbreviations

DADHC	Department of Ageing, Disability and Home Care
DCS	Department of Corrective Services
DJJ	Department of Juvenile Justice
DoH	Department of Housing
HASI	Mental Health Housing and Accommodation Support Initiative NSW
ISP	Integrated Services Project for Clients with Challenging Behaviour
SPRC	Social Policy Research Centre
TCO	The Cabinet Office
UNSW	University of New South Wales

1 Introduction

This document outlines the methodology that will be used to conduct an evaluation of the Integrated Services Project for Clients with Challenging Behaviour (ISP). This research will address the questions that DADHC set forth in the request for tender. This evaluation will investigate whether the model of integrated service delivery has:

- Increased the capacity of local services to manage clients with challenging behaviour;
- Improved the level of well being of clients by decreasing challenging behaviour;
- Improved service access, service coordination and service durability for ISP clients;
- Decreased the impact of challenging behaviour on individual clients, the service system and wider support system; and
- Contributed to the evidence base of supporting people with challenging behaviour.

To meet these aims, this evaluation will examine ISP governance, the capacity of the wider service system to support these clients as well as the outcomes for individual ISP clients, including family members, carers and other members of the community.

This work plan describes the methodology that will be used to address the evaluation questions. Specifically, the plan details:

- ISP background information;
- Overview of roles and responsibilities;
- Conceptual approach to the evaluation and key questions;
- Data framework and collection;
- Cost effectiveness and full evaluation analysis; and
- Research management, including reporting and timeframes.

2 ISP Background, Objectives and Service Delivery

2.1 Background

Challenging behaviour is defined as any behaviour that 'is a barrier to a person participating in, and contributing to their community; undermines, directly and indirectly, a person's rights, dignity or quality of life, and poses a risk to health and safety of a person and those with whom they live and work' (McVilly, 2002: 7). While the term is problematic and used interchangeably with other terms (including high and complex needs and very high support needs), it is accepted discourse within the disability sector and for individuals with acquired brain injury (Carter, 2006; Kelly, 2006).

International research suggests that approximately five to 15 percent of adults with intellectual disability demonstrate severely challenging behaviour, such as aggression and self-injury (Emerson et al., 2001). Within Australia, it is estimated that one-third of people with dementia experience moderate to severe behavioural and psychiatric symptoms (Brodaty et al., 2001). These studies exclude others who may also exhibit challenging behaviour, such as people with mental illness or acquired brain injury.

In simple terms, the problems associated with challenging behaviour translate to cost. This cost manifests at a personal level, a social level and an economic level. At a personal level, people with challenging behaviour are often excluded from the communities in which they reside. Challenging behaviour may hinder the development of relationships (Anderson et al., 1992), diminish opportunities to engage with community-based activities (Hill and Bruininks, 1984), and prevent access to health and social services (Jacobsen et al., 1984). As Carter (2006) states, 'At best… access to community living and its facilities is restricted and limited; at worst, such access is denied. Exclusion from its facilities and rejection by the community of the particular person must surely represent the most destructive and damaging affront to the human dignity of that person.' (30-31). At a social level, family members and service providers who support people with challenging behaviour also experience dire consequences. With limited resources, they often feel unsupported, stressed and experience burn out (Quine and Pahl, 1985, 1991; Qureshi, 1992; Saxby and Morgan, 1993; Sloper et al., 1991; Stores et al., 1998). Related to this is the economic consequence associated with challenging behaviour. The management of these behaviour is resource and time intensive, often beyond the capacity of one source of support (Carter, 2006; Lowe and Felce, 1995a, 1995b).

Collectively, these costs demonstrate the need to identify strategies to manage challenging behaviour effectively. Since deinstitutionalisation, service providers have used a variety of strategies to assist people with challenging behaviour. Some of these, like behavioural interventions, are based on empirical evidence (Ball and Bush, 2000; Carr et al., 1999; Didden et al., 1997; Emerson, 2001; Koegel et al., 1996; Lennox et al., 1988; Luiselli and Cameron, 1998; Scotti et al., 1991). Others however, like antipsychotic medication, are not (Baumeister et al., 1998; Brylewski and Duggan, 1999).

Recent evidence suggests that a piecemeal, transitory approach to accommodating people with challenging behaviour is largely futile. Instead, it requires an integrated, community-based approach that involves various stakeholders. A review of relevant literature suggests that the behavioural and/or social outcomes for people with challenging behaviour are improved by:

- Personal care (Geary, 2007);
- Support contributed by various disciplines (Geary, 2007);

- A tiered support system comprised of mental health professionals as well as peer support and social support (Geary, 2007; K. R. McVilly, 2004);
- Coordinated support (Geary, 2007);
- An established link between home and identity (Ramcharan et al., 2007);
- Small, non-clustered, community-based accommodation (Ramcharan et al., 2007; Robertson et al., 2004); and
- Settings that encourage residents to associate with heterogeneous groups of people (Ramcharan et al., 2007).

Some of these elements are reflected in current state government policy and programs (Disability Services Queensland, 2007; Meehan et al., 2004; NSW Council for Intellectual Disability, 2007; NSW DADHC, 2007; NSW Health, 2006a, 2006b).

The Integrated Services Project for Clients with Challenging Behaviour arose out of the work of an interdepartmental committee called the Challenging Behaviour Taskforce, which was led by NSW Health. The Taskforce conducted a review of the literature and developed an integrated services model. A joint funding submission, led by NSW Health, was approved by Treasury and resulted in Treasury allocating funding in early 2005 with the project accepting its first clients in September that year.

2.2 Objectives of ISP

ISP supports people who have multiple needs that are not being met under existing service arrangements, are in insecure accommodation and pose a threat to themselves or others. The project aims to:

- Develop better intervention and support plans which reflect the individual needs of clients with challenging behaviour;
- Improve service access, coordination and durability of engagement with services for client with challenging behaviour by specifying roles and responsibilities of service providers;
- Decrease the adverse impact of challenging behaviour on clients, others and the service system; and
- Improve housing, health, social connections and safety issues for people through increased coordination of case management, multi-disciplinary assessment and clinical interventions.

In the long term, this project aims to foster:

- Improved life outcomes for clients with challenging behaviour;
- Reduce the cost to services and the wider community; and
- Contribute to the evidence base surrounding supporting people with challenging behaviour.

2.3 Framework for Service Delivery

To be eligible for the Integrated Services Project for clients with challenging behaviour, people must be 18 years or older, exhibit self-harming behaviour or behaviour that precludes their involvement with other services, and have one or more disability or diagnosis, or there must exist a dispute over the client's diagnosis. In addition, they must require a high level of

coordinated multiple agency response, live in insecure accommodation and have been denied access to essential services due to their behaviour. The final requirement is that all other options for support have been exhausted.

Potential clients are nominated quarterly by one of seven NSW Government human services departments. Following the approval of a nomination by the interdepartmental Project Management Committee, people are assessed by the ISP's multidisciplinary support team, which provides assessment, develops case plans and provides support to residential staff. The support team provides person-centred case management, supports existing service providers and ensures that the client's needs are comprehensively addressed.

In the initial stages of the model, the emphasis is on placing people into appropriate accommodation with the required level of support (Appendix A: Model of ISP Accommodation and Support Services). Depending on the client's need, the accommodation provided may be a 24-hour group home, a self-contained unit with staff on site, or other community housing with staff on call assistance.

The ISP currently maintains a total of seven accommodation settings across the greater Sydney metropolitan area with clients also residing in a property in Sydney's north managed by a non-government organisation.

Aside from accommodation, the Project provides clinical support to service providers that are involved with clients with challenging behaviour. To build the capacity of the system to better manage such people, the ISP aims to keep agencies that nominated the client involved even while the client is in the ISP. The support team also addresses the challenge of getting service providers on board if none were previously involved, if the nominator is not the appropriate agency to do this, or if a client is moved to an area outside of the jurisdiction of the existing service provider.

2.4 Roles and Responsibilities of ISP Partners

The ISP is led by DADHC (Appendix B: ISP Responsibility Matrix) in cooperation with NSW Health and Housing NSW. 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 and the Office of the Public Guardian are represented on the Interagency Reference Group, which provides a consultative body that informs ISP activities. Along with the this group, ISP is informed by a Clinical Reference Group, which consists of independent consultants, and senior clinical staff from NSW Health and DADHC, and provides expertise to ISP staff about both the management of current clients and the capacity of the wider system to handle specific illnesses and disorders that contribute to the challenging behaviour encountered in the community.

The majority of ISP staff provide on-site accommodation support to clients in 24-hour supported accommodation. The ISP also employs clinical staff who are responsible for providing clinical support to clients, accommodation staff and services in the wider community.

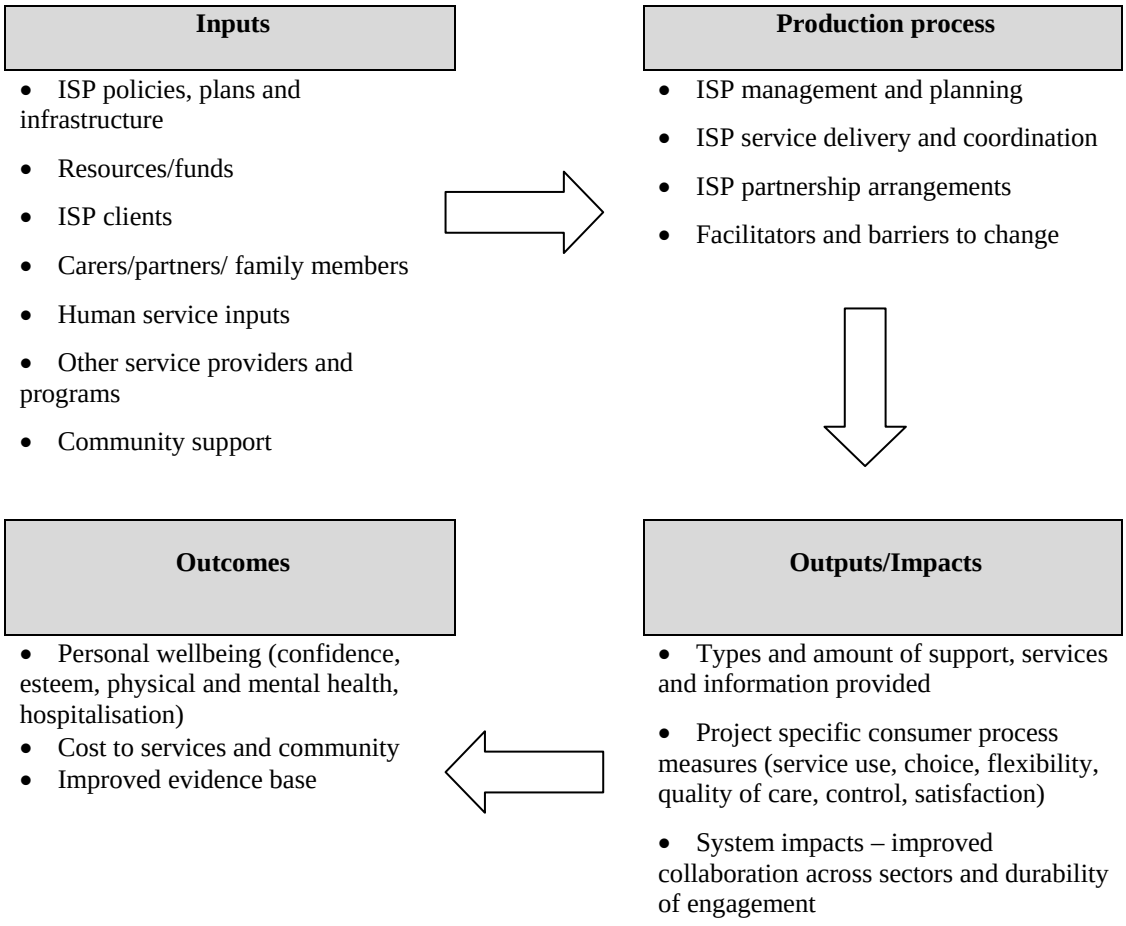
3 Framework for the Evaluation of the ISP

This evaluation sets out to explore the ISP at three levels:

- Governance: whether the implementation of the project has been consistent with the project aims. Involves exploring overarching arrangements and responsibilities within the ISP;
- Service system: cost, linkages between services, impact, processes, and staff of the project and local agencies;
- Individual clients: Outcomes experienced by clients receiving service, as well as the wider support network, including families and the wider community.

These three areas will be addressed using a systematic conceptual approach derived from program theory (Figure 3.1).

Figure 3.1: Conceptual Approach for Evaluating the ISP



This approach will clarify the relationships between project governance, service system and outputs of the project to the outcomes of individual clients. Within this framework, the methodology will utilise a mix of methods over the two year evaluation period. The methods are specifically addressed in Section 4 (Methodology and Instruments) of this document.

3.1 Key Evaluation Questions

The questions for this evaluation cover the areas of governance, service system and individual clients, as set out in the framework for analysis.

Governance: *Are appropriate and effective governance arrangements in place to support the project?*

- Are all relevant agencies represented at appropriate levels within the current governance arrangements?
- What are the critical factors and barriers to actively engaging relevant stakeholders in the project?
- Do the current arrangements support appropriate leadership, accountability and decision-making?
- How effective are the current processes (documentation) for meetings, planning, monitoring and reviewing the Project?
- Has adequate data and information been available to monitor progress and results?
- What improvements could be made to current governance arrangements?
- What, if any, elements of the Project's governance arrangements could be of value if maintained or introduced to the wider service system in the long term?
- What results are due to establishing a short term project? What performance issues are because it is only short term? What mechanisms did they try and test and can be separated from the timeframe?

Service system: *To what extent has the project identified, via its work with individual clients, areas where the existing human service system could be improved? What are the strengths and weaknesses of the services provided within the Project and to what extent are they influencing practice within those local service providers that have had a client with the ISP?*

- Is the initiative providing a cost benefit in relation to service provision for people with challenging behaviour?
- What are the strengths and weaknesses of the Project's intervention model?
- What improvements could be made to the Project's service responses for the target group?
- How can specific strengths in the intervention model be sustained in the longer term and/or influence change within the local service system?
- Based on the outcomes and experiences of the project what methods could be adopted by NSW for future management of the target group?
- Are there any specific legislative or industrial factors assisting or inhibiting provision of services across the target group?
- Identify the service system factors that facilitate and inhibit the effective and efficient implementation of the Project
- What service system priorities could be adopted to allow earlier intervention before people's circumstances reach the level of project eligibility criteria?
- To what extent did the Project garner and maintain active involvement of local services?

- Has the Project explored and acted on capacity building opportunities including sharing of project experiences and outcomes?

Individual clients: *To what extent has the project helped clients and the people they relate to, and in what areas have they been helped?*

- Is the initiative leading to better outcomes for the people receiving service through the project?
- Which clients benefited most/least? Are there any particular characteristics that appear to have contributed to better or less effective outcomes?
- What other people have directly or indirectly benefited from the management and support of the clients with challenging behaviour through the ISP?
- Did the Project adhere to its own criteria and target the client group it was tasked to target? What were the characteristics of clients not accepted and how were they different to those who were?
- Did the nomination criteria allow for those clients who were in the most need of the project to gain entry?
- Did the process of nominating clients result in any secondary gains for those clients not accepted?

These questions will be fully addressed by the methods that are outlined in the next section.

4 Methodology and Instruments

The evaluation will use both qualitative and quantitative methods. This section specifies the sources of data for the evaluation and how the data will feedback into the framework set out by DADHC.

4.1 Data Framework

Questions of governance will be addressed via financial and administrative data to be collected from DADHC, Department of Health and Department of Housing and though interviews with 15 key stakeholders. Key stakeholders include ISP staff, service providers, partner agencies (DADHC, NSW Health and Department of Housing), nominating human service departments, other NSW government agencies, NGOs, interest groups and family and carers. Other stakeholders include other disability clients and other human service providers.

Service system capacity will be evaluated through interviews with key stakeholders, financial and administrative data, observational and outcome data collected by ISP staff. Outcomes for individual clients will be analysed through client information about all clients from their service providers, longitudinal interviews with four clients, interviews with key stakeholders, outcome and observational data collected by ISP staff and financial and administrative data (Table 4.1).

Table 4.1: Data Framework

		Data applied to general framework		
Data	Source	Governance	Service system	Individual clients
Outcome data	ISP staff		x	x
Case file data	ISP staff			x
Financial and administrative data	DADHC NSW Health DoH	x	x	x
Interviews – Clients	SPRC			x
Interviews – ISP staff, service providers, partner agencies, human service departments, government agencies, NGOs, interest groups, family and carers	SPRC	x	x	x
Observation data	SPRC		x	x

4.2 Data Collection

Data collection be informed by a review of the literature that will provide detailed conceptual overview of managing challenging behaviour and evaluating related programs. In addition, it will involve a review of various programs that have been implemented in Australia and internationally to manage challenging behaviour. The review will assist in contextualising the findings from this research, which will be discussed in the interim and final reports. Also prior to data collection, data approval was sought and granted by the UNSW Human Research Ethics Committee. If further ethics approval is needed from government agencies, the ISP will arrange it.

Primary data collection methods will be applied to collect data from clients, ISP staff and other stakeholders and will take place at the beginning, middle and end of the evaluation (March 2008 and September 2008 and 2009). This will supplement data analysis of the outcomes data from ISP staff, case files and other financial and administrative data from DADHC and partner agencies (Table 4.2). The rationale for the composition and size of the samples is discussed below.

Table 4.2: Samples and Data Collection Timing

Task	Measurement	Approximate number
Clients – interviews	Mar 08, Sep 08, Sep 09	4
Other stakeholders – interviews	September 08	15
Clients – case files, outcomes and KPIs	Mar 08, Sep 08, Sep 09	40
Financial and administrative data	Mar 08, Sep 08, Sep 09	40

ISP staff and other service providers

A sample of approximately 15 stakeholders will be interviewed in September 2008. This sample includes government officials responsible for the project implementation and policy; workers responsible for service delivery; service providers in other government and non-government organisations; and informal carers and family if applicable. People who have service contact or managerial responsibility for the people taking part in the client interviews will be recruited to take part in this research via a phone call or letter inviting their participation.

Subject to their role in the Project, stakeholders will be asked to address their experience of project implementation, governance, accountability and sustainability. They will also be asked about their experience of service coordination, outcomes for clients, barriers to outcomes and any vision they may have for the future of the Project.

Interviews with clients

Four ISP clients from recent intakes will be interviewed in March 2008, September 2008 and September 2009. Sustained contact with these people will make it possible to analyse participants' experience of this project and the changes that the project facilitates in their life over time. Following four people from baseline to exit will also provide a focal point for interviewing family, carers and other formal service provider staff. To ascertain the outcomes for these clients, questions will be drawn from validated instruments and will cover such topics as social isolation, confidence, community participation, wellbeing, service use and quality of care.

Clients will initially be invited by a trusted person to take part in this research. The trusted person might be a family member, friend, carer or, in the absence of any social networks, another person with a relationship to the participant, such as a formal carer. The particular trusted person at the time of the research will depend on the personal circumstances of the participant. We will ensure that clients participating in the evaluation will have access to clear, accessible information and the voluntary consent to participate (with continuous opportunities to withdraw).

Secondary outcome data

ISP staff will be asked to collect additional administrative data about all ISP clients. The data will draw from and complement existing case management tools and include a supplementary set of validated instruments on health and wellbeing (See Appendix C: Topic Guides). Preference for both sets will be to build on existing 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) UK study of support for people with challenging behaviour.

The purpose of this dual approach is to ensure understanding of the participants' experiences in the project and facilitate comparability to similar programs. This is particularly important given the small number of participants in the pilot. Likely client outcome fields will include client outcomes (such as quality of life, physical and mental health, challenging behaviour, goal attainment, Personal Wellbeing Index, participation in domestic activities, Life Skills Inventory, social networks and isolation, community participation and employment, confidence, esteem, housing stability and project specific process measures – decision making, choice, service use, flexibility, quality of care, control, satisfaction). Other instruments will measure outcomes and process measures for government, service providers and carers to cover the fields for analysis.

In March 2008, ISP staff will be asked to provide a case study description of all ISP clients. Applying existing instruments to client files is challenging because the information contained in client files varies significantly. To overcome this, the ISP has been asked to provide a list of information that is common to most client files, which will be formed into an instrument to and applied confidentially to case files in March 2008, October 2008 and October 2009. All ISP data will be fully de-identified.

4.3 Cost Effectiveness Analysis

The cost effectiveness analysis in the evaluation will identify and quantify the expenditure and benefits associated with ISP to provide the basis for assessing its budgetary impact. The main focus is attempting to answer the following questions:

- What is the ISP expenditure in terms of establishment, trial, wind-down and recurrent costs?
- What is the average cost per person in the ISP compared to cost prior to ISP?
- What is the likely average cost person after ISP?
- What are the benefits to the person, government and community during ISP?
- What are the likely benefits to the person, government and community after ISP?

The hypothesis is that government costs while client is in ISP and after they leave ISP are less than costs before they enter ISP; and outcomes and sustainable service support for the person improve. The extent to which these questions can be answered depends on the availability and quality of expenditure and benefit data provided by ISP. A preliminary analysis will be conducted mid 2008 based on retrospective data to March 2008. A full analysis will be completed at the end of the project.

Cost framework during ISP

Financial data

We will calculate a unit cost of ISP as the financial expenditure of ISP divided by the number of clients in ISP. The economic evaluation will use a subset of the financial data – the ongoing administrative and service costs of ISP services. The costs will include the financial costs of managing ISP, the costs of support services and the costs of supported living services. If possible, the following categories of cost will be collected by ISP for transfer to the evaluation (Table 4.3):

- Establishment costs to set up the eg. establishing new procedures;
- Wind-down costs to finish the project eg. staff payouts;
- Costs specific to the trial that would not be incurred in an on-going project eg. evaluation;
- Recurrent costs divided into the minimum following categories (more detailed categories are also good if they are available):
    - Project management – costs not specific to one client eg. management committee, training;
    - Support services – costs specific to one client eg. care planning, arranging services, direct services; and
    - Supported living – housing and accommodation support costs.

Timeframe

We will analyse costs by quarter because of the changes in expenditure and number of clients in the project. We expect the analysis will concentrate on costs in the middle quarters of the project, once the project has matured and costs have stabilised, more closely reflecting recurrent costs.

We suggest that analysis include the sub-periods:

- Start to project to first client entry April – Sept 05;
- First clients to end of assessment unit period October 05 to December 06;
- Readjustment of project after closure of assessment unit – January to June 07;
- Stable project – July 07 to March 08; and
- Wind down to end of project – April 08 – December 09.

Use of these sub-periods not only provides an indication of change in project costs during project development, but also helps to isolate the extent and nature of one-off set-up, trial and wind down costs. A preliminary analysis will be included in the June 2008 report based on data about the clients who entered the project prior to 2008.

Cost analysis

Economic data on financial and other resources will be analysed in terms of cost to clients, government and service providers for the purpose of economic evaluation of efficiency and effectiveness. It will include analysis of comparative cost per client; service appropriateness per client; impact on the service system; and opportunity costs to the service system.

If possible, the costs should be provided in the following way:

- Actual cost – if this is not available, budgeted cost or description of cost;
- Who paid the cost – ISP budget, client, other service providers not as part of ISP budget or absorbed by ISP providers but not covered by budget.

Table 4.3: Cost Data per Quarter

	Establishment, trial-specific, wind-down or recurrent	Financial cost to ISP budget	Financial cost to client	Cost of other services used, not in ISP budget	Other costs not covered by ISP budget
Project management and support services					
Management team					
Clinical team					
External consultants, specialist staff					
Evaluation					
Operating (details)					
Assessment unit (to 07)					
Supported living					
Staff					
Operating (details)					

Notes: Explanations of cost data
Operating costs – details …
Support services – assessment, clinical support, training
Supported living – housing and accommodation support
Client fees – 60% of DSP

The most important columns for the quantitative cost analysis are the first two: whether the cost is recurrent and what the cost is to the ISP budget. If financial data for column 3-5 are not available, descriptive data will be included in the analysis instead.

The cost analysis will exclude the following costs:

- One-off costs of establishment, wind-down and evaluation because these are not comparable to the operational systems in other health, community and criminal justice service systems;
- Costs incurred by other agencies, not allocated to the ISP budget;
- Indirect costs to clients or other stakeholders;
- Non-financial costs, such as time, stress and impact on other service providers.

Costs are likely to be taken at the dollar value at the time of measurement because the analysis is a relative comparison of simultaneous service provision over a short evaluation period. We will assume all other costs for ISP clients and other clients are the same, except the financial cost of the ISP project (eg housing, criminal justice, drug and alcohol management and mental health services).

Client numbers

We will summarise the client flow data by showing the numbers of clients in each quarter, their status on the project and the number of days spent on the project in each quarter. The project is designed to service 30 clients. Blockage due to no housing or support available means that more clients are sometimes in ISP.

Table 4.4: Number of Clients and Months in ISP by Status, by Quarter

Status during period	Quarter 1		Quarter 2		Quarter …		total	
	clients	months	clients	months	clients	months	clients	months
Nominated for ISP								
Started ISP								
Temporarily left ISP								
Unsuccessful exit from ISP								
Ready for completion but no transition housing or support available								
Completed ISP								
Continuing in ISP								
Total								

Total costs (C) can be expressed on an average basis by dividing by the number of months (M), C/M, or by the total number of project participants (PP) over the period, C/PP, or by the total number of person-months (PM), C/PM. These are related, since PM = PP.m, where m = the average duration of project participation for all participants. Thus, C/PM = C/(PP.m) = (C/PP).(1/m). Another calculation is the average cost on leaving the project (PG), which can be calculated as the product of C/PM and m^* where m^* = the average duration of project for graduates. A qualification on this is also to distinguish duration to the point when participants are ready to leave the project but are delayed by a lack of alternative housing or support; and duration to actually leaving the project.

None of these methods is necessarily the 'right' way of expressing the costs – they give different indications depending on the particular element of interest. For all of these cost calculations, averages have been broken down into the cost components identified below, and comparisons will be made between the entire project and the quarters within it.

Deriving average costs

The cost analysis will estimate average monthly cost of providing the project to participants. This involves combining the total cost figures (Table 4.3) with the information on client days that has been derived from the client flow information provided (Table 4.4).

Costs before and after ISP

Estimates of costs before and after will be derived from ISP records. The nomination process included records of costs and support services before ISP, from which ISP staff and UNSW researchers will estimate costs. If the records are incomplete, ISP staff will retrospectively gather the information.

Completion of ISP includes a financial contract package for ongoing support after ISP. If the records are incomplete, ISP staff will gather information about other costs, from which ISP staff and UNSW researchers will estimate costs. Interview data gathered by the UNSW researchers will be used to estimate the sustainability of the post-ISP support.

Effectiveness

Outcome data for the cost effectiveness analysis will be derived from the data collection used in the management of the project supplied by ISP. This will also be supplemented with qualitative data from interviews. Comparative data on population norms and people with challenging behaviour population norms will be managed by the evaluators (Table 4.5).

Table 4.5: Measures of Effectiveness

Outcome	Comparison groups	Analysis	Explanation
Stable housing	Before and after, ISP clients who leave the project	C/E*	Change in length of tenancy compared to before ISP by unit cost of ISP
reduced hospitalisation	Before and after, ISP clients who leave the project	C/B	financial savings from relative change hospitalisation compared to before ISP by unit cost of ISP
Personal Well-being Index (PWI)	Before and after, ISP clients who leave the project, Population norm	C/E	Change in PWI towards population norm by unit cost of ISP
ABS Health questions	Before and after, ISP clients who leave the project, population norm	C/E	Change in health towards population norm by unit cost of ISP
Employment, education, community participation	Before and after, ISP clients who leave the project	C/E	Change in participation compared to before ISP by unit cost of ISP
Social and family relationships	Before and after, ISP clients who leave the project	C/E	Change in relationships compared to before ISP by unit cost of ISP
imprisonment	Before and after, ISP clients who leave the project	C/E*	Change in imprisonment rate compared to before ISP by unit cost of ISP
substance use	Before and after, ISP clients who leave the project	C/E	Change in substance use rate compared to before ISP by unit cost of ISP

notes: C/B cost benefit; C/E cost effectiveness; * C/B if financial impact data available.

4.4 Evaluation Analysis

The analysis will include five parts: outcomes, process and economic analysis; discussion of the evaluation questions on governance, service systems and individual clients; and implications for improving the model and applying the lessons to other clients, service types and service integration.

Outcomes for clients and the service system will be analysed by comparing the longitudinal outcomes, KPI and interview data; and normative data from similar programs and the

validated instruments used in the data collection (mental health; disability; challenging behaviour; criminal justice; hospitalisation; social isolation; housing stability; satisfaction; confidence; community participation; employment; social networks; wellbeing; and service use). It will include both expected and non-expected outcomes, both positive and negative.

The process data will be analysed in terms of the impact of features of the project through the experience of clients, government officials, ISP staff, service providers, carers and other stakeholders. It will describe the experience of these stakeholders in the implementation of the project compared to the Project design, quality of care, accountability, effective use of resources, efficiencies in costs, service integration, facilitators and barriers to outcomes.

Economic data on financial and other resources will be analysed in terms of cost to clients, government and service providers for the purpose of economic evaluation of efficiency and effectiveness. It will include analysis of comparative cost per client; service appropriateness per client; impact on the service system; and opportunity costs to the service system.

The discussion will address the three groups of evaluation questions about governance (agency representation; engagement of relevant stakeholders; leadership, accountability and decision making; processes for meetings, planning, monitoring and review; data and information; improvements; implications for service system); service systems (cost benefits; strengths and weaknesses; improvements; sustainability and generalisability; legislative and industrial facilitators and barriers to target group; service system facilitators and barriers to implementation; priorities for early intervention; involvement of local services; capacity building experiences) and individual clients (change in outcomes; reasons for differences between client outcomes; benefits to other clients; implications for future management of target group; reach to target group; effectiveness of target criteria).

It will draw conclusions and implications for project improvements – appropriateness (client characteristics and needs, service types and level, policy directions, stakeholder acceptance); efficiency (processes, resource use, quality); and effectiveness (fidelity, outcomes, most effective elements, unintended effects, relative cost, sustainability, generalisability, accountability, participation); models for prioritising and assessing most suitable clients; applicability to other clients with challenging behaviour; and applicability to other service integration policies.

5 Management

5.1 Deliverables

Four evaluation reports will be submitted throughout the evaluation process. The timing and general nature of the content of each report is described below.

Methodology (February 2008)

- Evaluation framework: project logic
- Evaluation questions: governance, service systems and individual clients
- Methods: outcomes, process, economic (including instruments)
- Management: timeframe, deliverables, researchers, quality control

Project establishment report (June 2008)

- Method
- Description of the Project: governance, service system, individual clients
- Profile of each client: characteristics; direct and indirect costs; baseline outcome measures in comparison to prior to entering the Project
- Case study summaries
- Cost effectiveness analysis for clients who entered the project before 2008
- Discussion
- Implications for project improvements and modifications to the evaluation

Interim report (November 2008)

- Method
- Analysis of project process and outcomes: governance, service system, individual clients
- Profile of each client: characteristics; direct and indirect costs; comparative outcomes from prior, baseline, 12 month and post Project (where relevant) measures
- Case study summaries
- Discussion
- Implications for Project improvements and modifications for final evaluation

Final report (November 2009)

- Summary of findings and implications
- Background and method: aims, evaluation questions
- Findings
    - Project description: establishment, first and second evaluation 12-month periods
    - Outcomes for all clients and service system: mental health; disability; challenging behaviour; criminal justice; hospitalisation; social isolation; housing stability; satisfaction; confidence; community participation; employment; social networks; wellbeing; service use

  - Process impact on outcomes: implementation, quality of care, accountability, effective use of resources, efficiencies in costs, service integration, facilitators and barriers to outcomes
  - Economic: financial and other resource cost per client to clients, government, service providers; comparative cost per client; service appropriateness per client; impact on the service system; and opportunity costs to the service system

- Discussion
  - Governance – agency representation; engagement of relevant stakeholders; leadership, accountability and decision making; processes for meetings, planning, monitoring and review; data and information; improvements; implications for service system
  - Service systems – cost benefits; strengths and weaknesses; improvements; sustainability and generalisability; legislative and industrial facilitators and barriers to target group; service system facilitators and barriers to implementation; priorities for early intervention; involvement of local services; capacity building experiences
  - Individual clients – change in outcomes; reasons for differences between client outcomes; costs and benefits to other clients; implications for future management of target group; reach to target group; effectiveness of target criteria; effect on clients not accepted
- Implications and options
  - Project improvements: appropriateness (client characteristics and needs, service types and level, policy directions, stakeholder acceptance); efficiency (processes, resource use, quality); and effectiveness (fidelity, outcomes, most effective elements, unintended effects, relative cost, sustainability, generalisability, accountability, participation)
  - Model for prioritising and assessing most suitable clients
  - Applicability to other clients with challenging behaviour
  - Applicability to other service integration policies

5.2 Evaluation Timetable

The research timetable was initially delayed while contract details were finalised. The following table presents the revised evaluation timeframe.

Table 5.1: Evaluation Timeframe

Task	Output	Month
Meet with Project Manager		Dec 07
Ethics approval – UNSW	**Approval**	Dec 07
Literature review		Dec 07
Finalise evaluation design		Jan 08
Present work plan	**Work plan**	**Feb 08**
Baseline fieldwork: participants, service providers, family interviews and observation		Mar 08
Baseline analysis of case file, financial and administrative data, including cost effectiveness analysis for clients in the project before 2008		Apr 08
Draft, final and presentation of project establishment report	**Project establishment report**	**June 08**
Mid fieldwork: participants, service providers, family interviews and observation		Sep 08
Mid analysis of case file, financial and administrative data		Oct 08
Draft, final and presentation of interim report	**Interim report**	**Nov 08**
Final fieldwork: participants, service providers, family interviews and observation		Sep 09
Draft report outline		Sep 09
Final analysis of case file, financial and administrative data		Oct 09
Draft final report to DADHC		Oct 09
Final report and presentation	**Final report**	**Nov 09**

5.3 Communication with Clients and Key Stakeholders

The benefits of an evaluation design stage and incorporating formative evaluation are the opportunities to engage early with and provide feedback to stakeholders in the project and evaluation. The purposes of this engagement are to: improve the evaluators' understanding of the project and their evaluation needs; discuss evaluation design considerations; communicate progress in the evaluation design; and establish working relationships with the stakeholders to effectively implement the work plan. To communicate effectively, a single member of the evaluation team will be the primary point of contact for project stakeholders.

We will maximise communication with project stakeholders through the following methods (within the constraints of the design period and budget): visit the Project; attend collective

meetings; contact by telephone and email; distribute components of the draft evaluation design for feedback as authorised by the Department; and advise on integrating evaluation processes into project management. Techniques developed to promote participation include: becoming visible to the agencies; fostering trust and an understanding of the purpose of the evaluation; designing effective data collection instruments; and providing feedback to stakeholders to inform future planning and monitoring after the completion of the evaluation.

We are also acutely aware that we must communicate with people using the project in order to recognise their contribution to the evaluation and to maintain good relations with people who have contributed insights from their experience. Thus, whenever research involves direct interaction with clients, the evaluators ensure that their input is acknowledged, both in the research itself and in feedback provided to them. Our commitment to ethical practice is described in our Quality Assurance and Ethics and the SPRC Indigenous Research Protocol.

The third aspect of the communication plan relates to researchers, policy makers and the public. The purposes of communication with these groups are: to encourage engagement with the participants in the project; and to broaden engagement with researchers and policy makers in similar programs. In cooperation and agreement with the Department, we will disseminate information to researchers, policy makers and the public. We suggest using media such as: the SPRC newsletters (printed and electronic); SPRC, the Department and other websites; 1800 telephone number through the SPRC; and the distribution networks of the project stakeholders. With the prior agreement of the Department, we will also pursue any opportunities for presenting the evaluation at seminars, conferences and peer-reviewed academic publication.

5.4 Ethical and Equity Considerations

The researchers adhere to the various research management guidelines of the University, including the UNSW Code of Conduct for the Responsible Practice of Research. The Centre is also committed to principles of equal opportunity, cultural diversity and social justice. Potential participants will be supplied with clear information statements about the ways in which the information collected will be kept private and confidential. Participants will also be required to sign consent forms before they can become involved in the research. The researchers will ensure that all participants give informed consent to participate in the evaluation. To this end, all consent forms and other information about the evaluation are written in simple English and are culturally appropriate.

In addition, the researchers will be sensitive to participants' needs and requirements relating to gender, cultural issues, disability and sexuality. We anticipate that family members and support and housing service staff will also flag any issues of concern. The literacy and linguistic needs of participants from a Non-English speaking or Aboriginal and Torres Strait Islander background will be accommodated through the provision of translators and interpreters as required. Where literacy is an issue, all forms can be delivered through sound recordings in English or in the appropriate community language. Fieldworkers from support organisations, trusted persons or peers will be engaged when necessary. The team includes researchers who have extensive experience in developing and conducting effective consultation processes with people who have cognitive impairments.

At each step of the research process confidentiality will be assured. All data collected will be de-identified and stored in a secure location at the SPRC.

5.5 Quality Considerations

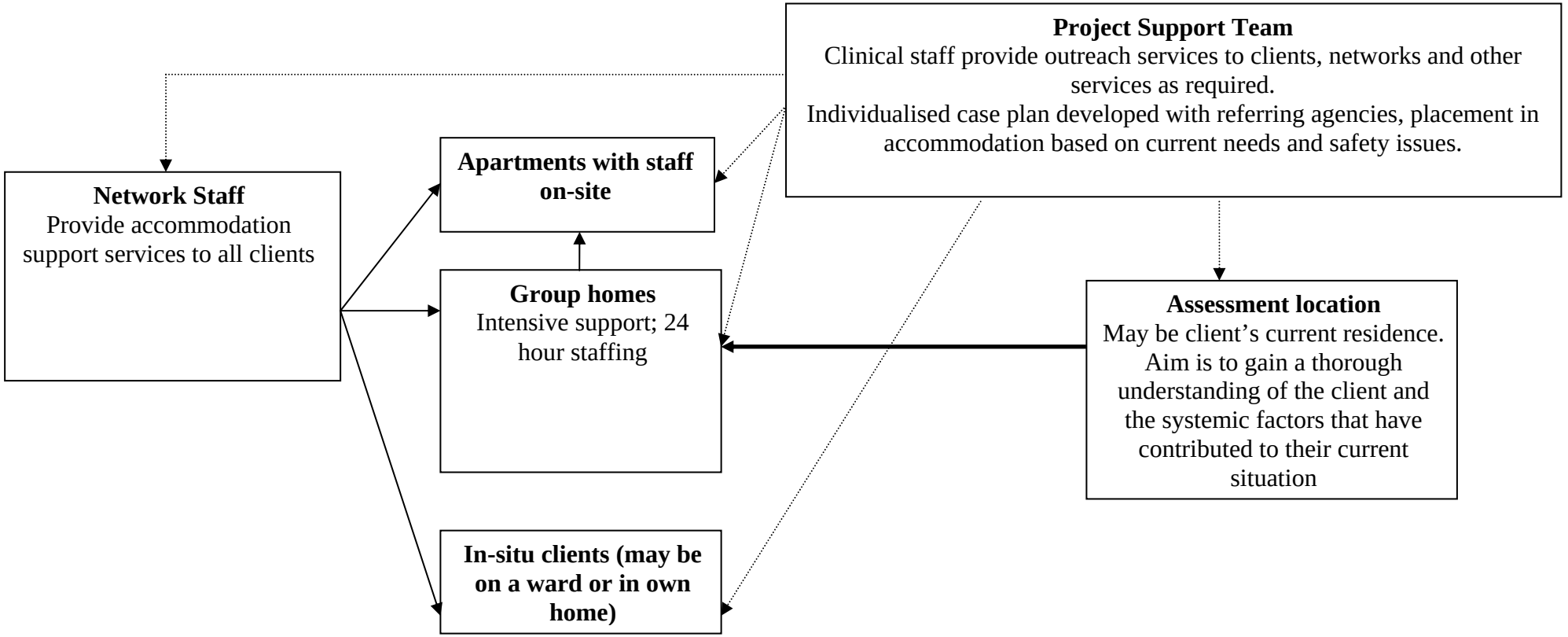
The SPRC is supported by high quality infrastructure that contributes to the conduct of the evaluation. The project will draw on existing evaluation instruments where they are available. Where new instruments are required, the SPRC will adopt outcomes and process measures consistent with national and international methods. The methods will be developed in consultation with the Department and participants. Timely agreement is necessary to enable the evaluation to proceed. The SPRC will also ensure standards of quality by responding to feedback from the Project Manager.

The SPRC pays particular attention to the quality assurance of outputs from research consultancies, ensuring quality control by measuring against rigid standards for project management, reporting and publication. Effective quality assurance mechanisms will guarantee that the evaluation and other products delivered to DADHC are of the highest standard. The accepted method for achieving quality assurance in research is through peer review. Each project undertaken by SPRC is subjected to independent review of the quality of the research and the robustness of its findings.

Within the SPRC, a senior manager and two research support staff are allocated responsibility for information management systems. Their capacity is supplemented with UNSW support. Standards of quality data management described above are implemented to ensure data are stored in a secure, confidential and non-identifiable manner, as required by UNSW codes and ethics requirements.

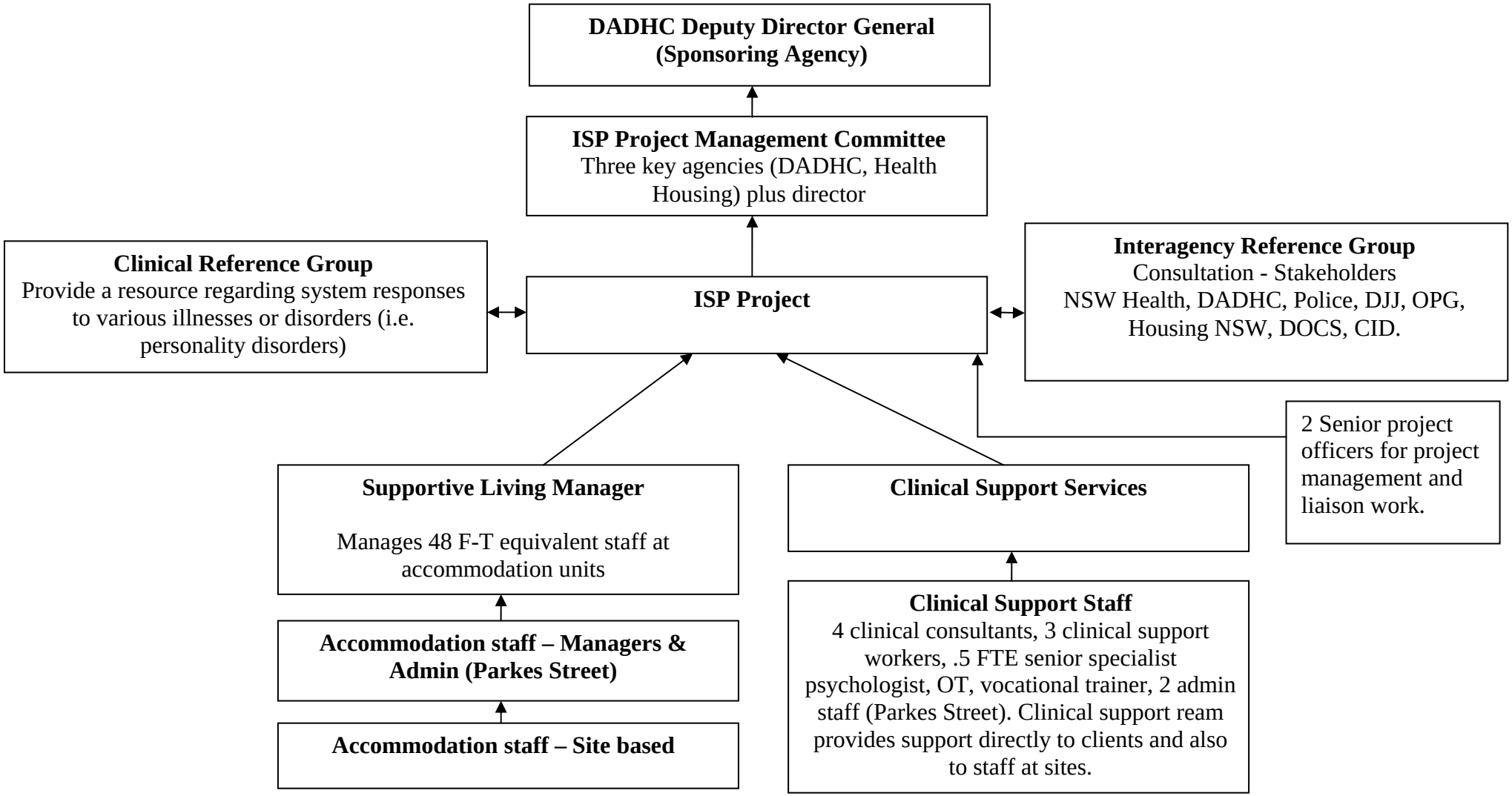
Appendix A: Model of ISP Accommodation and Support Services

See section: Framework for Service Delivery



Appendix B: ISP Responsibility Matrix

(See section: Roles and Responsibilities of ISP Partners)



Appendix C: Topic Guides

Client topic guide

Housing

1. Where you were living before you became an ISP client?
2. Where do you live now?
3. Do you like living here? What do you/don't you like? (Accommodation, privacy, other people, workers, location, transport, community, neighbours)
4. What would make it better?
5. What are your long term plans for housing?

Social connections

6. Do you have friends? Do you have contact with them regularly?
7. Do you have family? Do you have contact with them regularly?
8. Would you like to change your relationships in any way?

Health

9. How do you feel about your physical and mental health, emotions and behaviour?
10. Do you see a doctor or psychiatrist regularly?
11. Is there anyone else helping to look after your health, emotions and behaviour?

Community participation

12. What do you do during the day?
13. Do you have any interests or hobbies?
14. Do you currently work? Would you like to change your work in any way? Have you worked in the past?
15. Do you study? If so, how is it going? Would you like to change your study in any way? Have you studied in the past?
16. What are your long term plans for work, study or other participation?

ISP and other services

17. Do you like being involved with ISP? What do you/don't you like?
18. What has been your experience of the:
    - ISP case manager?

- Clinical staff?
- Residential staff?

19. Do you receive the services that you need? (enough support, access, gaps, coordination)

20. Is there anything else you would like to tell me or ask me about?

Family members and carers topic guide

1. What is your relationship to [name of client]? If friend/carer/guardian, how long have you known [name of client]?

2. How regularly are you in contact with [name of client]?

3. What kind of support do you provide for [name of client]?

4. How did your family member/friend come to be involved in ISP?

5. What did you think about the project initially?

6. What are your perceptions about the accommodation that your family member/friend has been provided with as part of the ISP? (Prompts: location, condition of property, neighbourhood)? How satisfied are you with the accommodation provided to [name of client]? Why?

7. What are your perceptions of other services that have been provided as a part of the ISP?

8. What is your experience of how your family member/friend's ISP worker has worked with other organisations your family member/friend is involved with?

9. Overall, how satisfied are you with the quality and amount of support that your family member/friend is receiving from ISP?

10. Overall, how satisfied are you with the communication between you and the case manager(s)?

11. Have your perceptions changed over time?

12. Do you feel your family member/friend's life has changed since being involved in ISP? If so, how has it changed? (Prompts: health changes, life skills, relationships with family, social interaction, community participation)

13. How would you compare ISP to some of the other programs that [name of client] has been a part of?

14. Do you have any other comments you would like to make about ISP?

ISP worker topic guide

1. What is your role at ISP? How long have you been in this role?

2. How many clients do you work with?

3. Do you have any comments about the administration of ISP? e.g. funding or service design; adequate resources to support clients; contract management and support from DHS; other service viability issues?

4. Have you been involved in the development of any protocols on the operation of ISP? What are they?

5. Are there any internal policies/procedures that specifically relate to ISP clients? What are they?

6. Do you have any comments about the referral and assessment processes?

Process/management of support provided

7. What process do you go through when you meet a client for the first time?

8. Can you explain how you work with the clients? What support do you provide in the home and outside of the home (domestic, social, recreational, educational/training)?

9. What processes do you go through in planning and providing support to clients (prompt: individual service agreements & goals set with clients)? Have there been any issues for you in this process (e.g. service coordination)?

Outcomes

10. What are the benefits of ISP for clients? Can you give examples of these?

11. Are there downsides of ISP for clients (prompts: loneliness, isolation, vulnerability, hospitalisations, exits)? Can you give examples of these?

12. Did some clients benefit more from this project more than others?

13. Do you feel that the clients are increasing their community participation? Can you give examples of this?

14. Did you set short and long term goals with your client? Have they achieved any of these goals?

Tenancies data for each ISP tenant

1. What do you think of the accommodation provided by ISP? Does ISP has sufficient scope to address the housing needs of the clients?

2. How long did it take to house the person after he/she was admitted into the project?

3. Have you received any complaints about the ISP tenants? How many?

4. What have the complaints been about (e.g. inability to pay rent, property damage, nuisance or annoyance to neighbours, etc.)?

5. How do you resolve any complaints against ISP tenants?

6. Are the clients able to sustain their tenancies?

7. What complaints mechanisms are available to the tenants? How do you resolve these complaints?

8. Would tenants complain if they were unhappy? Have any tenants used the complaints process? How has your agency responded? Can you give an example please, if appropriate?

Final

15. What do you think will happen with these clients in the future?

16. What do you see as happening with this project in the future? What methods could be adopted by NSW for future management of the target group?

17. Do you have any further comments you would like to make about the ISP?

Other stakeholders/community organisations

1. How long have you been working with [ISP provider]?

2. How long have you been a key person/support worker?

3. What support do you provide to this client in the home and outside of the home (domestic, social, recreational, educational/training)?

Process/management of support provided

4. What has been your experience of the services provided by the ISP?

5. What do you think of the accommodation provided by ISP?

6. Do you have any comments about the referral and assessment processes?

7. What processes do you go through in planning and providing support to clients (prompt: individual service agreements & goals set with clients)? Have there been any issues for you in this process (e.g. service coordination)

Outcomes

8. What are the benefits of ISP for clients? Can you give examples of these?

9. Are there downsides of ISP for clients (prompts: loneliness, isolation, vulnerability, hospitalisations, exits)? Can you give examples of these?

10. Did some clients benefit from this project more than others?

11. What type of accommodation has been provided? Are you satisfied that the housing provided via the ISP has met the clients' needs in a timely way?

12. What do you see as the future of the project?

13. Are there any other experiences of the ISP that you'd like to be included in the evaluation?

ISP manager topic guide

1. How long have you been working with ISP?

2. How many support workers do you manage? Do you work with any clients?

Operation/management of support provided

3. Do you have any comments about the administration of the ISP? eg funding or service design; adequate resources to support clients; referral and assessment processes and support from DHS; other service viability issues?

4. Have you been involved in the development of any protocols on the operation of ISP (eg. referral process, range of agreements, resource manual)? What are they? What issues have you needed to take into consideration in developing these protocols?

5. Are all relevant agencies represented at appropriate levels of the governance structure?

6. What are the critical factors and barriers to actively engaging relevant stakeholders in the project?

7. Do current arrangements support appropriate leadership, accountability and decision-making?

8. What improvements could be made to current governance arrangements? Could any of these arrangements be of value if introduced into the wider system in the long term?

Outcomes

9. Has adequate data been available to monitor progress and results?

10. What are the benefits of ISP for clients? Can you give examples of these?

11. Can these strengths be sustained in the longer term? Can they influence the wider system of service provision?

12. What are the downsides of ISP for clients (prompt: loneliness, isolation, vulnerability, hospitalisations)? Can you give examples of these?

13. Have you had any tenants leave the ISP? Why? What happened to the resources – housing, furniture & funding?

14. Are there any legislative or industrial factors assisting or inhibiting provision of services across the target group?

15. Can anything be done to foster earlier intervention in such situations?

16. To what extent did the project garner and maintain active involvement of social services?

17. Has the project acted on capacity building opportunities?

18. How do you see the future for the clients?

19. How do you see the future of the project?

20. Are there any other experiences or issues with the implementation and conduct of ISP that you'd like to be reflected in the evaluation?

21. Do you have any ideas about how ISP could be improved?

22. Do you have any further comments you would like to make about the ISP?

ISP Interagency Reference Group topic guide

Governance

1. Are all relevant agencies represented at appropriate levels in the current governance arrangements?

2. What are the critical factors or barriers to actively engaging relevant stakeholders?

3. How effective are current processes for meetings, planning, monitoring and reviewing the project?

4. What improvements could be made to current governance arrangements?

5. Could any elements of the project's governance be of value if maintained or introduced into the wider service system?

Client outcomes

6. In terms of the actual clients do you think ISP is working effectively?

7. What do you think are the major successes of the project?

8. How do you think the project can be improved?

9. What do you see as the future for this Project?

References

Anderson, D. J., K. C. Lakin, B. K. Hill and T. H. Chen (1992), 'Social integration of older persons with mental retardation in residential facilities', *American Journal on Mental Retardation,* 96, 488-501.

Brodaty, H., B. Draper, D. Saab, L. F. Low, V. Richards, H. Paton, et al. (2001), 'Psychosis, depression and behavioural disturbances in Sydney nursing home residents: Prevalence and predictors', *International Journal of Geriatric Psychiatry,* 16 (5), May, 504-512.

Ball, T. and A. Bush (2000), *Clinical practice guidelines: Psychological interventions for severely challenging behaviours in people with learning disabilities*, British Psychological Society, Leicester.

Baumeister, A. A., J. A. Sevin and B. H. King (1998). 'Neuroleptic medications', in S. Reiss & M. G. Aman (eds.), *Psychotropic medications and developmental disabilities: The international consensus handbook* (pp. 133-150), Nisonger Center, Ohio State University, Columbus, OH.

Brylewski, J. and L. Duggan (1999), 'Antipsychotic medication for challenging behaviour in people with intellectual disability: A systematic review of randomized controlled trials', *Journal of Intellectual Disability Research,* 43, 360-371.

Carr, E. G., R. H. Horner, A. P. Turnbull, J. G. Marquis, D. M. McLaughlin, M. L. McAtee, et al. (1999), *Positive behavior support for people with developmental disabilities*, American Association on Mental Retardation, Washington, DC.

Carter, W. J. (2006), *Challenging behaviour and disability: A targeted response*, Jul., Queensland Government, Brisbane, QLD.

Didden, R., P. C. Duker and H. Korzillius (1997), 'Meta-analytic study on treatment effectiveness for problem behaviors with individuals who have mental retardation', *American Journal on Mental Retardation,* 101, 387-399.

Disability Services Queensland (2007), *Investing in positive futures: Response to recommendations*, May, Queensland Government, Brisbane, QLD.

Emerson, E. (2001), *Challenging behaviour: Analysis and intervention in people with severe intellectual disabilities*, Cambridge University Press, Cambridge.

Geary, P. (2007), *Draft report: Investigation of support needs and service models for younger people with high clinical care needs,* Jan., Australian Healthcare Associates, Carlton, VIC.

Hill, B. K. and R. H. Bruininks (1984), 'Maladaptive behavior of mentally retarded individuals in residential facilities', *American Journal of Mental Deficiency*, 88, 380-387.

Jacobsen, J. W., E. J. Silver and A. A. Schwartz (1984), 'Service provision in New York's group homes', *Mental Retardation,* 22, 231-239.

Kelly, G., Todd, J., Simpson, G. K., Kremer, P. J., and Martin, C. M. (2006). The Overt Behaviour Scale (OBS): A tool for measuring challenging behaviours following ABI in community settings. *Brain Injury,* 20, 307 - 319.

Koegel, L. K., R. L. Koegel and G. Dunlap (1996), *Positive behavioural support: Including people with difficult behaviour in the community*, Paul H. Brookes, Baltimore.

Lennox, D. B., R. G. Miltenberger, P. Spengler and N. Erfanian (1988), 'Decelerative treatment practices with persons who have mental retardation: A review of Lowe, K. and D. Felce (1995a), 'The definition of challenging behaviour in practice', *British Journal of Learning Disabilities,* 23, 118-123.

Lowe, K. and D. Felce (1995b), 'How do carers assess the severity of challenging behaviour? A total population study', *Journal of Intellectual Disability Research,* 39, 117-127.

McVilly, K. (2002), *Positive behaviour support for people with intellectual disability: Evidence-based practice promoting quality of life*, ASSID (Australian Society for the Study of Intellectual Disability), Sydney, NSW.

Meehan, T., P. O'Rourke, P. Morrison and S. Drake (2004), *Evaluation of Project 300: Results at 3 years post-discharge: Summary*, Jan., Queensland Health and University of Queensland, Brisbane, QLD.

NSW DADHC (Department of Ageing Disability and Home Care) (2007), *Request for tender: Integrated services project for clients with challenging behaviour*, May, NSW DADHC (Department of Ageing, Disability and Home Care), Parramatta, NSW.

NSW Council for Intellectual Disability (2007), *Framework plus 5*, NSW Council for Intellectual Disability, Surry Hills, NSW.

NSW Health (2006a), *Housing and Accommodation Support Initiative (ISP) for people with mental illness*, Nov., NSW Health, Sydney, NSW.

NSW Health (2006b), *Summary report: The management and accommodation of older people with severely and persistently challenging behaviours*, NSW Health, Sydney, NSW.

Quine, L. and J. Pahl (1985), 'Examining the causes of stress in families with mentally handicapped children', *British Journal of Social Work*, 15, 501-517.

Qureshi, H. (1992), 'Young adults with learning difficulties and challenging behavior: Parents' views of services in the community', *Social Work and Social Services Review*, 3, 104-123.

Ramcharan, P., K. Nankervis and G. Abdilla (2007), *What does the research say about achieving housing and support outcomes?*, Statewide Forum, Melbourne, VIC.

Robertson, J., E. Emerson, L. Pinkney, E. Caesar, D. Felce, A. Meek, et al. (2004), 'Quality and costs of community-based residential supports for people with mental retardation and challenging behavior', *American Journal on Mental Retardation*, 109 (3), 332-344.

Saxby, H. and H. Morgan (1993), 'Behaviour problems in children with learning disabilities: To what extent do they exist and are they a problem?' *Child: Care, Health & Development*, 19, 149-157.

Scotti, J. R., I. M. Evans, L. H. Meyer and P. Walker (1991), 'A meta-analysis of intervention research with problem behaviour: Treatment validity and standards of practice', *American Journal on Mental Retardation*, 93, 233-256.

Sloper, P., C. Knussen, S. Turner and C. Cunningham (1991), 'Factors relating to stress and satisfaction with life in families of children with Down's syndrome', *Journal of Child Psychology and Psychiatry*, 32, 655-676.

Stancliffe, R. J., A. D. Harman, S. Toogood and K. R. McVilly (2007), 'Australian implementation and evaluation of active support', Journal of Applied Research in Intellectual Disabilities, 20, 211-227.

Stores, R., G. Stores, B. Fellows and S. Buckley (1998), 'Daytime behaviour problems and maternal stress in children with Down's syndrome, their siblings, and non-intellectually disabled and other intellectually disabled peers', *Journal of Intellectual Disability Research*, 42, 228-237.