New Approaches to Community-based Services for Younger People with Disabilities: The Evaluation of the Individual Needs Analysis Pilot Projects

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by

Megan Mitchell and Sara Graham

Foreword

The evaluation described in this report was commissioned by the Disabilities Services Program of the Commonwealth Department of Human Services and Health, (then the Department of Health, Housing, Local Government and Community Services) to inform policies for people with disabilities. These policies are currently being developed within a framework which espouses the principles of equity and access. A key component of this framework is the use of valid and reliable methods of assessment which determine individuals' requirements for services on a uniform basis and aim to ensure that needs are met in the most appropriate ways. For government, the longer term objective is to provide services in a cost effective manner such that available resources are matched to the assessed needs of individuals. It was intended that the findings of this evaluation would be used to further refine policy directions and advice to the field in the area of assessment.

The report provides an account of the evaluation of the four pilot projects in Queensland, the Australian Capital Territory, Victoria and South Australia. Although all very different in character, the intention of each of these projects was to develop and test an assessment instrument for people with disabilities, covering all areas of their lives. This approach to assessment was called Individual Needs Analysis.

The report examines a range of operational aspects of the pilot projects, gives an account of their adoption of the principles of Individual Needs Analysis and provides relevant outcome data. An important component of the research was a series of interviews with a number of clients of the services involved. The report also includes some broadly based impressions of the pilot projects gained by the evaluation team, a summary of the lessons learnt for policy and program development, and some recommendations.

The study was conducted as part of the Centre's ongoing program of research in the area of community support services for people with disabilities and it is to be hoped that it will be helpful not only to policy makers and service providers but also and, most importantly, to people with disabilities themselves and their families.

Peter Saunders
Director

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1 Policy Background to the Individual Needs Analysis Pilot Projects

Since the introduction of the Disability Services Act by the Federal Government in 1986, the Department of Health, Housing and Community Services has gradually introduced a range of policy and program initiatives which have as their aim, to improve the quality and responsiveness of services available to people with disabilities across Australia. As part of this process, the Government is exploring ways of developing a co-ordinated approach to service delivery which will:

- distribute resources more equitably among people with disabilities;

- improve methods of assessing and meeting individual needs;

- enable people with disabilities to have greater involvement in decisions which affect their lives;

- target funds more effectively;

- improve accountability; and

- co-ordinate the various elements of assessment, planning and delivery of services.

In order to achieve these outcomes, the Government has recognised the need to develop a standard and universal approach to assessment (called Individual Needs Analysis or INA) so that individual requirements can be determined on a uniform basis for all people with disabilities. This, it is hoped, will lead to greater equity in the receipt of services. A number of safeguards are anticipated within this arrangement both to protect the rights of the individual and to ensure that the funds provided by Government are appropriately spent. These are incorporated in the following general guiding principles (DHH and CS, 1991). The assessment should:

- be multi-dimensional and look at the whole person in the context of their community and the range of formal and informal supports required to maintain their preferred life style (or 'quality of life' as it is described in the INA project principles);

- involve the individual, their family and significant others in the process of assessment and planning;

- be seen to be independent from service delivery and as independent as possible from the source of funding so that it does not become service defining and restrictive;

- be carried out by an accredited person with good local knowledge;

- be flexible and responsive to meet changing needs;

- have a strong values base;

- provide adequate safeguards and grievance procedures;

- provide an individual plan which should consider both Disability Services Program (DSP)-funded services and other available generic options in each individual's community; and

- ensure that planning is centred around the aspirations of people of similar ages, cultural and socio-economic backgrounds.

A number of pilot projects were funded to develop and trial different forms of funding, assessment and planning tools which embrace these principles. Whilst the pilot projects not included in this evaluation focused on funding issues, the group of pilot projects included were set up primarily to test different approaches to assessment and planning. The Social Policy Research Centre at the University of New South Wales was commissioned to undertake the evaluation of four of these projects. These were LINKS (ACT), the Disability Assessment Service (Victoria), CHOICES (South Australia), and Fraser Coast Quality Lifestyles Inc. (Queensland).[1]

Although they shared a set of guiding principles, the INA pilots varied greatly in their character: they were located in a range of urban and rural centres, targeted different types of disability groups, used a variety of assessment methods and differed widely in their sponsoring arrangements. The projects were permitted considerable leeway in developing their schemes, having only to adhere to the broad principles outlined above. No specific operational directives were imposed on the projects. However, all were time-limited, usually for one year.

Ultimately, from this and other work the Government proposes to develop a framework within which to make decisions about how available resources can best be matched to the needs of individuals with disabilities. These initiatives are intended to empower individuals and families in their relationships with the service sector and, on grounds that provision would be demand rather than, as at present, supply led, encourage services to become more efficient.

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1   These were only four of a number of pilot projects which were funded to test approaches to funding and assessment and planning mechanisms.

2 The Evaluation Methodology

The evaluation of the four pilot projects took place between May 1992 and May 1993. The aims of the evaluation were set out by the Social Policy Research Centre in their proposal for the evaluation. They were to explore:

- the extent to which the projects had incorporated the principles of Individual Needs Analysis and the difficulties that they had encountered in doing so;

- the relationship between projects' methods and objectives;

- the effectiveness of case management and brokerage approaches and the difficulties associated with the implementation of these;

- whether being a client of a pilot project had proved beneficial for the clients and their families and in what ways; and

- whether the effects achieved (through participation in the project) were sustained once the seeding money had terminated.

2.1 Issues Associated with the Projects and Their Evaluation

It is important to draw attention to some of the conceptual and methodological problems associated with the setting up and conduct of the evaluation. To an extent these limit the capacity of the evaluation to provide definitive answers to some of the questions posed. A number of difficulties can be identified.

Although an evaluation was built into the design of the pilot projects, the relationship between the projects as experiments to be evaluated and the goals of the evaluation was not thought through in enough detail at a sufficiently early stage. Ideally the evaluation should have provided the capacity to examine the target group at entry to the project, during participation in it and after sufficient time had elapsed for the project to have taken effect. This would have allowed the impact of the project on client outcomes to have been assessed and, in addition, for the process by which this had occurred to have been understood. As it was, there was no opportunity for this. The evaluation began well after the pilot projects had been established. Consequently there was no opportunity to objectively assess the clients' circumstances prior to their involvement in the project. A further constraint (but one which, it has to be recognised, would have been very difficult to overcome given the range and complexity of the variables involved in clients' lives) was that the evaluation lacked a control group; that is, a similar group of clients with disabilities which did not benefit from the kind of additional attention provided to INA clients. These constraints have limited the value of the evaluation for policy purposes in that it has not been possible to postulate causal links between the activities of the projects and the outcomes for clients.

Because the four pilot projects lacked shared goals, formal structures or directions, our capacity to make systematic comparisons between their outcomes is limited. In particular, the Department's brief to the projects failed to communicate adequately the meaning and intention of INA (see Appendix One). This allowed projects to pursue their own interests without constraint such that the four projects lacked any real commonality.

It is also worth noting that although the purpose of a pilot or demonstration project is to learn lessons which can be generalised to the field, their very nature makes this problematic. This is because people's behaviour is likely to be affected by the knowledge that they are under scrutiny and that the project with which they are associated has a limited life span. It is therefore unwise to assume that what occurs in a pilot project is also likely to occur under more 'normal' circumstances.

2.2 Methodology

The evaluation was divided into two stages.

Stage One comprised a familiarisation visit to each project followed by detailed face to face interviews with staff and a sample of clients and carers. Between three to four weeks was spent with each of the four projects. This stage was undertaken between June and September 1992. It involved an analysis of written materials provided by the projects, interviews with workers in the pilot projects (project managers, co-ordinators and direct care staff) and others affected by the project, interviews with clients and carers and observation during the fieldwork.

In all interviews both factual and attitudinal information was sought and the interview provided considerable scope to explore issues in depth. The interviews with project managers and co-ordinators covered the following broad areas: roles and responsibilities, working conditions, training and development received and needed, rewards and stresses of the job, general views on the project's aims, objectives and achievements and personal details such as occupational and educational background.

Interviews with direct care workers covered much the same areas. However, for these workers particular emphasis was placed on questions which explored the relationship between the direct care workers and the people they supported.

The interviews with clients and carers covered the following: family circumstances and domestic circumstances, health status, employment, financial position, social and family relationships, leisure time activities and interests, support needs and receipt of support and their involvement in the pilot project as well as their attitudes to it. Advocates, friends or others were present at client interviews when clients requested this.

Stage Two of the evaluation involved follow up interviews with clients, managers and support workers approximately four to six months after the cessation of funding

for the pilot project. The second round of interviews took place from mid-January to March 1993 and between one and two weeks was spent with each of the projects.

2.3 Workshop

Between the two stages of the evaluation a one day Workshop was held at the Social Policy Research Centre. Two representatives from each of the participating pilot projects and an official from the Disability Services Program of the then Department of Health, Housing and Community Services were invited to attend. The purpose of this Workshop was to provide the opportunity for participants to describe their projects for the benefit of the others, discuss some of the key issues which they felt had emerged in the course of their pilot project, explore the projects' experiences in the implemention of the INA principles and respond to the evaluation team's report of the first stage of the evaluation.

2.4 Sample Selection

In order to provide a picture of the characteristics of the projects' clientele and also to enable the selection of a representative sample of clients to be interviewed, the project manager or co-ordinator was asked to provide the evaluation team with an anonymised list of all current and past clients. This list also contained specific descriptive characteristics relating to each client. After controlling for living circumstances and level of disability (two factors which it is believed have an important impact on outcomes for people with disabilities) a sample of clients was selected on a random basis.

The sample of clients selected for interview normally comprised about 40 per cent of the total population of the projects' clientele. However, in one of the projects it is unknown exactly what proportion of the total clientele the sample constituted. This is because of the difficulties encountered in determining which of the service's clientele was unequivocally linked to the pilot project.

In addition to the clients, both their unpaid carers and the staff who worked directly with them were interviewed. In all, 93 people were interviewed in Stage One of the evaluation. Of these 34 were clients, 14 were informal or unpaid carers and 45 were either managerial staff or support workers. In Stage Two, 78 people were interviewed. Thirty of these were clients, 12 were unpaid carers and 36 were either managerial staff or support workers. Nine of the clients originally selected for interview were not interviewed. This was either because they did not wish to be or because the evaluation team were told by support workers or others that it would be inappropriate to conduct an interview with them. In these cases, substitute clients were selected who were in similar circumstances to those originally chosen.

Appendix Two contains a more detailed account of the way the samples were selected and of the clients included in the sample populations.

3 Establishment and Implementation of the Pilot Projects and Their Aims and Objectives

Each of the pilot projects was developed within a unique service environment. To understand why the projects have evolved in the way they have, we need to know something of their history and place in the service worlds of which they are a part. In this section we briefly describe each of the projects included in the evaluation and provide an account of the contexts in which the pilots were developed and implemented. Of particular importance is the sponsoring arrangements for each of the pilots.

In the course of the evaluation we found that three of the projects (those in the ACT, Victoria and South Australia) had either significantly departed from or were unable to meet their original aims. In this section we also examine the original aims of the projects, describe any changes to these which have occurred in the course of the projects and postulate reasons as to why aims were not met.

3.1 The ACT Project

The Sponsoring Body

The ACT pilot project, called LINKS, was sponsored by FOCUS, an established accommodation support service for people with disabilities. Funding of $86,000 was provided for this pilot project over a 12 month period, commencing in June 1991. The funding was originally due to cease at the end of June but, on account of slippage of various kinds, the project was extended into July 1992.

FOCUS had previously been part of a large charitable organisation providing a range of services, including accommodation, for people with intellectual disabilities. About four years previously, due in part to both external and internal pressures to move away from institutionally-based 'whole of life' forms of service provision, the welfare and supported accommodation elements of this organisation split. The eventual result was the establishment of FOCUS as a separate supported accommodation service.

FOCUS is administered by a manager and a small team of assistant managers who supervise the activities of approximately 55 support workers. Most of these are employed on a casual basis to provide direct care/support to clients. FOCUS seeks to assist people who are regarded as having an intellectual disability to live in their own residential arrangements.

The agency currently supports just over 100 people in community-based accommodation settings. Most clients reside either in state owned group homes or in privately rented accommodation. A small number live with their families. Workers assist people in their living arrangements in various ways, but their primary role is to help with personal care, such as toileting and hygiene and with household tasks such as cleaning and the preparation of meals, household budgeting and management, shopping and the like. Support workers do not themselves 'live in' the homes of the people with disabilities but some 'sleep over' on a regularly rostered basis. Workers are employed to assist people outside traditional working hours, that is, in the evenings, overnight, in the early mornings and on weekends.

The philosophy of FOCUS has been greatly influenced by the principles of 'normalisation' and 'social role valorisation' and the writings of people such as John McKnight (1989), John O'Brien (O'Brien and Lyall, 1987) and Michael Kendrick (Schwarz, McKnight and Kendrick, 1987).

Increasingly, the agency has come to identify a role for itself in assisting people with disabilities to activate natural and informal relationships with others in the community, rather than merely with the provision of accommodation support. The INA funds provided FOCUS with the opportunity to explore how this could best be achieved, in ways which would enrich, both socially and emotionally, the lives of 20 people using FOCUS services.

The Pilot Project

Development work for the pilot project, LINKS, began in May 1991, with the first clients being taken on in June. Its establishment coincided with a recruitment drive for accommodation support staff by FOCUS and many of the workers for the pilot project were selected from this field of applicants. Others were selected from amongst the existing pool of FOCUS workers. However, the main criterion for recruitment to the position of LINKS worker was a 'good values base'. A professional welfare background or experience with people with disabilities was not thought to be necessary or even desirable.

Most LINKS staff were employed on a casual basis and worked part time. However, some of those recruited were also employed as accommodation support workers in FOCUS or were engaged in other employment or occupations, such as study or child rearing.

The staff selected were initially provided with basic information about the pilot project and their potential role in it. Each LINKS worker was matched by the management team to one of their clients. This matching was based on such factors as personality, age and experience and the wishes of the client. People matched together, either staff or clients, were allowed to veto their match if they did not consider it suitable. The role of the LINKS worker was confined to assisting people to develop meaningful, lasting and valued links within the community. The management of LINKS believed that through the fostering of these links their clients

would become less dependent on the service sector to meet their social and emotional needs and would instead be supported through the natural and informal relationships that were expected to develop.

It was also expected that by helping people to develop more valued roles in their own communities, community attitudes towards people with disabilities would become more positive.

Following an initial meeting or meetings with their 'friend' (the term preferred by a number of the LINKS workers to describe the client they were matched with), a weekend workshop was held for the LINKS workers in order to introduce them to the concepts of normalisation and to explore the lives and personalities of the people they would be getting to know. *Framework for Accomplishment* (O'Brien and Lyall, 1987) was used to develop personal profiles of the clients. Ongoing and regular arrangements were then established between support workers and the people they were assisting so that they could develop their relationships and examine opportunities for forming other relationships with 'valued' people in the community. Over the period of the pilot 21 clients and 23 support workers were involved in the LINKS project.

Assessment of social needs was undertaken on an informal basis during a period of observation and 'getting to know' the client. After this, plans to initiate social contacts were mutually agreed. The amount of contact between LINKS workers and the person they were assisting was generally between three and six hours per week, depending on the characteristics of the particular relationship and the social and relationship-building activities that were planned. LINKS workers kept a record of the hours they spent in activities related to the person they were assisting and submitted an account to FOCUS management at fortnightly intervals. Many of the LINKS workers also spent time with (or related to) the person outside of these 'billed' hours.

LINKS was managed by a project manager and administered by four assistant managers who, between them, supervised the activities of the LINKS support workers. All members of the management team were involved in other work for the sponsor body. The manager of LINKS was also the manager of the FOCUS accommodation service.

Aims and Objectives

FOCUS saw the pilot project as an opportunity to put more intensive efforts into the development of the potential of the agency's clients and to test their beliefs about alternatives to formal support for people with disabilities. These beliefs centred around the notion that, in many ways, the human services sector is self serving, fostering client dependence through social isolation and the exercise of control over their lives. With assistance to develop their own informal friendships and networks, it was believed that their clients would be in a better position to achieve greater independence from the formal services and attain a more valued role within society.

In its original submission the project had three main aims:

- to informally assess 20 people receiving support;

- to identify the optimal living situation for each person and assist them to achieve this; and

- to develop a formula to determine the costs of supporting these individuals in ordinary community settings.

Prior to actual implementation, a staged approach was developed which differed markedly from that described in the original submission. The revised aims were described by the project manager at interview as:

- to assist people to become less dependent on the human services sector by facilitating the provision of support through natural networks; and

- to look at ways in which to attach funds to individuals with a disability, that is, how best to determine the resources required to meet their needs.

As it was, by the time of the evaluation only the first of these aims had been actively pursued; that is, **to assist people to become less dependent on the human services sector by facilitating the provision of support through natural networks**. Some of the methods developed to achieve this, such as the use of formal assessment tools, had also evolved in ways that were different from those originally envisaged.

Whilst it is not entirely clear why the second aim was not pursued, it appeared to the evaluation team that the first aim had, from the outset, held much greater interest for the FOCUS management. Once immersed in this part of the project, the project team became even more convinced of its relative importance and consequently devoted all their energies to it. In fact, for FOCUS the variation between people and the dynamic nature of their needs meant that the notion of attaching dollars to individuals in a systematic way was rather meaningless.

Because the focus of the project shifted and confined itself to the enhancement of individuals' social networks, it largely failed to assist people in aspects of their lives relating to their residential situation, although this had been one of its original intentions. While natural networks within the community were facilitated for some clients, this was limited, and without continued support these networks tended to weaken over time. It could be argued that one year is insufficient time to allow natural networks to develop as, for most of us, these are established over many years. In addition, the high level of dependency of the client group leads one to suspect that they will, in many cases, require substantial preparation and ongoing support to take full advantage of the kinds of opportunities that may exist.

As one support worker commented:

> *If you give someone the avenue, the more people he's involved with, the more likely he is to form relationships. Sol needs a lot of opportunities, that's all, because some contact will be a bit hit and miss.*

Another commented:

> *... It would take more than a year. A support person might also not be there at the time. Things happen like that in any relationship. Like when I had to cut down contact and finish my thesis. Even simple things in the community like going to an art class, takes a lot of preparation and many issues arise.*
>
> *It's made me realise the huge barriers out there to community networking. Even seemingly simple things can be hard to arrange and maintain. The opportunity to form relationships is so often denied to people with disabilities, sometimes you think you're really helpless and can do so little for a person. You also get to consider about a person that even though they mightn't be able to do one thing they may be able to do another thing. One shouldn't assume anything about person.*

Over the course of the project 21 people were assisted. However, there was little concrete evidence that natural networks replaced formal services or even made people less dependent on formal services.

One worker commented that there were further hurdles to overcome before this could be achieved:

> *There are social barriers which Michael needs to learn more of... And it may be an expensive lesson for Michael.*

A number of workers appeared to run out of ideas in terms of assisting their clients. This could indicate a lack of experience or skill on their part. An additional issue for some LINKS workers was where to go next within the relationships they had developed. Some were keen to sustain their relationship with the person. For others, there were potential problems in easing out of what had become a very significant and intense relationship both for the person with a disability and the worker. Although the need to distance themselves from the people being assisted was recognised, the workers' level of personal involvement with clients sometimes prevented this goal from being realised. Many workers were unclear as to what the status of their relationship with the people they were assisting would be once the funding for the project had terminated.

Some members of the management team felt that they themselves could benefit from further training in supervision, organisational skills and counselling. This, it was

felt, might help them to respond more effectively to the number of competing tasks and pressures in what was an extremely busy and emotionally laden work environment.

3.2 The Victorian Project

The Sponsoring Body

The Victorian pilot project, the Disability Assessment Service (DAS), was sponsored by the Inner East Region of the Intellectual Disability Services Office (IDS) of the Victorian State Department of Community Services (CSV). Funding of $53,656 was provided for this pilot project for a twelve month period commencing in September 1991. INA funding provided CSV with the opportunity to put more resources towards a project which had already been planned and put in place by the organisation.

CSV provides a range of programs and services for people with intellectual disabilities through the Intellectual Disability Services, which has regional teams (Client Services Teams) throughout the State. The aim of these Teams is to improve the quality of life of people with intellectual disabilities and their families by helping them to access specialist or generic services and live as independently as possible within the community. Services and programs provided or funded by CSV include early intervention, respite care, foster care, recreation services, vocational training, independent living skills training and accommodation and accommodation support. Eligibility for IDS services is determined using a range of IQ and adaptive behaviour tests as well as biographical, medical and other information.

The pilot project was established to explore an alternative to the previously existing approach to assessment and case management. Under the system in place at the time the pilot project was set up, a person requiring assistance would have been referred to a Client Services Team, and, if not already registered with IDS, tested for eligibility by a psychologist. If deemed eligible for IDS services, the client would be accepted as a 'case' by a team member nominated by the team leader. This case management role was invariably undertaken by a social worker who sought, from within the Team, professional assessments, advice and services as considered appropriate. Assessment was not seen as a discrete task within this approach but as part of the whole case management function.

To clarify the complexity of the arrangements over times we list below, in chronological order, the different approaches to assessment and case management **prior** to the INA pilot project, **during** the pilot project, and **after** it.

a. **Case management** which includes some assessment but not as a discrete function undertaken by Client Services Teams. This system was in operation prior to July 1991 and at the commencement of the pilot project.

b.   **Assessment** undertaken as a discrete function by the Disability Assessment Service (DAS) and case management undertaken by Client Services Teams. This system was in existence between July 1991 and May 1992 and during the pilot project.

c.   **Case management** which includes some assessment but not as a discrete function undertaken by Client Services Teams. This system, which was operating at the time of the visit by the evaluation team, was a return to the system in operation prior to July 1991 and prior to the commencement of the pilot project.

d.   **Assessment and case management** undertaken as discrete functions by Client Services Teams. This is the current system which has been in operation since August 1992.

Prior to the commencement of the pilot project the primary role of the Client Services Team (as in a and c above) was to identify a person's needs, and obtain services or put in place mechanisms (such as placing someone on a waiting list) to meet these needs. For some time the CSV had recognised that there were a number of problems associated with this approach:

- there was no system in place to facilitate access to comprehensive assessment, referral and case co-ordination;

- assessments tended to focus on eligibility for the services of a particular agency and availability of services rather than on the overall needs of the person;

- because there was no formal or standard requirement to do so, an individual may not have received an adequate assessment; and

- Client Services Teams lacked the specific knowledge and skills necessary to deal adequately with clients who had physical or sensory problems. These were clients who may also have had an intellectual disability. These clients who, to an extent, had fallen between service stools, often underwent a number of assessments conducted by different service agencies in order to obtain assistance.

The Pilot Project

The project, the Disability Assessment Service (DAS), was originally established to provide, at a regional level, discrete assessment services. It was trialled in one CSV region only. The ultimate aim was to provide a single assessment point for all people with disabilities who resided in the Region. The focus was on the provision of comprehensive specialist information and high quality assessments which would be needs-based and enable case managers to develop case plans aimed at accessing appropriate services.

The project was split into two stages. The first stage involved the development of a Disability Assessment Service for clients with a intellectual disability. In the second stage the service was to be expanded to provide assessments for people with physical and sensory disabilities.

The team for the DAS project was made up of staff already working within the organisation; either in Client Services Teams, in accommodation services, or elsewhere. Two staff (additional to establishment) were expected, with the help of the Commonwealth INA grant, to be appointed to DAS for a period of six months.

Development work for the pilot project began in May 1991, with the first clients being taken on in late July. The establishment of the project was overseen by an Advisory Committee which comprised representatives from CSV, disability service provider organisations and consumer groups. The ongoing role of the Advisory Committee was to assist in the development of policy and practice principles, provide ongoing advice, make recommendations about the future development of the service and oversee an evaluation of the project.

The project manager who was located at the Region's Head Office also managed a number of other CSV activities. The project was administered on a day to day basis by a team leader who supervised the activities of nine 'assessors'. This team comprised professional staff from a range of health and welfare backgrounds. The DAS team was located in the smaller district office within the Region. Once recruited, staff attended a two week induction course which included visits to local service providing agencies, information sessions on health and disability issues, and training in the operational aspects of the project. A large amount of documentation was provided to the project staff such as service directories, procedural manuals and policy documentation.

Once operational the project evolved in various ways. As a first step the DAS team targeted the students of a school (which, for the purpose of this evaluation we call the Perse School) for children with visual and multiple disabilities. CSV funded the respite facility attached to the school. The purpose of this exercise was to determine, through assessment, the long term accommodation and vocational needs of students at the school. This was intended both to inform future service planning within CSV and to develop appropriate plans for individuals. In particular, CSV was interested in making alternative arrangements for students at the school who were using the respite facility as a residential arrangement, and/or were above school age or nearing this.

At the same time, work with the Perse School was seen as an opportunity for the DAS team to gain experience with clients who had physical and multiple disabilities. Although assessment leading to individual plans was the main focus of the team's work, case management was also provided in some instances. The Perse School component of the project was limited to a period of six months.

Following this phase, and after refining aspects of their assessment tool, the DAS team undertook assessments of clients referred to them from a range of sources from

within the community. Once an assessment had been completed the case was then referred, if requested by the client, to the Client Services Team for service plans to be drawn up and activated. These plans were based on information and recommendations provided through the DAS assessment.

Originally the project was intended to operate until July 1992. However, due to a number of factors which we describe below, the project was terminated in May (two months before our evaluation began), and the project staff were re-integrated into the previous Client Services Team structure (see c above) where a non-delineated approach to assessment and case management was undertaken once again.

Because our evaluation was not undertaken until July 1992 it must be regarded as, in some senses, retrospective. The fact that the DAS project had been terminated prior to our visit added a further difficulty to the evaluation task, particularly in terms of sample selection. It has also proved difficult to isolate those parts of the project which pertained to the use of the Commonwealth INA funds from the broader (DAS) project undertaken and funded by CSV. As it turned out, the funds obtained for the INA pilot project provided the salary of one of the workers in the project for one year (from September 1991 to September 1992) instead of two workers for six months each, as had originally been planned.

The worker employed with INA pilot project funds (a social worker) was involved first on the DAS team undertaking assessment and case management for Perse School students and others (see b above). When DAS was disbanded she worked in the integrated system of assessment and case management (see c above). Indeed, at the time of the evaluation, the INA worker engaged for the pilot project was working in a case management role on one of the two Client Services Teams in the Region. As such she supported a number of the clients for whom she had conducted assessments as part of the DAS project. In terms of the evaluation it was her particular involvement with the pilot project and its aftermath which became the focus of our evaluation.

Aims and Objectives

In its original submission the Victorian project's key objectives were:

- to develop and cost a model of user-driven individual assessment, case planning and management for people with a range of disabilities that could be implemented Statewide; and

- to target disability services more efficiently.

It was also proposed to develop and evaluate a 'purchase of service' model.

While these broad aims remained relevant over the life of the project a number of secondary aims emerged. These were:

- to provide assessment and sometimes case management to a group of pupils who were considered to be inappropriately placed at the Perse School, and facilitate a change in their arrangements; and

- to establish the expertise and credibility necessary to become a first point of assessment and referral not only for people with intellectual disabilities but also for those with physical and sensory disabilities.

However, the fundamental aim of the project which emerged for CSV was **to establish an improved system of assessment and case planning: improved because unlike the former system the assessment component would be discrete, comprehensive and based on individual needs.**

As it was, the project was terminated prior to its original completion date, many of its aims being still unmet. Over the period of the project 39 clients had been assisted with assessment and case management by the INA worker. However, a number of barriers to the completion and acceptance of the results of the project were identified.

The first of these was a perceived lack of management support at higher and more central levels of the organisation. One difficulty was that some of those responsible for the original impetus, development and management of the project moved to another job at an early stage in the project's establishment. This appeared to result in a diminished vision and drive at the management level within the Region sponsoring the project. A significant problem for the Disability Assessment Service (DAS) team, recognised by all involved, was that the manager was located in a different office from the DAS team and was therefore not always immediately available to deal with issues associated with the project. This situation, whilst in no way reflecting on the individuals involved, led to day to day management difficulties for the DAS team leader. The dispersed character of the organisation also caused some personnel, external to the DAS, to view it as having too few operational controls.

One worker, external to the DAS team, commented:

> *In DAS there was a specialised comprehensive assessment tool. Assessments have become compartmentalised from on-going work.*

Another said:

> *The DAS project wound up prematurely so it didn't have an adequate trial. It wasn't fitting in with the new model, the direction the Department was taking. If the design had been clearer it might have survived in some form (if it had been admitted that assessment was part of case management and vice versa).*

Interviews with CSV staff working in Client Services Teams during the operation of the DAS revealed somewhat strained relationships between the DAS and the Client Services Team. These seem to have been related to a number of organisational problems some of which may have been avoidable had the implications of the project been more fully recognised in the developmental stages. First, most client services staff felt they had not been made adequately aware of what DAS was trying to achieve. Second, many recognised that there were a number of overlapping functions between the two teams and believed that this had created some tension and confusion. Third, as a result of setting up of the new DAS, the breadth and variety of work undertaken in the Client Services Teams was diminished. Fourth, the large number of assessments processed by the DAS over the life of the project resulted in a backlog of case work for the Client Services Teams which they were unable to manage. Another problem associated with the separation of responsibility between assessment and case management was that assessment staff felt frustrated because they did not know what had happened to their clients, that is, the extent to which their recommendations had been put in place.

Arguably, an even greater problem was that the project resulted from an initiative at the regional level only and, from the outset, did not have the full support or interest of the central administration. This became particularly obvious and also problematic when the central administration decided, in a separate initiative, to introduce a new system of assessment and case management part way through the operation of the project (see Section 3.2). The lack of central management push for the DAS project caused some motivational problems for the DAS team, and, we believe, may have contributed to its early dismantling. It probably also made the task of promoting the project to the Client Services Teams (the case managers working with DAS clients) more difficult.

The experience of the project - for example, the lessons learned, the expertise gained and the tools developed - was not utilised in any systematic way by CSV. The DAS was simply disbanded with the decision to introduce a new system of assessment and case management on a state-wide basis.

There were also a number of difficulties associated with the deliberate separation of assessment from case management (see Section 3.2). Both DAS and Client Services Team staff commented that the DAS assessment process had the potential to raise client expectations for assistance when, in fact, no services were available or were likely to be.

> *Sometimes I got the feeling that I was dangling a carrot when I knew there was nothing for the person to access.*

> *Assessment was done for assessments sake and we didn't know what would happen to clients. There were also problems with boundaries with case management.*

Client Services Teams were often left in the difficult position of attempting to implement the plans derived from the assessment when the services simply did not

exist. As a result, it was the Client Services Teams, not the DAS, which bore the brunt of the disappointment of clients and their families.

The issue of raising unrealistic expectations was also of concern to the Principal of the Perse School and to the parents of the students there. Whilst for some there was an increase in their receipt of services as a result of the CSV intervention, others expressed considerable anger and frustration at the absence of services available to help them and their sons and daughters outside of the school. Their view was that there was little point in conducting endless assessments if nothing was to come of them.

Another factor which inhibited the success of the project at the school was a general suspicion of the motives of CSV. Parents were approached directly by letter in which CSV outlined their specific concerns about the client's place at the Perse School and suggesting a Departmental assessment. Parents experienced considerable anxiety and confusion over this approach, reacting defensively to the letter and in their subsequent relations with DAS staff. Parents did not perceive a problem with their child's arrangements at the school. Indeed, they were most content with these and with the work of the school. In many cases they felt that they had been pressured into participating in the assessment and planning process. A number believed that CSV was, in fact, intending to close the school and feared that their son or daughter would be left with no support at all.

Thus the Perse School component of the pilot project seems to have been characterised by poor communication and methods of consultation between the school and the parents of the students. Because of this, very little success was achieved in finding alternative arrangements for the students which parents were prepared to accept. However, even though the aim was to develop plans to determine the services that would be required it has to be recognised that in most cases there were simply no services available to meet the assessed and immediate needs of the students.

In terms of the assessment process parents believed that CSV staff had spent too little time in discussion with them and in observation or interaction with their offspring for them to be able to form an accurate impression of their needs. Consequently, most were unimpressed with the whole experience and considered the DAS staff to be unprofessional, unrealistic, idealistic and somewhat insensitive to their circumstances. It is worth noting that where a suitable alternative arrangement had been found, the parents concerned expressed considerable satisfaction with both the process and DAS staff involved.

The goal of broadening the role of the DAS to include people with physical and sensory disabilities (the second stage of the project) was not achieved. The long term vision had been that assessment of people with disabilities of all kinds could eventually be undertaken jointly by relevant community-based organisations and consumer groups, the service sector and CSV. A panel of representatives from these sectors were to develop an agreed assessment tool, to be administered through CSV. In this way, there would be one point of assessment only, reducing the need for

multiple assessments at each point of service delivery. Due to resistance from the non-government sector and because the DAS experiment was terminated early, this objective was never fully explored.

The project manager commented:

> *The disability sector (physical/sensory) is very rigid. Organisations like the Perse School create dependency. Parents find it difficult to conceptualise anything different. The resistance from the School was based on the the desire to retain a segregated form of service delivery. The broader assessment process threatens that and parents are sceptical about anything governmental.*

Some of the difficulties faced by government bureaucracies were evidenced by the failure to build up productive relationships with the disability sector providing services to people with physical, sensory and multiple disabilities. While the Department (CSV), due to its long history of direct service provision, was perceived as having a legitimate role in the area of intellectual disability, its involvement in the area of physical and sensory disability was apparently treated with some scepticism by the non-government service sector. Two explanations suggest themselves. The first is that there is a tradition of specialised service provision (including assessment) for people with physical, sensory and multiple disabilities, and consequently the non-government sector perceives itself as having a 'natural right' to the exercise of responsibility for this group of people and CSV staff were perceived as having insufficient expertise to service this group adequately. Second, there is a fundamental lack of trust in the motives of government especially as these pertain to the continued funding of non-government agencies. To some extent, therefore, any dealings with the government sector are strained. There seems to be a barrier to fully open relations between representatives of funding bodies (government) and funded bodies (charitable and/or community groups). Because it controls the purse strings and has the capacity to withdraw funds, the funding body is seen as holding the balance of power. In these circumstances, non-government agencies appear unable to fully disengage themselves from their own organisational and sectoral interests for fear that they will be further controlled by government. Collaboration with government is seen as potentially self destructive to their separate identity and it is perhaps for this reason that they may be unwilling to contribute fully to government-initiated schemes.

3.3 The South Australian Project

The Sponsoring Body

The South Australian pilot project, called CHOICES, was sponsored by the Spastic Centres of South Australia (SCOSA) and was located within the Western Region of Adelaide. INA funding for this pilot was $40,000 over a twelve month period,

commencing in June 1991. The funding gave SCOSA the opportunity to put resources towards an idea already under consideration by the organisation: the development of methods by which individuals with multiple and severe disabilities could be enabled to live independently, that is, in their own homes, within the community.

SCOSA's clientele tend to be people with severe and multiple disabilities. A large proportion also have intellectual disabilities. The organisation provides a range of programs and services including early intervention, respite care, recreation services, educational services, aids and appliances, independent living skills training, and accommodation and accommodation support.

SCOSA is managed by a Board of Directors which is dominated by parents of children with disabilities. Originally the Spastic Centres operated a number of facilities which included, on one central campus, a nursing home, respite care facilities, a school, a day care centre and an equipment design centre. It was typical of a large institution of its day, providing 'whole of life' services using a primarily medical model of care.

More recently, with some resistance from within the organisation, plans were introduced to relocate services in the community, at a regional level. These plans are now well advanced with the closure of the nursing home and day care centre, the introduction of more flexible, community based respite arrangements and the relocation of clients into group homes in the community. The Community Access Service (CAS) has been an important feature of the plan which has accompanied the move to community based accommodation, and, by means of which, adult clients without employment can access activities and/or educational courses during the weekdays. Through this service, Community Access workers, some of whom also work in the accommodation services, facilitate the interaction of clients with the community by providing transport and assistance with community based activities such as TAFE courses, bowling and swimming.

SCOSA currently supports, in a variety of ways, about 300 people, the majority of whom live in the Western Region. Some 140 SCOSA clients attend special schools, whilst others are students within the mainstream school system where they are supported by SCOSA staff. SCOSA also supports 255 clients for up to 50 days respite per year in group houses managed by the agency but owned by the South Australian Housing Trust. In addition, the organisation provides accommodation services for 45 clients. A large proportion of the clients, who may either be accommodated in group houses or living with their families, utilise the Community Access Service.

Clients accessing accommodation or respite services are supported in various ways within the accommodation setting with all forms of personal care and household management tasks. At each house there is usually a house manager assisted by several direct care workers all of whom work on rostered shifts. Only in the last few years has SCOSA departed from a system of 'live-in' house or 'cottage' parents.

To offset the costs of the accommodation service, clients contribute 66 per cent of the Disability Support Pension to SCOSA . Generally, this is either forwarded directly to the agency or to the agency via the parents of clients. The remainder is controlled and managed, in most cases, by parents or guardians and rationed out to clients in various ways. Some will be used to buy items such as clothes and toiletries, or will be put towards the cost of extra-curicula recreation. Some is provided as pocket money or is kept or invested by parents.

A number of the parents of adults and children accessing SCOSA services have found some of the changes made by the organisation over recent years difficult to accept. In particular, they have been reluctant to afford adult rights and responsibilities to their offspring.

In responding to the dramatic changes brought about as a result of the move from its heavily institutional style of operation, SCOSA has also retrained and redeployed a number of its staff.

The Pilot Project

The initial submission for the CHOICES project was developed in May 1991 by a small steering group. The SCOSA Western Regional Manager was responsible for the project. She was assisted by a project co-ordinator who was also in charge of the accommodation services in the Region. A committee was formed comprising the project management, parents and consumer representatives to draw up terms of reference for the pilot project. This involved ten elements or goals. These were:

- to develop a shared living cost accommodation model;

- to identify the needs of each individual within the model;

- to identify mechanisms to assist consumers gain control over their accommodation and other life arrangements;

- to identify mechanisms to assist clients manage and dispose of their own personal income;

- to assist individuals to identify and utilise advocates;

- to educate individuals in the concept of financial management;

- to identify a process whereby individuals could purchase the necessary supports to live in the community;

- to develop a process for assessing individual needs which promotes empowerment and independence;

- to develop and implement training packages for consumers, their families, advocates and staff to facilitate increased consumer skills in financial management and decision making; and

- to produce a report which would provide information to the Commonwealth Government.

Many of these goals were not achieved during the life of the pilot project due to a series of unanticipated obstacles which will be discussed in greater detail later. Nevertheless, considerable progress was made **towards** these aims, and further, a number of transitional steps were identified as necessary to bring the project's objectives to fruition. Perhaps the two most crucial of these were to prepare clients for independence by a gradual extension of their social and community participation and to implement organisational changes within SCOSA which would allow it to provide more individualised and client focused services. SCOSA'S new Corporate Plan was also intended to facilitate these kinds of changes.

Developmental work on the project began in June 1991 and proceeded for three months. During this stage, research was undertaken by SCOSA into alternative living models. A range of possible monetary arrangements were explored and, as part of this process, the financial benefits of different arrangements were investigated. Advocacy groups were also approached about their potential role in the project.

As a first step towards implementation SCOSA originally targeted 20 adults who lived in SCOSA-sponsored accommodation located in the Western Region. Many of these clients had once been residents of the nursing home. Few had much experience in the exercise of choice or in decision making. Over the course of the project 24 clients were assisted.

The second step involved the development of client profiles based on interviews with clients and consultations with parents and carers. This work was undertaken by the project co-ordinator. Subsequently the clients were approached directly, some on an individual basis and others in a group situation, about the issues surrounding shared living arrangements. Initially, all the clients (and their families) who were approached agreed to participate in the CHOICES project and to explore options for shared living. However, some resistance was encountered even at this early stage from parents and others when **practical** steps were taken to begin to put clients' incomes under their own control, for example, by establishing bank accounts and enabling them to have personal access to their accounts. The Board was unwilling to force families to give their offspring access to any portion of their incomes. The Board, therefore, would not enforce changes to the pre-existing arrangements whereby 66 per cent of the amount of the pension was paid directly to SCOSA .

Despite these setbacks, work was undertaken on the development of training packages for staff, parents and clients. It was intended that these would influence the attitudes of staff and families and facilitate clients' independent living skills. In this way it was expected that clients would be able to enjoy greater control over their

lives. Some in-service training to promote CHOICES was provided to direct care staff. However, because progress on assuring additional financial independence for clients had been slower than expected, the related staff training was also slow and, it seemed to direct care staff, unconnected to actual practical initiatives or changes.

Only six clients were, in fact, targeted for a move to new living arrangements. This group was selected because its members were thought to have a strong wish to move, because their families appeared to be supportive and because it was believed that the clients were sufficiently able to make the transition. Two housing units in a suburb of Adelaide were obtained from a local housing association for these clients. Living arrangements for these units were determined, as far as possible, in accordance with the CHOICES model such that clients would make decisions about the hiring and firing of staff and all other aspects of household management. A Committee was formed (involving SCOSA staff, parents and clients) to develop and monitor the move to shared living and a worker was appointed to assist clients prepare for this move. A financial training package was developed to help clients better understand and manage resources in the context of shared living arrangements. This package was implemented for those clients moving to the new units. In the event, two clients who were being prepared by SCOSA for a move dropped out of the scheme. In the main, this appears to have been due to parental pressure.

In the course of the pilot project, the need for greater experience and strengthened ties with the mainstream community were identified as a vital part of the transition to community based living and self reliance. Another committee was formed and a scheme called Community Links was framed to facilitate this. A co-ordinator was engaged to work on the project. While Links began as a peripheral project, it later became an integral part of the CHOICES project.

Community Links was in its early stages of implementation at the time we visited the pilot project. It involved the matching of clients with 'key workers' who had the potential to develop a friendship with clients. It was anticipated that through these friendships clients' interests and skills would be explored and developed at the community level. This involved the encouragement of natural relationships within mainstream society. At the time of the evaluation, matches with 'key workers' had been made for a number of the clients in the pilot project, some initial staff training had been undertaken and client profiles developed for those involved. For some clients, action plans had also been prepared. It was envisaged that in the long run this scheme would be available for all SCOSA clients.

SCOSA management also believed that it was essential for each client to have an advocate who could provide safeguards against possible service and family pressures. However, it did not prove possible to secure access to advocacy for CHOICES clients because local advocacy groups in the area were apparently not appropriately skilled or prepared to assume responsibility for clients with severe and multiple disabilities, particularly those with profound communication difficulties. However, negotiations are now underway with a local agency to train advocates for SCOSA clients.

In summary, although some progress was made in enabling people with severe and multiple disabilities to live more independently and exercise greater choice and control over their living arrangements, many unanticipated problems were encountered.

Nevertheless there have been a number of spin-offs from the project. These have included the development of the Community Links program, the development of an accommodation model which is to become part of the organisation's business (or corporate) plan and which will provide a more client-focused approach to service provision and, finally, the development of training packages for clients and staff.

Aims and Objectives

The original objective of the CHOICES project was **to develop and cost a method whereby individuals with multiple and severe disabilities could be enabled to live co-operatively and take control of all areas of their own lives.** This was to be achieved through individual needs assessment which would identify those areas in which individuals required support and assistance in order to be able to live in shared accommodation.

SCOSA believed that through the CHOICES project it was acknowledging the need to make a greater effort to empower adults with disabilities, provide choices and encourage planning for their futures. CHOICES was also seen by SCOSA as providing the opportunity to shift control of resources to adult clients and to provide more suitable home environments.

Initially the project aimed to explore the opportunities for individuals to use their own incomes for living and leisure options in a way that they had been unable to do in the past. The goal was to put the residents themselves in charge of the management and use of their own resources. As members of the project, clients were to have control of their entire income. This, in most instances, was confined to the Disability Support Pension. Residents, it was proposed, would, in collaboration with fellow residents and with assistance from staff, allocate parts of their incomes to recurrent living expenses such as food, rent and electricity in a shared accommodation arrangements. They would also be encouraged to make individual choices about the use of the remainder of their income. Within such an arrangement, it was envisaged that clients themselves would become individual tenants of the South Australian Housing Trust as this would enable them to be charged a lower level of rent than SCOSA was currently charged as the rental client. In turn, this would release more money for the clients' personal use.

Whilst it has been slow, some progress has been made in securing greater financial independence for clients in the pilot. Over three quarters of the group now have their own bank accounts and a significant number are making choices about how to spend their residual incomes. Two clients have moved into a new house and established themselves on a shared living basis, controlling the appointment and management of support staff and exercising organisational control over matters

relating to household management. These clients have also been able to become individual tenants of the Housing Association in their own right. Another two clients have moved into an artists' colony where they have established similar arrangements.

However, as we noted earlier in the report, most of the goals set for the project were not achieved. For the management team at SCOSA a number of important lessons have been learned from the failure of the pilot project to achieve all its goals for any of its clients. Most significantly, the unexpected resistance to client independence and self management in areas relating to finance, accommodation and leisure arrangements has brought SCOSA management to a recognition that these represent critical barriers to the improvement of the quality of life of their clients.

In general, parents felt left out of the process and feared that a deterioration in their relationship with their adult children might result. In some cases parents were sceptical of the potential of clients to benefit from the scheme and considered that significant damage to their children was possible. Many of these concerns appeared to be associated with the an anticipated breakdown of the parent/child relationship which had existed in a relatively stable form for many years into the child's adulthood. Within this relationship parents frequently exercised considerable power and control. Whilst acknowledging this, some parents felt so undermined by any proposals that might affect their influence over their children that they did not allow them to participate further in the project.

Some clients seemed unable to handle the pressures of such rapid change and expressed bewilderment and confusion about their involvement in the project. Many, it appeared, did not have sufficient experience of the world or adequately developed skills, especially in the area of communication, to make the kinds of important life choices which were being asked of them. Clients may also have faced particular dilemmas when they recognised that the plans they were developing for themselves were contrary to the wishes of their families and that they might, therefore, be putting valued relationships at risk.

Interviews with staff working in direct care roles revealed somewhat strained relationships between the SCOSA management and themselves. Most staff felt they had not been made adequately aware of what the project was trying to achieve, and further, were unsure of their role in it.

Staff tended to feel that their traditional roles as carers were threatened and one might suggest that accommodation staff exercised a level of control and power similar to that of parents. Many of the direct carers who had been with the organisation for a number of years saw themselves as having personal and positive relationships with the clients, which were now being questioned. They had found the pace and style of changes in recent years overwhelming, and their incapacity to cope with these often resulted in considerable anger and frustration directed towards management. The introduction of CHOICES initiatives was therefore seen by these staff not only as a personal indictment of their mode of operating with clients but also as impractical and unrealistic. A number of direct care workers also commented

that they felt torn between the directives issued by SCOSA and the wishes of families.

Workers summarised the problem as follows:

> *Some of the choices they are giving are ridiculous. They over-estimate the capacities of people with I.D. and some of the parents think this, too. The organisation is moving too fast for some its clients. We must take the people shopping to choose their own food. We need three staff and we don't have the resources. And some of the clients don't want to be in control, they don't want to go to a supermarket. They don't know whether potatoes cost 20 cents or two dollars and they never will know and it doesn't matter.*

> *I am pushed in different directions and this is a difficult position. We aren't asked what our perceptions are. They (the management) need people skills, and this is a little lacking. Sometimes it feels like it isn't support at all. They come in with massive changes. We (staff) felt pretty isolated. There is a lot of secrecy about business plans and so on. It often feels like them and us.*

> *Ideas from the ground up get over ridden. Decisions have already been made by the hierarchy.*

Structural and organisational issues were also highlighted in the evaluation. It was difficult to accommodate much of the CHOICES philosophy and focus on individual needs within the existing SCOSA organisation, concerned as it was with the provision of certain services. In addition, SCOSA's role as an employer sometimes came into conflict with its commitment to the clients in the pilot project, for instance, when staff believed they were being asked to undertake activities for which they did not have sufficient resources.

3.4 The Queensland Project

The Sponsoring Body

This pilot project, the Fraser Coast Quality Lifestyles, was framed by a group living in the Fraser Coast area of Queensland. The group comprised people with disabilities, the parents of children and adults with disabilities and professional people, all of whom had a particular interest in improving the quality of life for people with disabilities. Funding of $49,644 over a twelve month period was secured for the pilot project, which began in October 1991 . The group formed an incorporated body called the Fraser Coast Quality Lifestyles Incorporated with the objects of facilitating:

- self determination, empowerment and competency of people with disabilities;

- empowerment of parents and advocates of people with disabilities;

- consumer focused funding;

- identification of personal needs and concerns of people with disabilities and their personal network;

- increased formal/informal supports for people with disabilities;

- appropriate financial strategies to enable people with disabilities to manage their own funding;

- safeguards to enable people with disabilities to assess the quality of the supports they receive;

- community opportunities and education by providing appropriate training activities; and

- operations and outcomes consistent with the Commonwealth Disability Service Act 1986.

The INA pilot project was seen as a way of testing a model which would facilitate these objectives.

Some members of Quality Lifestyles were already active within the local community in attempting to secure supports for people with disabilities such as respite and supported employment and also had strong links with a recently established accommodation support service. This service was, at the time of the evaluation, supporting a number of people by means of 'mentors' who provided friendship and support and assisted clients to facilitate links with other members of the community.

The Pilot Project

The Board of Fraser Coast Quality Lifestyles appointed a project co-ordinator with a background in business management who was also a parent of a person with a disability. The co-ordinator had a strong personal commitment to the project and indeed had played a key role in the development of the submission for its funding.

Preparatory work on the project, undertaken largely by this co-ordinator, involved developing procedures, documentation, assessment and planning tools and recruiting and training staff. This work continued until March 1992. However, the project took on a small number of clients, prior to this, in November 1991, and a second wave in the following March.

Once the developmental stage was underway, the role of the co-ordinator was to supervise the activities of a number of 'consultants' whose primary task was to

assess the needs of people with disabilities and their families and develop personalised plans to meet these needs. The co-ordinator was also responsible for drawing up individual funding plans to be put to government. Had funds been available, it was envisaged that the co-ordinator would have been responsible for assisting clients and their families to gain access to the supports specified in their plans.

Six consultants and a part time administrative assistant were recruited between December 1991 and March 1992. The consultants came from various occupational backgrounds but all had had considerable experience of with people with disabilities. Four held professional qualifications and had worked in the health and welfare field for some time, one was a church Minister, and another was the parent of a person with a disability. Having the 'right values base' was considered to be an important criterion for the selection of consultants. All were employed on a part time basis for the project and were also employed either part or full time in other jobs. Once recruited, consultants underwent a weekend induction course which, for the most part, consisted of instruction in *Framework for Accomplishment* (O'Brien and Lyall, 1987).

It was envisaged that people with a wide range of disabilities would be represented in the pilot project. Clients and their families were selected by the Board and invited to participate. Consultants were matched with clients by the co-ordinator using such criteria as compatibility of personality and age. Clients had the opportunity to select a different consultant if they so wished. The first client/consultant matches were formed prior to the *Framework* training. In this way, the training had an immediate relevance for consultants.

The process of assessment began with a period of familiarisation. Each consultant spent time getting to know their client in a range of settings such as at work, on social occasions or at school. In addition, there were discussions with others close to the clients, including family members, teachers, or neighbours. Commonly, the familiarisation process involved a few hours each week over several months. In assessing the clients' needs and circumstances, in conjunction with the clients and significant others, consultants used the *Framework* assessment instruments.

The consultant next developed lifestyle or action plans. These will be discussed in detail later. Clients and families were also actively involved in this part of the planning process. The final plans were presented to clients and their carers at a meeting, usually held at the client's home. A copy of the agreed plans would subsequently be provided to the co-ordinator and a copy, or parts of it, might also be forwarded to certain service providers.

Individual plans were devised by consultants within a notional ceiling of 30 hours of assessment and information gathering for each client. Consultants could also recommend a review of the clients' circumstances at a later stage. In the course of their assessment, the consultants might provide additional supports to clients by assisting them to obtain a service or putting them in touch with a community group.

Consultants commented that they often spent time outside their formal work hours on client-related issues.

The final phase in the process was the development of costings to achieve the goals specified in the lifestyle plans. These were undertaken by the project co-ordinator and were based on hourly rates for various service categories as specified in the Commonwealth Government funding guidelines for disability services. The notional ceilings (for example, up to 35 hours per week for accommodation support) were also kept in mind in the development of costings and indeed had often played an important part in the formulation of plans.

The co-ordinator also had responsibility for the development of a framework for a brokerage model whereby clients and families could be assisted to obtain the supports required, should the resources specified in the plans become available under an individualised funding arrangement. Within this framework the co-ordinator or broker would be responsible for a) facilitating the assessment of people with disabilities by consultants and the formulation of individual plans, b) developing and monitoring individualised costings on the basis of these assessments and c) linking a limited number of clients (say between 30 and 40) with available resources and supports. This model was never realised in practice.

Aims and Objectives

In its original submission, the main aims of the Queensland project were described as:

- the development of a system of co-ordinators and consultants to assess the needs of individuals; and

- the development of a costing tool for individualised service provision.

This was to be achieved by employing a number of consultants to identify needs and develop strategies to meet these needs, assessment of the resources needed to meet these needs, facilitating service delivery and planning and facilitating community development and education.

An additional aim was to develop mechanisms which would assist clients and their families to have their needs met under an individualised funding approach (such as through a brokerage system) where they would be able to retain basic control of resources.

The Queensland pilot project assisted 25 people and was successful in achieving all that it set out to do. However, one of the frustrations associated with the pilot project was that it lacked the capacity to secure services. In this respect, the project had much in common with the Victorian Disability Assessment Service (DAS) project. In both that project and this, the expectations of clients and their families may have been raised through the development of plans based on need alone, regardless of service availability.

However, considerable effort was made to ensure that clients and their families understood that the project was being conducted as a pilot only.

> *People were generally told that this was a pilot project, and we were told there **might** be dollars. We never raised expectations.*

It was emphasised that the outcomes of the project were assessment, lifestyle plans and costings alone and that securing services and supports would possibly be part of a different, subsequent process. Nevertheless, from our observations, many families were primarily motivated to participate in the pilot project because of the chance, however remote, of obtaining some assistance.

Workers summed up their frustrations as follows:

> *On paper we're setting in place things that are long term, but we're not really able to follow them up. For example, one lady needs to live away from home but she needs 24 hours support and funding isn't available. Its difficult to make people believe that things mightn't happen. Sometimes we have to be careful not to plan things that won't happen. We make a judgement about that after getting to know a person and determining what they can handle. I don't like to leave a person without facilitating something though so that I haven't just taken from them.*

> *They (parents) are empowered by the thought that they don't have to rely on other people to plan futures. They have to rely on other people as far as funding is concerned but when they get the funding they will be empowered. They've been given ideas that they've never thought of before.*

It is worth noting that the policy of the project was to leave each family with at least something, as a means, as the co-ordinator described it, of 'honouring their dreams'. What this 'something' was depended on the individuals involved - it might have been helping to put them on a waiting list for services, introducing them to a community based group, providing information, obtaining some actual support such as respite or a 'mentor', or providing them with the action plans themselves.

One advantage that this project appears to have had over the other three studied was that it was organisationally separate from the activity of service provision. This allowed the workers in the project to continue to pursue the original aims and objectives in a way many of the others were prevented from doing due to the every day pressures associated with providing, procuring or funding services. It also sheltered the workers from the difficult decisions associated with the prioritisation of clients' needs.

3.5 Relationship Between Aims and Methods Used in the Pilot Projects

The projects varied greatly in nature: in their goals and the methods they used to achieve them, in their target groups and in their organisational arrangements.

In two of the projects (ACT and South Australia) the form of contact between workers and clients was unstructured and personalised, mostly involving informal discussion. Both of these projects emphasised a program of personal development for clients. In the ACT project the idea was to get to know clients over time and assist them to build up natural networks within the community gradually. In the South Australian project, individual plans were developed over a period with the help of direct care staff to enable clients to improve their home life, be more involved in personal decision making and gain access to and manage their own finances. This process involved considerable negotiations between clients, staff, and family members.

In the other two projects (Queensland and Victoria) the approach was more systematic, focusing on holistic assessment and planning for clients. This resulted in documented individual plans to which clients formally agreed. Neither of these projects necessarily took into account the likely availability of services, either in their identification of needs or in the plans that were subsequently developed.

In the ACT and South Australian projects most clients had contact with the project workers at least once a week for almost the entire period of the project. In the other two projects, however, more limited contact over a few months, which focused on assessment and planning, was the rule.

3.6 Summary of Reasons Why Aims Were Not Met

Table 3.1 provides a summary of the extent to which the original aims of the four pilot projects were realised in practice. Only the Queensland project met all its original aims. Three of the projects were unable to meet those aims which related to the costing of plans to meet individual needs. In the ACT only limited progress towards the establishment of natural networks for people with disabilities was achieved. The South Australian project went only part of the way to developing and implementing plans to improve the living circumstances of some clients and experienced particular problems in securing greater access to finances for its clients. The Victorian project encountered considerable problems in gaining widespread acceptance of its model of assessment and planning and it was terminated prior to the original completion date.

The major barriers which the evaluation team identified as having limited the achievement of the project's aims are summarised below.

Lack of Commitment to and Understanding of INA

The objectives of the INA exercise were to develop a mechanism for assessing needs and to derive a way of costing these needs. However, there was limited understanding within the pilot projects of their collective role in meeting these objectives. Because of this they failed to develop their own projects in such a way that these objectives could be achieved, even though their submissions appeared to harmonise well with Departmental objectives. This, in turn led them to rely on their own organisational structures and experiences to frame the operations of their projects. Had the Department been able to monitor the projects more closely they might have remained on track to a greater extent than they did. However, in most cases practical and operational aspects were not addressed at the outset, nor were the likely constraints on the achievement of objectives adequately taken into account.

Stakeholder Resistance

Unexpected resistance was encountered, especially in South Australia, to client independence and self management in areas relating to finance, accommodation and leisure. This resistance was found amongst both staff and family members and proved a major barrier to the development and implementation of plans involving change. Much of the resistance appeared to be based on fear: of loosing influence, of loosing valued services and of putting clients at unnecessary risk. In South Australia and Victoria a general lack of understanding amongst stakeholders of the aims of the project and the limited involvement of key players in the project's development, appeared to form an additional constraint.

Limits to Community Responsiveness

Most of the projects emphasised the need to increase the level of interaction in mainstream community activities as a means of personal development. However, experience showed that there were many barriers to this. These, for the most part, related to the absence of suitable networks in the community, to negative community attitudes and to insufficienct time and resources to facilitate ongoing access to the community.

Needs for Experiential Development

All projects recognised that the high level of social isolation experienced by people with disabilities throughout their lives had played a significant part in inhibiting their development and access to opportunities in a range of life areas. The need for greater experience and strengthened ties with the mainstream community were identified as necessary for the transition to community based living and self reliance. Phased programs to facilitate social and decision making skills through practical experience were therefore seen as an important element in the development and implementation of individual plans for people with disabilities.

Table 3.1: The Extent to Which the Original Aims of the Four Pilot Projects Were Realised in Practice

Original aims as stated in submission	Aims met	Aims not met[a]	Reasons for not meeting aims[b]
ACT **Main Aims** • Informally assess the needs of up to 20 people receiving support. • Identify the optimal living situation for each person and assist them to obtain this. • Develop a formula to determine the costs of supporting individuals in normal community settings.	• Informally identified the needs of 21 people. • Allowed limited facilitation of natural networks, but some improvement in level of social interaction.	• Were unable to assist a number of people to obtain an optimal living situation. • Failed to develop a cost formula for the support of people in normal community setting.	• The focus was confined to the enhancement of social networks and therefore failed to address all aspects of an optimal living situation. • There was reluctance to address issues relating to costs.
Secondary Aims • Gradually develop a support network which would actively involve neighbours, friends etc.		• Limited success in the facilitation of support of people through natural networks, especially over time.	• The pilot allowed insufficient time for natural networks to develop, or for the confidence of clients to be gained. Also time did not allow clients to be sufficiently prepared for radical changes in their lives. • Some workers lacked appropriate skills and experience for the tasks they were set.
Victoria **Main Aims** • Develop and cost a model of user-driven individual assessment, case planning and management for people with a range of disabilities, to be implemented state-wide. • More efficiently target disability services resources.	• Established a system of user-driven assessment and case planning and management and undertook a large number of assessments. • Refined existing system of prioritisation for targetting of resources.	• Unable to develop a state-wide system of assessment and case management. • Failed to develop a state-wide cost formula. • Made unsuccessful attempts to collaborate with service sector for people with sensory and physical disabilities. • Were often unable to realise plans based on need only.	• The efforts of the group which undertook the pilot project were superseded by alternative policies of the larger organisation, that is, by the imposition of a different state-wide system during the life of the project. • Claims were made by project workers that costings were being developed in a separate exercise by the larger organisation, rendering this aim irrelevant. • Workers were insufficiently prepared for resistance from the disability sector, service managers and parents some of whom were co-opted into the scheme without their agreement. • Availability of local service provision was inadequate, particularly accommodation and employment.
Secondary Aims • Develop and evaluate a 'purchase of service' model.		• Failed to develop and evaluate a purchase of service model	

South Australia **Main Aims** • Provide a group of 20 clients with funding, on an individual basis, to purchase the support necessary to live co-operatively and to develop links with their local communities. • Teach and empower clients to manage their own financial resources to enable them to access the community services of their choice. • Establish a system of case management and advocacy to assist clients achieve the above.	• Developed tools and training packages for clients and staff to enable 24 clients to **move towards** co-operative living and take control of their lives. • Developed and implemented a program to facilitate social interaction and access to social networks for all clients. • Set up co-operative living arrangements for 4 clients based on elements of the scheme's model.	• Unable to implement the shared living model or part thereof for 20 clients. • Unable to identify or provide funding on an individual basis for the shared living model. • Unable to secure advocacy services for clients.	• Considerable resistance was encountered from staff and parents to any major changes in the living circumstances of clients or to their to financial arrangements. • Insufficient time/resources were available to develop client confidences and skills. • Communication skills were limited amongst the client group making aspects of co-operative living difficult. • Lack of support from the Board to enforce full scope of the pilot project. • No advocacy group was prepared to take on clients with such severe disabilities. • Failure to communicate with and adequately involve stake holders in a timely manner. • The distinctive character of the model was not sufficiently promoted amongst interested parties (residential workers and parents) and this led to misunderstandings and insufficient commitment by workers.
Queensland **Main Aims** • Develop a system of co-ordinators and consultants to assess, plan for and obtain supports to meet the needs of individuals. • Assist up to 50 individuals. • Develop a costing tool for individualised service provision and an 'ideal' life style and supports. **Secondary Aims** • Develop personal profiles and action plans.	• Developed and implemented a system of co-ordinators and consultants who assessed and planned for the needs of 25 individuals. • Developed assessment and planning tools. • Developed a brokerage model for accessing resources and services. • Costed action plans developed to meet individual needs.	• In most instances, were unable to obtain the services and supports identified as needed.	• Unavailability of local services to meet identified need coupled with lack of resources to establish them. • Unrealistic and uncompromising expectations for the level of resources that were likely to be provided to meet people's needs.

Notes: a) Based on the perception of the evaluation team.
            b) Based on the judgement of the evaluation team

Structural and Organisational Barriers

An important organisational issue which proved a barrier to implementation was the relationship of the sponsor organisation to the pilot projects.

Three of the projects were sponsored by agencies which already provided services to people with disabilities. For these organisations, activities associated with the work of the pilots were, to some extent, seen to be part of their existing service and this had an important impact on the success of at least two of the projects. For example, the existing structures through which SCOSA services are provided and through which the pilot was intended to operate, had been established on the basis of philosophies which were contrary to those underlying the pilot project. This prevented the aims of INA from being fully realised.

Within SCOSA, staff were confused about the difference between their every day work and their work with CHOICES. In the Victorian project the problem was quite the reverse in that this project was unable to mesh successfully with the activities and policies of the broader organisation. For this reason it was easy for senior management to terminate the project without this having any impact on the organisation of which it was a part. It was perhaps the very absence of a sponsor organisation operating as a service provider which allowed the Queensland project to meet its aims.

Lack of Local Resources

The limited availability of supports to meet identified needs was a major source of frustration in all the projects. This was a particular difficulty in those projects (Victoria and Queensland) which provided comprehensive assessment and planning regardless of the availability of local resources. As a result unrealistic expectations were raised amongst clients and their families, followed by a good deal of disappointment when supports did not materialise. This situation was equally frustrating and dispiriting for the workers who had put considerable effort into the development of plans which were unlikely ever to be realised.

4 Incorporation of the Principles of INA by the Pilot Projects

Earlier in the report we listed the nine principles upon which INA is based (see Section 1). These principles provided the framework for the activities of the pilot projects. Managers of projects, as part of their brief, were asked to address these. Needless to say the principles were interpreted and implemented in a variety of ways. In this section we describe how each of the projects incorporated the principles and the difficulties they encountered in doing so. Tables 4.1 to 4.4 provides a summary of the analysis undertaken. In our commentary the principles are grouped together, where appropriate.

4.1 Principles

Principles 1 and 8

INA should be multi-dimensional and look at the whole person in the context of their community and the range of formal and informal supports required to maintain their preferred life style (or 'quality of life').

and

INA should provide an individual plan which should consider both Disability Services Program (DSP) funded services and other available generic options in each individual's community.

Only two of the projects (Victoria and Queensland) emphasised the development of multi-dimensional plans for individuals which considered both formal and informal supports. The plans developed in the other two projects were less holistic, being confined in the case of the ACT to social needs and in South Australia to accommodation and social supports.

Principle 2

INA should involve the individual, their family and significant others in the process of assessment and planning.

Although in broad terms this principle was incorporated in the activities of all the projects, the extent to which they involved the client, the family and significant others in the INA process differed.

Table 4.1: The Extent to Which the Four Pilot Projects Incorporated the Nine Principles of Individual Needs Analysis: Australian Capital Territory

Principles of Individual Needs Analysis (INA)	Project undertaken by an accommodation support agency for adults with intellectual disabilities
It must be multi-dimensional and look at the whole person in the context of their community and the range of formal and informal supports required to maintain their preferred quality of life.	• Confined to the individual's social needs and need for friendship. • Confined to the facilitation of informal social networks.
It should involve the individual, their family and significant others in the process of assessment and planning.	• By and large confined to the individual (most clients lived apart from their families). • Identification of needs was an interactive process and not based on formal assessment, observation, or planning.
It should be seen to be independent from service delivery and as independent as possible from the source of funding so that it does not become service defining and restrictive.	• Conscious decision made to separate INA project from service delivery. • Later moved towards integrating with accommodation support services provided by sponsor.
It should be carried out by an accredited person with good local knowledge.	• Workers were not accredited, and not required to have professional qualifications. • Workers lived in close proximity to client's community.
It should be flexible and responsive to meet changing needs.	• Ongoing process of interaction which allowed for revised arrangements to be negotiated by clients and workers.
It should have a strong values base.	• Strong commitment to SRV[a] and normalisation. • Values base was the main criterion for staff selection. • SRV incorporated into staff training which also emphasised the damaging and self serving nature of service agencies.
There should be adequate safeguards and grievance procedures.	• Informal and interpersonal approach to airing and resolution of grievances (internal to sponsor body). • Sponsor body against the formalisation of procedures. • Importance of confidentiality recognised. • Limited documentation of personal information only.
The individual plan should consider both DSP-funded services and other available generic options in each individual's community.	• Not relevant to goals of pilot project which was to natural networks. • Later recognised the value of some generic services. • No formal plans developed.
Planning should be centred around the aspirations of people of similar age, cultural and socio-economic background.	• Activities facilitated by workers of similar age to clients. • Plans emphasised social integration and took into account the preparation needed to enable clients to participate in age and culturally appropriate ways.

Note: a) Social Role Valorisation.

Table 4.2: The Extent to Which the Four Pilot Projects Incorporated the Nine Principles of Individual Needs Analysis: Victoria

Principles of Individual Needs Analysis (INA)	Project undertaken by government agency providing case management for children and adults with intellectual disabilities
It must be multi-dimensional and look at the whole person in the context of their community and the range of formal and informal supports required to maintain their preferred quality of life.	• Took into account the totality of needs (a strongly holistic approach). • Plans devised to maximise use of formal and informal supports.
It should involve the individual, their family and significant others in the process of assessment and planning.	• A formal assessment and planning process involving the individual, the immediate family and others. • Described as a 'user-driven' model but this was generally confined to planning aspects.
It should be seen to be independent from service delivery and as independent as possible from the source of funding so that it does not become service defining and restrictive.	• Assessment and case management provided separately from most other services. However, sponsor body (CSV)[a] is a government agency providing some services, e.g. accommodation.
It should be carried out by an accredited person with good local knowledge.	• Workers were health and welfare professionals from existing staff pool of sponsor body. • Training included familiarisation with local service providers.
It should be flexible and responsive to meet changing needs.	• In-built review dates and regular follow up. • Clients could re-refer with new needs at any time. • Plans covered up to a 5 year period.
It should have a strong values base.	• Workers committed to citizenship and rights based philosophies. • Focus on de-institutionalisation.
There should be adequate safeguards and grievance procedures.	• Formal grievance mechanism (internal to sponsor body). • Professional standards applied to use and storage of personal information. • Written plans formally agreed by clients.
The individual plan should consider both DSP-funded services and other available generic options in each individual's community.	• Assessment identified gaps and needs, but did not necessarily take account of service availability. Formal plans based on assessments took into account available disability services and some generic options.
Planning should be centred around the aspirations of people of similar age, cultural and socio-economic background.	• Planning emphasised, in particular, age appropriate options in a range of life areas. • Plans took into account the preparation needed to enable clients to participate in age and culturally appropriate ways.

Note: a) Community Services Victoria.

Table 4.3: The Extent to Which the Four Pilot Projects Incorporated the Nine Principles of Individual Needs Analysis: South Australia

Principles of Individual Needs Analysis (INA)	Project undertaken by disability agency providing accommodation and day services for people with severe and multiple disabilities
It must be multi-dimensional and look at the whole person in the context of their community and the range of formal and informal supports required to maintain their preferred quality of life.	• Confined initially to home life and financial management. • Emphasis on formal supports and the improvements of these. • Later broadened to the facilitation of informal social networks and the development of life skills and experience.
It should involve the individual, their family and significant others in the process of assessment and planning.	• A relatively informal process, based on interviews (rather than assessment) with clients, a limited number of family members and and workers. • Reliance placed on residential workers to develop and implement plans in collaboration with clients and family. • Plans had begun to be incorporated into formal planning structures.
It should be seen to be independent from service delivery and as independent as possible from the source of funding so that it does not become service defining and restrictive.	• Pilot project integrated with activities of sponsor body (SCOSA)[a], a major provider of accommodation and day services.
It should be carried out by an accredited person with good local knowledge.	• Workers came from existing staff pool of the sponsor body and were experienced and accredited, but not necessarily professionally qualified. • Workers knowledge of the local community varied.
It should be flexible and responsive to meet changing needs.	• Ongoing process of identification of needs which allowed for revised arrangements for clients. • Moving towards more formal monitoring systems.
It should have a strong values base.	• Commitment to normalisation and SRV. • Emphasis on maximising potential for independent living and choice.
There should be adequate safeguards and grievance procedures.	• Formal internal grievance mechanism (internal to sponsor body). • Applied rules to storage of information. • Attempted to enlist independent advocacy support. • Plans agreed by clients.
The individual plan should consider both DSP-funded services and other available generic options in each individual's community.	• Individual plans, where fully developed, were largely based on the sponsor body's wide range of disability services. • Additional plans developed to enhance community links emphasised generic social and recreational options. • Later, some attempts were made to improve access to external disability and other generic services.
Planning should be centred around the aspirations of people of similar age, cultural and socio-economic background.	• Planning emphasised adult appropriate living options for clients. • Plans took into account the preparation needed to enable clients to participate in age and culturally appropriate ways.

Note: a) Spastic Centres of South Australia.

Table 4.4: The Extent to Which the Four Pilot Projects Incorporated the Nine Principles of Individual Needs Analysis: Queensland

Principles of Individual Needs Analysis (INA)	Project undertaken by a group specifically established to trial an assessment and brokerage model for people with disabilities
It must be multi-dimensional and look at the whole person in the context of their community and the range of formal and informal supports required to maintain their preferred quality of life.	• Took into account the totality of needs (a strongly holistic approach). • Plans devised to maximise use of formal and informal supports.
It should involve the individual, their family and significant others in the process of assessment and planning.	• Most emphasis placed on the family unit and significant others. • Client, family and others actively involved in assessment and planning processes.
It should be seen to be independent from service delivery and as independent as possible from the source of funding so that it does not become service defining and restrictive.	• Assessment and planning services separate from service provision. • No formal links with other service providers. However, some indirect links existed.
It should be carried out by an accredited person with good local knowledge.	• Most workers held health or welfare qualifications or, though not accredited, had considerable disability experience. • Experience, rather than accreditation, was the major requirement for workers. • Workers usually lived in the same locality as clients.
It should be flexible and responsive to meet changing needs.	• Procedure allowed for three month follow up. • Proposed brokerage model included regular review of plans.
It should have a strong values base.	• Strong commitment to SRV. • Values base was one of the main criterion for staff selection. • SRV incorporated into staff training and used as the basis for developing individual plans. • Focus on empowerment for families.
There should be adequate safeguards and grievance procedures.	• Formal but interpersonal approach to airing and and resolution of grievances. • Importance of confidentiality recognised, rules applied to storage of information. • Written plans formally agreed by clients and their families.
The individual plan should consider both DSP-funded services and other available generic options in each individual's community.	• Formal individual plans considered disability services and generic options based on need, but did not take account of service availability.
Planning should be centred around the aspirations of people of similar age, cultural and socio-economic background.	• Planning emphasised normalisation principles and age appropriate options in a range of life areas. • Plans took into account the preparation needed to enable clients to participate in age and culturally appropriate ways.

In the ACT project, informal plans were generally a matter between support workers and clients. However, where radical changes were proposed, such as moving house, family members might also become involved.

In Victoria, although plans were formulated at meetings attended by clients and all the people significant to them, it was the client who was most actively encouraged to develop and realise their own plans. For instance, one young woman with an intellectual disability experiencing difficulties in her living circumstances had been encouraged and supported by the project staff to identify the problems with her present situation, examine options available to her and develop the skills to obtain different and more appropriate accommodation. And she was able to achieve all this.

In South Australia support requirements identified to meet individual needs were determined in conjunction with the clients and others who had a close personal knowledge of them, such as family members and direct care staff.

Finally, in Queensland a range of discussions were held with clients and others close to them at the consultation stage. In both the assessment and planning stages, care was taken to actively involve clients and their carers in all aspects of the process. The Queensland project attached particular importance to the involvement of the parents of people with disabilities.

It has to be recognised that the incorporation of the principle of engaging relevant parties is not simply up to the projects. Whilst maximum involvement can be their intention it is not always the case that others are willing participants. For example, in Victoria and South Australia, resistance to involvement was encountered by some of the parents of children targeted by the projects.

Principle 3

INA should be seen to be independent from service delivery and as independent as possible from the source of funding so that it does not become service defining and restrictive.

Only the Queensland project could be said to be independent of service delivery. All other projects were sponsored by an agency charged with providing services to people with disabilities on the basis of the service's own assessment, and this dual role did lead to some difficulties.

In the ACT, for example, INA activities were deliberately separated from the delivery of accommodation support which INA clients were receiving from the sponsor body, FOCUS. This separation, we believe, proved valuable to the clients because they were able to distinguish the friendship provided by the INA workers from the accommodation support provided by other agency workers. However, the experience of the project has brought the sponsor organisation to the view that it is inappropriate to confine the social and emotional support to only some of its clients,

and it is now ensuring that all clients receive this kind of support as part of the accomodation support function. This may have the effect of diminishing the impact achieved by the separation of INA-type support from accommodation support.

In Victoria, the identification of DAS with its sponsor body - a government funding agency with responsibility for a very large clientele - proved a major stumbling block and resulted in a failure to build up relationships of trust with some clients and with parts of the non-government sector. The hostile attitudes of some of the parents of the Perse School students exemplify this tension.

In South Australia, too, SCOSA's commitment to activities associated with the pilot project sometimes came into conflict with its role as an employer and as a provider of accommodation support and day services. For example, whilst the project called for staff to be involved in one-to-one activities with clients, such as going to the pub, many staff complained that they did not have the time to do this.

Principle 4

INA should be carried out by an accredited person with good local knowledge.

Once again, projects held different philosophies on the importance of professional skills and qualifications for their staff. Professional qualifications were not considered by management of the ACT project to be essential or even desirable. Despite this, all members of the management team had qualifications in welfare related fields (for example, physiotherapy and nursing) and considerable experience in the human services sector. The direct care staff (LINKS workers), on the other hand, came from a variety of occupational backgrounds. About half had already attained or were currently undertaking tertiary studies in social science or welfare related fields. However, it was for their values base and lack of connection with the 'service world' that they had been recruited. Arguably workers' lack of professional training as well as their relative inexperience may not, in the long run, have stood them in good stead.

The team for the Victorian project comprised professional staff from a range of health and welfare backgrounds. In general, members of the project, both management and direct support workers, believed that professional expertise and knowledge was required in order to undertake holistic assessments and develop plans for people with disabilities. Whilst there is no strong evidence that Victoria's use of professional staff has resulted in better outcomes for clients, their codes of practice reflected a high degree of professionalism which, in the view of the evaluation team, appeared to result in efficient practice.

Management staff originally recruited to the South Australian project had considerable experience in the disability field and many of the direct care staff had a long history in care for people with disabilities often in nursing or cottage parenting roles. However, the evaluation team felt that the backgrounds of the support staff did not, in general, prepare them for the activities of the CHOICES project and that

many of them did not fully understand its goals. Conversely, in the opinion of direct care workers, the lack of hands-on experience of the management team, meant that they sometimes did not fully appreciate the practical difficulties involved.

Experience with people with disabilities and a good values base were the only criteria for recruitment as a consultant with the Queensland pilot project. However, the professional skills and contacts possessed by the consultants contributed, we felt, to the quality of the assessments and plans developed by them and also proved influential in locating and obtaining services for clients.

Principal 5

INA should be flexible and responsive to meet changing needs.

We do not consider that there was sufficient time to test whether the approaches of the projects provided the capacity to respond to the changing needs of clients. The projects differed in the ways in which they incorporated mechanisms that would allow flexibility and responsiveness. It seemed to the evaluation team that in those projects with more formal approaches (that is, Victoria and Queensland), it was the incorporation of follow up and review procedures which provided the opportunities for flexibility whereas in the other two projects it was the intensive and ongoing character of the personal relationships between support workers and clients which were conducive to an adaptation to changing needs and wishes.

Principle 6

INA should have a strong values base.

All projects demonstrated a strong values base and an orientation towards normalisation. In the ACT and Queensland projects, the workers were familiar with the *Framework* approach developed by John O'Brien (O'Brien and Lyall, 1987) and utilised *Framework's* tools in the process of needs identification. The formal plans developed in the Queensland project were also based on *Framework* material. Both of these projects had access to a number of other resources associated with normalisation principles. In the Queensland project there was a particularly strong emphasis on parent empowerment.

As a consequence of their expressed values base, the workers in the ACT project sometimes came into conflict with other more traditional services. The management commented on the damaging role service agencies can play in inhibiting a person's life experiences and opportunities to form natural links in the community.

Workers in the Victorian project were also committed to the principles of normalisation particularly as they applied to issues such as deinstitutionalisation, integration, and the exercise of rights and responsibilities. In the South Australian

project the focus was on maximising individual potential through experience, decision making and co-operative living.

Principle 7

There should be adequate safeguards and grievance procedures.

Mechanisms employed to protect the clients who participated in the projects took various forms. These included the application of grievance procedures, the use of monitoring arrangements, and the treatment of personal information about clients.

Only clients in the ACT project did not have access to formal grievance procedures, where there was an informal and personal approach to conflict resolution. The South Australian and Victorian projects used the grievance mechanisms which were established as part of the sponsor bodys' operations, while the Queensland project established an internal mechanism where grievances could be resolved through the project co-ordinator.

Whilst one might suggest that for those projects which provide a service to clients, independent advocacy should be available to safeguard clients against the influence of service staff, only in the South Australian project was there an attempt to secure independent advocacy for clients.

All projects employed a range of internal monitoring procedures and applied certain rules to the treatment of personal information.

The accountability of the projects was generally limited, but especially for those projects which were not open to public or other forms of independent scrutiny. One might suggest that clients rights were not, on the whole, adequately safeguarded. This is not by any means to imply that there was an abuse of power or position but rather that clients relied heavily on the goodwill of those upon whom they were dependent to exercise their rights.

Principle 9

INA should ensure that planning is centred around the aspirations of people of similar ages, cultural and socio-economic backgrounds.

All the projects were well aware that it was important for plans to be age appropriate but recognised that most clients would require considerable preparation to realise plans of this kind. However, the interpretation of this principle varied between projects. In the ACT emphasis was placed on activities, for example, such as attending a club, going to the pub, going out to dinner, just as other members of the community. For the Victorian project, on the other hand, this principle was interpreted at a much more fundamental level, for example, in moving from an institution to a house or in leaving school once you turn eighteen. In the Queensland project, both age and cultural appropriateness was emphasised. This was

demonstrated by attempts to relocate two Aboriginal clients closer to their communities and indeed closer to each other. The emphasis in South Australia was on making the choices that we expect all adult people to be able to make in their lives, such as who you live with and what you have for dinner.

4.2 Conclusion

All projects strove to incorporate the principles of INA. However, with the marked exception of the Queensland project, they did not operate independently of existing service structures. Perhaps this was inescapable given the auspicing arrangements of most of the projects which involved existing service providers. There is, of course, almost an inevitability that existing services will be the ones funded to trial innovative models and it should be recognised that, in these circumstances, the value of independent advocacy, which maximises the opportunity for clients' interests to be met, becomes all the more important. On a related point, client empowerment was diminished due to the inadequacy of grievance and complaints procedures in nearly all cases. This situation was exacerbated by the fact that few clients had access to independent advocacy support.

5 Effectiveness of the Different Approaches to Case Management and Brokerage

In the last section, we examined the extent to which the various pilot projects incorporated the principles of Individual Need Analysis. In this section we look at the approaches that they adopted to achieve the principles of Individual Needs Analysis, how these varied between projects, and the effectiveness of the various approaches.

The Department sees case management and brokerage as key elements of an Individual Needs Analysis framework. One of the main aims of the pilot projects was to test different approaches to these, in the hope that as a result of the evaluation, an approach to Individual Needs Analysis would emerge which could have a universal applicability. However, comparing and evaluating the forms of case management and brokerage applied in the four pilot projects has been difficult because, as we have noted earlier, the projects did not appear to recognise the role that the Department intended each project would play in the development of a universal approach or framework.

As a first step, it is important to define the concepts which are to be explored in this section. Rosalie A. Kane et al., (1991), in a study of the costs of case management in long term care, provides three commonly used definitions of case management:

> a service function directed at co-ordinating resources to assure appropriate care for individuals on a case by case basis
>
> management of a specified group of services for a specified group of people
>
> a system under which responsibility for locating, co-ordinating, and monitoring a group of services rests with a designated person or organisation. (Kane et al., 1991: 281)

These definitions clearly contain common features and Kane et al. assert that there is also broad agreement on the principal operational components of case management. These are: screening (targeting resources to particular individuals or groups), identification of needs or assessment, care planning, implementation (service co-ordination or brokerage), monitoring and review.

Brokerage, as a specific concept, requires further definition. For the purposes of this evaluation we define it as the linking of resources (finances, supports and services) to people with identified needs.

All projects, whether intentionally or not, incorporated elements of case management, and perhaps brokerage, in their approaches to Individual Needs Analysis. One project, Queensland, specifically investigated the concept of brokerage and developed a theoretical framework within which this might work in practice.

In addition to exploring the components of case management described above, we shall also look at the effectiveness of the different approaches in terms of the resources used by the projects to achieve their outcomes and, in particular, at the costs involved.

5.1 Approaches to Individual Needs Analysis

Figure 5.1 summarises the approaches to INA which the pilot projects used, especially as these relate to concepts of case management and brokerage.

In this section we discuss some of the implications of the various approaches, especially in terms of their potential application within an Individual Needs Analysis approach.

Screening

Screening refers to the procedures which identify those in the targeted population who need services. As we shall see, in most of the projects the target population was confined to people who were already accessing certain services. From these populations, decisions were then made about who might benefit from INA support. In our view, these decisions were, in many cases, somewhat arbitrary.

In our discussion of screening procedures we shall also examine the process of allocation of workers to clients, as this appeared to be another area where screening occurred.

ACT. Clients of the ACT project were **selected** by the project management team from the pool of existing clientele who were already being supported by the agency. These clients were then invited to participate in the INA project. Thus, eligibiity to the services provided by the sponsor agency served as the first point of screening. From this client base the agency targeted people who they believed to be particularly isolated within their communities. An important part of this process was matching workers and clients of similar age and complementary personalities. Because there was a large group of project workers from which to choose (approximately one worker for every client) the task of matching was relatively easy. Workers were generally responsible for one client.

Victoria. Clients of the Victorian project were either **referred** or they **self-referred**. Because of this, clients' needs had, to some extent, already been identified. At the

Figure 5.1: Four Different Approaches to Individual Needs Analysis

	ACT (LINKS)	Vic (DAS)	SA (CHOICES)	Qld (QUALITY LIFESTYLES)
Screening	Client Selection (management)	Client Referral (clerical)	Client Selection (management)	Client Selection (management)
	Allocation (management)	Review Information/ Allocation (co-ordinator 1)	Review information (co-ordinator)	Allocation (co-ordinator)
Needs identification	Personal Profile and Contact (support worker)	Observation and Contact (Assessor)	Interviews with clients, carers (co-ordinator)	Frameworks Personal Profile and Contact (consultant)
	Social Interaction (support worker)	Assessment (Assessor)	Allocation (co-ordinator)	Assessment (consultant)
	Identification of Needs (support worker)	Review/Assessment Prioritisation/ Allocation (co-ordinator 2)	Identification of Needs (support worker)	Life style Plans (consultants)
Care Planning and Implementation	Facilitation of Options (support worker)	Service Co-ordn (case manager)	Development of Strategies (support worker)	Costing of Plans (co-ordinator)
		Development of Plans (case manager)	Ongoing case management (support worker)	Follow up (consultant)
Monitoring and Review		Follow up (case manager)		Brokerage (co-ordinator)
		Review (case manager)		Review (co-ordinator)

referral stage a duty officer screened requests and completed a referral form. After eligibility was confirmed, an additional form was completed which contained basic personal details, the reason for referral, and information about the client's disability. Any person with a disability could be referred to the DAS team but only people with an intellectual disability (which was determined by means of a series of pychological tests) would be deemed eligible for assistance.

Once the referral information had been reviewed by the DAS team leader (co-ordinator) he allocated cases to individual members of the DAS team. Most often these allocative decisions were made on the basis of the reason for the referral as well as on the particular skills of team members. For example, a referral for vocational assistance might be allocated to the occupational therapist. Each assessor had a working case load of 10 to 20 people at any one time.

The Victorian project was the only scheme to address notions of horizontal equity in the selection of clients for the project, the single criterion being that the person should have an intellectual disability. Because eligibility for assistance was so broadly defined the INA services of assessment and case planning were spread relatively thinly amongst clients.

It is worth noting that later in the process, when clients were prioritised for case planning services (referred to in the project as 'case management and planning'), additional criteria were applied to direct scarce resources to those in greatest need (vertical equity).

Case planning was provided under two conditions. First, it had to be requested by the client and, second, no lead agency or family member could be identified to take on this role. In addition, priority for case planning was given to those clients who were part of a specific target group (for example, the students at the Perse School) or to those who met certain criteria (for example, were at risk of institutionalisation or were being cared for by elderly parents).

South Australia. As in the ACT project, clients for the CHOICES project were **selected** from the pool of existing adult clientele being supported by the agency. From this group the agency targeted clients who, it was believed, would most benefit from the opportunity to exercise greater control over their lives. These clients were then invited by the co-ordinator to participate in the project.

Later in the evolution of this project, the Community Links component (which was separately co-ordinated), targeted all clients using the agency's services. 'Key workers' were appointed from existing direct care staff for this component of the project to work with clients on an ongoing basis.

When it was recognised that the orginal aims of the project would not be fully realised for the majority of clients, six of the more able were targeted from amongst the original group to move into a shared living arrangement.

Queensland. Clients of the Queensland project were also **selected**, in this case primarily by its Board of Management. The policy of this Board was to target people with a range of disabilities, in a variety of domestic arrangements. Prior to their selection, information about potential clients was obtained by word of mouth from the personal and professional networks of Board members and other workers. Participation was by formal invitation to clients and their families.

Workers (consultants) were matched to clients by the project co-ordinator on the basis of the relevance of the consultants' experience and professional skills, and on their personality.

Needs Identification and Planning

Needs identification, often referred to as assessment, relates to the means by which a person's needs and circumstances are evaluated. Commonly, needs identification includes a review of the adequacy of a person's present support arrangements (both formal and informal). Within the projects the approach to needs identification ranged from very loose and informal processes to standardised professional formats.

The use to which information gained in the assessment phase was put to derive individual plans also varied between the projects. We include, in this section, a description of the different approaches to planning because, in two of the projects (the ACT and South Australia) the activities of planning were not easily distinguishable from those of needs identification.

ACT. For most LINKS workers, the process of needs identification was described in terms of 'getting to know' a person, exploring his or her interests, and 'trying out' a variety of activities in a range of settings. Little biographical information about the client was made available to the workers on which to base either assessments or plans.

No formal assessment tool was used other than an initial 'Frameworks Personal Profile', developed over a couple of days by LINKS workers at the beginning of their association with the client. Formal assessment instruments were deliberately avoided because it was thought that these might impose too much rigidity on the development of the relationship between the worker and his or her client.

The process of getting to know a person usually involved spending a few hours a week with them (that is a minimum of about 150 hours for each client for the period of the project). Client contact was most often in the form of social outings. It will by now be apparent that little structure was imposed on the interaction between worker and client. Furthermore, workers were not expected to focus on particular functional aspects of a person's life, but rather on the client's social needs.

No formal plans either were developed in the ACT project. For the most part, LINKS workers relied on their own experiences to identify barriers to social interaction and develop appropriate solutions.

Victoria. Assessments which determined the physical, intellectual, psychological and social needs of clients were made by DAS 'assessors' in conjunction with the client. As part of the assessment process a suitable combination of services were recommended to meet these needs. The DAS team took a multi-dimensional and professionally-oriented approach to assessment.

A distinguishing feature of the process of needs identification in the Victorian project was that it moved from a narrowly to a broadly based assessment. That is, the original assessments were made in terms of the particular presenting need or needs, for example, 'vocation'. Although the assessment subsequently covered functionality in a range of other life areas, recommendations were generally confined to the presenting need or needs. Using this approach, workers with the appropriate professional skills (for example, occupational therapy) would undertake the initial assessment and further assessments could be recommended in other areas if these were considered necessary. It is worth noting that CSV has recently introduced a new procedure which has adopted the reverse approach, that is, one which moves from a broad to a narrow assessment of need.

The DAS assessment process involved interviews with the client over a period of time held at the CSV Office, at clients' homes or at other locations, as well as the completion of individual assessment documentation. The assessment process involved approximately six to nine hours of contact with each client and up to an additional 60 hours in administrative work (including meetings, information gathering and paper work).

The assessment documentation provided detailed information about the client's history, current circumstances and health. It also included a scale of independence in a range of functional or skill areas such as community living, academic ability, domestic and personal care skills, communication/social skills and work potential. Finally, the assessment tool documented recommendations about future service requirements. This documentation was sighted and signed by the client and forwarded at their request to relevant service agencies.

Individual plans were not developed specifically for the pilot project. This was the task of another section of the organisation known as Client Services Teams. These also provided case management services.

Within CSV, a General Service Plan (GSP) - the formal documented planning package developed in conjunction with clients and their families - is offered by the Client Services Teams as part of the case management function. These GSPs are formulated at meetings attended by the client and 'significant others'. Covering ten life areas, the plan describes the client's current situation, sets goals to meet any needs identified, develops strategies to meet those goals and identifies the people responsible to activate those strategies.

South Australia. Informal discussions with clients, carers, and staff were used as the basic building blocks for the CHOICES project and its offshoots - the Links scheme and the shared living initiative. Initially, this task was undertaken by the

CHOICES' co-ordinator. As a first step, a structured questionnaire covering key financial and accommodation preferences was completed for each client. The same questionnaire about the client was completed on the basis of interviews with the clients, their carers, and direct care staff. It covered such areas in the lives of clients as communication, skill acquisition, control over services, income and expenses and accommodation.

After the initial interview the process was more informal. Needs were determined through discussion with the clients and others with close personal knowledge of them, especially direct care staff.

Using some of the information from the initial interviews with CHOICES clients, consumer profiles were developed for the Community Links program. These were formulated in conjunction with house managers and specifically focused on the clients' opportunities for social interaction. The needs indentification process of both the CHOICES and Community Links projects generally involved a few hours a week with each client over a period of some months but the interaction was on a somewhat ad hoc basis and often indistinguishable from other daily activities. Morever, the time included aspects of planning as well as of assessment so that, like the ACT project, the process of needs identification and the process of planning were interlinked and ongoing.

The planning component of the process used in South Australia involved the use of a number of different instruments. Action plans of various types were developed for all three elements of the project (CHOICES, Links and the shared living initiative), usually by direct care staff.

At the time of the evaluation, General Service Plans (the individual planning tools utilised by SCOSA generally) were beginning to incorporate goals associated with CHOICES and Community Links. These plans were developed for each client following a meeting with the client and 'significant others' such as parents, house managers and direct care staff. General Service Plans incorporated a range of goals and strategies to achieve these in key life areas such as education, employment, leisure, and accommodation. As such, they supplemented the other assessment and planning tools developed for the project. In particular, the General Service Plan review process was now being used to explore financial options for clients which would enable them to have greater access to and control of their money.

Queensland. 'Consultants' matched with clients first carried out a **Frameworks** assessment for clients. Following this, the process of needs identification involved a range of discussions between 'consultants' and clients and others close to them. Interaction and observation of clients in a variety of settings were seen as an important way of gaining an overall picture of the clients' skills and interests.

Assessment of needs was generally based on an examination of the person's social networks, their financial position, the amount of choice and control they were able to exercise, their competencies and contributions, their interests, their past and present life experiences, and the attitudes of others towards them. The 'mapping' of a

person's position within their community was widely used as a way of identifying the client or 'focal' person's level of interaction within the community.

The plans which were developed on the basis of assessment incorporated a 'desirable' future for each client. They provided a range of positively framed information about the client including their goals for self development, and the supports required in a range of life areas such as networking, accommodation, and leisure (expressed as hours per week if applicable) and a personal action plan for every support need.

Based on information contained in the action plans, a funding plan was also developed by the project co-ordinator. This provided costings of the number of hours of support which would be required by clients to enable them to achieve specified goals. The funding plan also provided options for the management of funds associated with each type of support recommended and thus incorporated aspects of brokerage.

Implementation (service co-ordination and brokerage)

Implementation refers to the actualisation of plans developed to meet the assessed needs of clients. It usually includes activities which lead to the procurement of services. However, these activities may also include the 'broking' of resources, in the form of services or money, to purchase supports.

Projects approached the issue of implementation in very different ways. For the two projects already providing services to clients (the ACT and South Australia) the actualisation of plans generally involved either the re-organisation of existing supports or the linking of clients into natural (non-funded) support networks. For the other two projects the implementation of plans involved, in the main, the procurement of additional resources or services to meet certain often basic needs.

ACT. In the ACT project, as in the other projects, workers were not provided with any extra resources to implement plans and it was generally thought that the types of things required by clients of this project would not cost a great deal money, but that what clients needed most was the motivation and friendship of the support worker. If costs were involved in the actualisation of goals, these had to be met by the clients themselves. In the main these related to items such as club membership, the price of a movie ticket or new clothes.

Victoria. Once assessment had been completed, planning and service co-ordination were generally provided by Client Services Teams. These involved the development and co-ordination of a comprehensive service package designed to meet the needs of individuals and families. Where possible clients were immediately linked to available services. This process of service co-ordination was not strictly seen as part of the pilot project, (which was confined to assessment) but nevertheless, assessors did provide this kind of help in certain circumstances.

Plans generally emphasised the provision of CSV or other disability services but they often involved aspects that were not service-related. When plans could be actualised by the clients or the families themselves, this was encouraged. In many of these cases the costs involved were borne by the clients themselves.

South Australia. The kinds of plans developed to meet the needs of clients in the South Australian project fell into two main streams: those related to communal living and those related to social interaction.

The successful implementation of the first of these required negotiating the release of financial resources controlled by families and the sponsor organisation to the clients themselves. In addition, it required a systematic and ongoing program of training and skills development in areas associated with independent living. Thus the realisation of the plans for communal living proved to be an extremely difficult and resource intensive process for the organisation, at least in the short term.

For the second stream of goals, relating to social interaction, a re-organisation of existing staff resources was effected such that staff spent discrete time with each client in social activities. Additional training was also provided for the staff involved. Costs associated with these strategies, other than staff support, were borne by the clients.

Queensland. It was not within the charter of this project to implement the plans developed for clients and families, and the project did not have access to resources to do this. However, it became a policy to leave families with at least something. Consequently consultants were involved in a small amount of service co-ordination. Some plans also contained solutions for which there would be no cost or for a cost that the client or the client's family agreed to bear.

As mentioned earlier, however, this project did develop a theoretical model of brokerage within which resources (based on the costed plans developed for clients) could be secured to meet the needs identified. This model is yet to be tested.

Monitoring and Review

Monitoring refers to both the overseeing of client's progress and the assessment of the adequacy of the supports they receive. Review, on the other hand, is related to re-assessment at regular intervals. These elements were operationalised in a variety of ways. These differences had implications for projects' structure and organisation.

ACT. In the ACT project, an informal committee of office staff met on an ad hoc, but usually weekly, basis to discuss issues associated with the pilot project, including client progress.

Managers observed and spoke to their clients on a regular basis and, therefore, were in a good position to monitor the progress of relationships and address any issues which might arise. Within the office environment there was also a good deal of

interaction between members of the management team, providing a wealth of opportunity to share ideas, strategies and concerns about any aspect of the project and about the clients.

LINKS workers were required to submit three-monthly reports to the manager on how they were going with the person they were assisting. These reports took the form of modified Individual Personal Plans (IPPs).

Victoria. In the Victorian project formal staff meetings were held on a regular basis. The team leader attended a range of meetings related to the management of the project. Monthly reports were submitted to the project manager on caseload and staff issues.

Regular meetings were also held to discuss referrals and allocations and to make case presentations. In addition, the team leader set up fortnightly supervisory sessions for individual staff. Discussions between DAS workers and Client Services Teams were also held on an ad hoc basis.

Once a person had been assessed, a General Service Plan developed and all possible avenues for immediate action had been explored, the case would be closed by the Client Services Team. General Service Plans covered a period of up to five years ahead and had a built-in review date, but could be reviewed at any time upon the request of the client. At the time of review a client could request a further assessment.

South Australia. Both formal and informal meetings were held on a regular basis between those involved in the management and co-ordination of the project and its various offshoots. Because she was also the Accommodation Manager for the Region, the project co-ordinator was in regular contact with clients, their families and staff.

A fortnightly meeting was held with house managers at which all issues concerned with the project could be discussed. For the Links project, clients' progress was monitored indirectly by staff reporting back to the co-ordinator about every two to four weeks. Ad hoc meetings with the Accommodation Manager were also part of the monitoring process. The Community Links co-ordinator attended regional team meetings where aspects of the pilot project were regularly discussed.

Monitoring the progress of clients in all three elements of the project (CHOICES, Links, and the shared living initiative) was also possible through individual General Service Plans which were reviewed every six months or so.

Queensland. In the Queensland project regular meetings between the project co-ordinator and the consultants were held every six weeks or so to discuss progress and issues. The project co-ordinator commented that she often met clients or members of their families in ordinary community settings such as the local shops and that this provided additional opportunities for feedback on the project.

Informal discussions between consultants and the project co-ordinator and amongst the consultants themselves, took place on a relatively frequent basis (on average, weekly) and this provided an additonal layer of monitoring in the project. Consultants could also recommend follow up (generally three months after their plans had been in operation) of those clients for whom they thought this would be valuable.

5.2 Resources

The effectiveness of any program must be set against the resources used to achieve its goals. This section explores, as far as we are able, the costs involved in the different approaches to Individual Needs Analysis and, where possible, compares the costs of the different elements in each approach.

Table 5.1 provides a breakdown of the resources deployed in the pilot projects. The table also attempts to identify resources used over and above the INA grant.

From the information contained in this table we are able to estimate cost per client, excluding overheads and other costs not funded by INA. The figures below divide the INA grant by the number of clients assisted.

Costs per client

ACT	$4,095
Victoria	$1,375
South Australia	$1,666
Queensland	$2,083

For a number of reasons, these figures should be treated with considerable caution. First, the different goals of each of the projects required different methods of implementation. This, in turn, resulted in a differing use of resources. For instance, in the ACT project, the nature and level of contact was configured in ways which would assist the client to activate natural networks within the community. Consequently, in this project, support workers needed to spend on average three to six hours per week (a minimum total of 156 hours) on each client at a cost of about $12.00 per hour. In the Victorian project, on the other hand, where needs identification was the main goal, a process of formal assessment only was included in the costs. This averaged out at about nine hours in total per client for direct contact work at about $20.00 per hour and a further 60 hours per client for administrative work.

A second problem in estimating the costs was that in some projects there were many hidden overheads. By including an estimate of the costs of the part-salaries of supervisors, for instance, the cost in the Victorian project rises from $1,400 to approximately $1,600 per client. However, if we also include the costs of ongoing case management, which was not considered to be part of the direct costs of the pilot

Table 5.1: Total Resources Expended on the INA Pilot Projects and Number of Clients Assisted[a]

	ACT	VIC	SA	QLD
Grant	$86,000	$56,656	$40,000	$49,644
Direct Care Workers Funded	23 P/T	1 F/T		5 P/T
Co-ordinators/Assistant Managers	4 P/T		3 P/T	1 P/T
Manager	1 P/T			1 P/T
Other external resources put towards project	• Overheads	• P/T Salary-Manager • P/T Salary-Co-ordinator • Overheads	• P/T Salary-Manager • P/T Salaries-Direct Care Workers • Overheads	
Clients Assisted	21	39	24	25

Note: a) Figures are estimates based on information provided at the time of the evaluation.

project, this figure rises to between $3,500 and $5,000 per client for a one year period. Under the new system which combines the assessment and planning functions, however, the cost is more likely to be around $2,000 per client because there are economies associated with having the same person carrying out both the assessment and case management functions.

In the South Australian project most clients appeared to have contact with workers connected to the project at least once a week. However, the costs associated with this contact were not included as part of the original budget. Direct care workers reported that they spent about three hours per week on CHOICES work at a cost of about $12.00 per hour. By including these, and also the part-salary of the project manager, the cost per client rises from $1,700 to over $2,000.

The costs associated with the Queensland project are relatively straight forward given that the INA grant funded the entire costs of the project. Consultants spent up to 30 hours per client on assessment and the development of plans at a cost of $35.00 per hour. The total cost per client including administrative and managerial expenses was just over $2,000.

A third difficulty in comparing costs relates to the variation in these between clients, depending on the level of support they required. We have noted that the target

groups of the various projects varied in terms of the severity of disability and social circumstances. These differences will have affected the costs of developing the plans and the amount of support required to implement them but we are not in a position to determine the impact of these differences.

5.3 Discussion

In this section we have examined different approaches to case management in the pilot projects. In the course of this analysis, particular issues have emerged which have relevance to the formulation and application of a universal INA framework. The most important of these relate to issues of equity and access.

People with disabilities experience disadvantages within society such that they require specific programs and specially earmarked resources to help compensate for these. The programs are designed to secure the equitable treatment of people with disabilities *vis a vis* the ordinary population in terms of both the types of supports available to them and the opportunities to access these. Programs such as INA which are intended to direct resources towards people with disabilities are formulated within a framework which emphasises equity such that no person with a disability is unfairly prevented from accessing supports.

Our examination of the referral and selection (screening) procedures of the four pilot projects has shown that only one of the projects (the Victorian) adequately addressed the goals of equitable access. Not only was this the only project to pursue policies of horizontal equity, whereby all clients meeting certain criteria were eligible for assistance, it also included a transparent processes of vertical equity, that is, a system of prioritisation which was publicly articulated and thereby open to challenge at any time. In our view the three other projects used more personalised and ad hoc methods of screening and this must raise doubts, not only about their accountability to both Government and client, but also about the fairness of their approaches.

In terms of needs identification and planning, both Victoria and Queenland used structured approaches at both the assessment and planning stages. Unlike the other projects, both of these clearly differentiated between the assessment and planning functions. They therefore addressed questions of need as an autonomous issue. This appears to have resulted in the development of more comprehensive and focused plans which, to a greater extent than seems to have occurred in the other projects, were independent of issues of availability. Even though one recognises that there are disadvantages in too great a separation of need and implementation, there are also certain merits because such a separation allows for a clearer focus to be placed on what the person actually needs. In this way the focus is deliberately shifted, at least at the assessment phase, from considerations of how suitable a person might be to access certain services or how suitable that person might be *vis a vis* other people, to issues of need.

On the other hand, the experience of the Queensland project has shown that there is little point in developing plans outside the context of local service provision. This, as we have noted, merely raises expectations unrealistically and can ultimately diminish commitment to the plans developed.

The Victorian project, in particular, was characterised by a high degree of professional skill and within this project a good deal of emphasis was placed on the application of professional standards and practices. This meant that people could be assured of a standard service in all cases. On the other hand, the loose structures of the ACT project, and to some extent of South Australia also, allowed for personal relationships to develop which took into account the differences between clients.

The issue of implementation (service co-ordination and brokerage) has been the most difficult to compare across the projects. The main reason for this is that two of the projects (ACT and South Australia) concentrated on activities usually found at the post-implementation stage. In this way these projects expended most of their efforts on the provision of a program of ongoing support which also involved continued development and refinement of individual plans. These two projects were, then, about **making changes through a program of support to improve the quality of a person's life** which required, in the two projects, some hours a week spent in individual contact with each client over an extended period.

The Victorian and Queensland projects, on the other hand, focused on the development of plans and the provision of assistance to access services and supports which people with disabilities do not have, and without which they would continue to experience considerable disadvantage. This required an initial one-off burst of resources in terms of assessment and the development of plans, followed by the **facilitation** of supports (service co-ordination). For these projects, in the first instance at least, realising the plans developed for the individuals, involved the co-ordination of supports which were immediately available to meet a person's need followed by longer term strategies to implement the more inaccessible parts of the plans. In general, the development of plans appeared to be a more resource intensive part of the process than the actual assessment, and the co-ordination of services for the implementation of plans is also likely, from what we have observed, to involve considerable ongoing time and effort.

The activities of service co-ordination were not tested fully or costed separately in any of the projects. Judging from their experience, however, one might suppose that it is as difficult and resource intensive to make even a small change in the life of a person with a disability (such as establishing a personal bank account) as to help a person to access appropriate supports.

Client progress was monitored in different ways. Although most projects used formal and regular monitoring procedures involving discussion between direct care workers and their supervisors, some projects also relied on less formal processes. While follow up was a feature of all the projects, only in Victoria was formal and regular review involving re-assessment applied.

As we have already noted, the estimation and comparison of the costs involved in the various approaches that we have looked at, raises difficulties. This is because of the different goals of the projects, the diversity of methods employed to achieve these as well as the varying contributions made by sponsor bodies from their own resources towards the pilots. With these caveats in mind, we may conclude that the data indicate that for the assessment and planning phases at least the per client costs are fairly similar between the projects, that is, approximately $2,000 per client.

6 The Pilot Population and Sample Group

Thus far we have focused on the organisational aspects of the pilot projects. We now consider the people who the pilots assisted. In this section we provide a profile of the clients accepted by the four pilot projects (the client population), highlighting selected characteristics of these clients.

A descriptive account of the client population is important for several reasons. First, an understanding of the nature of the people targeted by the pilot projects enables us to better grasp why the projects employed the methods they did to achieve the goals that they set for themselves and their clients. Second, it allows us to examine some of the major areas of dysfunction and need which characterise this group and which, in turn, may account for the success or otherwise of the projects. Third, knowledge of the client population enables us to determine how far this group is representative of the entire population of people with disabilities in Australia. It also helps us to determine whether the client population has distinctive characteristics which may present particular challenges.

Table 6.1 provides a summary of selected characteristics of the total client population. Where possible, using the 1988 ABS Survey of Disability and Handicap (ABS, 1990), we have compared the client population with the people with disabilities Australia.[2] Table 6.2 looks separately at the characteristics of the clients of the four individual pilot populations.

ABS figures are provided to enable some comparisons to be made with a wider population. However, it should be recognised that such comparisons will have severe limitations. This is because of the special characteristics of the clientele of the pilot projects. On the whole these were more likely to have an intellectual disability than the ABS sample and were a relatively young group. These characteristics will undoubtedly have influenced other variables, such as domestic and employment circumstances.

6.1 The Total Client Population

The client population for the four pilot projects comprised 109 people. Three of the projects assisted between 20 and 25 clients over the period, another (the Victorian

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2   We note that comparisons between data sets based on different modes of collection and using different definitions can be misleading. In addition, in any interpretation of the figures it is important to bear in mind that the client population and the ABS population differ substantially in terms of factors such as age. The ABS survey has a high proportion of aged people; the client population contained very few.

Table 6.1: Selected Characteristics of Clients Accepted for All Pilot Projects

	All Projects		All handicap ABS
	No.	%(a)	%(a)
Total clients	109	100	
Age			
0-10	7	6	
11-20	26	24	
21-30	40	37	
31-40	23	21	
41-50	8	7	
50+	5	5	
Age groups for comparison with ABS			
0-29	74	68	19
30-59	34	31	34
60+	1	1	48
Sex			
Female	58	53	50
Male	51	47	50
Living circumstances			
Lives alone	12	11	16
Group living	47	43	2(b)
Family home	37	34	72(b)
Institution	13	12	8
People from non-English speaking backgrounds	11	10	
Aboriginal and Torres Strait Islanders	3	3	
Family support/contact			
Family contact	84	77	
No family contact	25	23	
Employment circumstances			
Sheltered employment	21	19	
Open employment	2	2	21.5(c)
School	37	34	8.1
Not in labour force (including unemployed)	49	45	31.1
Level of disability			
Mild	13	12	34(d)
Moderate	48	44	30(d)
Severe	48	44	36(d)
Disability type (multiple response)			
Intellectual	94	86	5
Physical	61	56	74
Sensory	32	29	14
Psychiatric	15	14	7
Behavioural	18	17	
Multiple	69	63	

Table 6.1 cont.

| | All Projects | | All handicap ABS |
	No.	%	%
Disability (single response)			
Intellectual only	32	29	4.4[(e)]
Physical only	8	7	70.4[(e)]
Psychiatric only	1	1	8[(e)]
Intellectual and physical only	8	7	
Physical and sensory	2	2	
Intellectual and psychiatric and/or behavioural	17	16	
Physical, sensory and intellectual	2	2	
Multiple (not specified)	35	32	
Other combinations	4	4	
Area of support needed (multiple response)			
Mobility	51	47	79[(f)]
Communication	61	56	19[(f)]
Personal care	83	76	44[(f)]
Continence management	30	28	
Full-time supervision	52	48	

Notes:
a) In this table, **as in all the tables in this section**, percentages have been rounded. Figures calculated as percentage of total handicapped persons (2,120,600 persons) unless otherwise stated.
b) % does not include persons who were visitors to private dwellings and residents in special dwellings
c) type employment not specified
d) figures calculated as % of total handicapped persons less total where severity was not determined
e) figures calculated as % of total persons with disabling conditions
f) figures calculated as % of total handicapped persons less total handicapped persons aged less than 5 yrs

project) assisted nearly 40 clients. The following discussion of the characteristics of the client population is divided into four main areas; disability and support needs, living circumstances, age and sex and occupation. The data we present on the client population are based on information provided by project managers.

Disability and Support Needs

We first look at the kinds of disabilities within the client population:

*   86 per cent of all clients had an intellectual disability;

*   56 per cent had a physical disability;

Table 6.2: Selected Characteristic of Clients Accepted for Each Pilot Project

	ACT		VIC		SA		QLD	
	No.	%	No.	%	No.	%	No.	%
Total clients	21	19	39	36	24	22	25	23
Age								
0-10	-	-	4	10	-	-	3	12
11-20	-	-	10	26	6	25	10	40
21-30	7	33	16	41	14	58	3	12
31-40	8	38	9	23	-	-	6	24
41-50	4	19	-	-	1	4	3	12
50+	2	10	-	-	3	13	-	-
Sex								
Female	11	52	21	54	14	58	12	48
Male	10	48	18	46	10	42	13	52
Living circumstances								
Lives alone	6	29	4	10	-	-	2	8
Group living	11	52	14	36	22	92	-	-
Family home	3	14	19	49	2	8	13	52
Institution	1	5	2	5	-	-	10	40
Family support/contact								
Family contact	11	52	30	77	23	96	20	80
No family contact	10	48	9	23	1	4	5	20
Employment circumstances								
Sheltered employment	11	52	5	13	-	-	5	20
Open employment	-	-	2	5	-	-	-	-
School	-	-	19	49	6	25	12	48
Unemployed	10	48	13	33	18	75	8	32
Level of disability								
Mild	3	14	10	26	-	-	-	-
Moderate	15	71	25	64	3	13	5	20
Severe	3	14	4	10	21	88	20	80
Disability type (multiple response)								
Intellectual	21	100	38	97	18	75	17	68
Physical	1	5	14	36	24	100	22	88
Sensory	-	-	7	18	15	63	10	40
Psychiatric	5	24	3	8	1	4	6	24
Behavioural	5	24	2	5	1	4	10	40
Multiple	9	43	19	49	19	79	22	88
Disability type (single response)								
Intellectual only	12	57	20	51.3	-	-	-	-
Physical only	-	-	-	-	7	29.2	1	4
Psychiatric only	1	5	-	-	-	-	-	-
Intellectual and physical	1	5	5	12.8	-	-	2	8
Physical and sensory	-	-	-	-	-	-	2	8
Intellectual and physical and/or behavioural	7	33	5	12.8	1	4.2	4	16
Physical, sensory and intellectual	-	-	2	5.1	-	-	-	-
Multiple (not specified)	-	-	7	17.9	16	66.7	12	48
Other combinations	-	-	-	-	-	-	4	16
Area of support needed (multiple response)								
Mobility	1	5	10	25.6	23	95.8	17	68
Communication	7	33	17	43.6	21	87.5	16	64
Personal care	5	24	32	82.1	24	100.0	22	88
Continence management	1	5	6	15.4	9	37.5	14	56
Full-time supervision	6	29	5	12.8	19	79.2	22	88

- 30 per cent had a sensory disability; and

- 63 per cent had multiple disabilities.

These figures are not surprising in view of the fact that two of the projects (the ACT and Victoria) targeted people who were considered to have an intellectual disability, the South Australian project targeted people with severe and multiple disabilities, whilst in the Queensland project people with a range of disabilities were targeted.

The **main** areas of primary disability (defined as the most significant disabling condition) were intellectual disability (29 per cent) and intellectual and psychiatric disabilities combined (16 per cent). Only seven per cent were reported to have a physical disability, alone. This distribution contrasts sharply with the distribution of disability in the general population in Australia. The 1988 ABS Survey of Disability and Handicap (ABS, 1990) showed that for 70 per cent of people with disabilities, the primary disabling condition was physical, for 18 per cent it was sensory and for 8 per cent it was psychiatric. Only 4 per cent had a primary disability which was intellectual.

The disabilities of the client population were at the severe end of the spectrum. Only 12 per cent of the clients had a disability which was assessed as mild. Most clients' disabilities were reported as being either moderate (44 per cent) or severe (44 per cent). In contrast, the 1988 ABS Survey showed similar proportions of people at all levels of disability (that is, 36 per cent as severe, 30 per cent as moderate and 34 per cent as mild).

Generally, the clients of the four pilot projects were highly dependent on others to meet even their basic needs. Personal care support was considered necessary for about three quarters of the clients, 56 per cent required assistance with communication and just under half needed help with mobility. Forty-eight per cent of all clients were assessed as requiring full time supervision. As Table 6.1 shows, for the population with disabilities as a whole, a lower proportion required help with personal care, but a higher proportion required help with mobility.

Living Circumstances

Although the majority of clients lived apart from their families, the greatest proportion resided in group settings and were assisted by direct care staff (43 per cent), reflecting their high dependency on others for support. Eleven per cent of the client population lived on their own, some with and some without formal assistance. Another 34 per cent lived at home with their families and 12 per cent resided in institutional settings. Of those who did not live with their families many, nevertheless, had fairly regular contact with them. In contrast to the client population, 72 per cent people with disabilities living in households in Australia, lived with their families.

Sex and Age

The clients of the pilot projects were, as a group, younger than the people with disabilities in Australia. Clients under 21 years of age accounted for just under a third of the clients. The majority (65 per cent) were of working age, that is between 20 and 50 years and a small proportion were over 50 years of age (five per cent). The average age of the client population was 26 years. In contrast, the population with disabilities in Australia were much older, almost 50 per cent being 60 years or over.

There were slightly more women than men in the pilot population and this parallels the sex ratio for the Australian population with disabilities.

Occupation

We have noted that the majority of the client population were of working age but, perhaps not unexpectedly, the largest proportion did not have a job. Of the 72 people of working age (defined here as between 20 and 50 years) just under 70 per cent were unemployed. Only 2 people had a job in open employment although 21 people were in sheltered employment, generally in sheltered workshops. Most of the people in sheltered employment resided in the ACT, connected as they were to an organisation which provided employment of this type.

There were similar rates of employment amongst the Australian population with disabilities generally but a higher proportion of the client population were not in the labour force.

Over one third of the client population were attending school. A proportion (11 per cent) of these were over 20 years of age. Most of those of working age who were not in employment were attending day activities.

Summary

The clients of the four projects had a multiplicity of difficulties and overall were a highly dependent group of people. In many respects they were not representative of people with disabilities in Australia, being much more disabled. A far higher proportion of the client population than of the Australian population with disabilities had an intellectual disability, a lower proportion had a physical disability and the number of people with multiple disabilities was higher amongst the client group. In addition, a much higher proportion of the clients than of the population generally had a disability at the severe end of the spectrum and, concomitantly, had high support needs. Part of the reason for the differences between these two populations is that the clients of the projects were primarily selected from existing service agencies and as such were particularly vulnerable and at risk. As we have noted, the disparity in the ages of the two populations is also likely to account for other differences.

In the following section we draw out some of the distinctive characteristics of the clients in each of the pilot projects.

6.2 Individual Pilot Populations

Appendix Three provides a full description of the client populations of the four pilot projects. In this section we briefly summarise the main characteristics of these populations and describe the differences between them. As will be observed, there is substantial variation between the project populations.

In terms of age, clients in the ACT were generally older than in the other projects and in the Queensland project they tended to be younger.

Whereas in the ACT and South Australia the majority of clients lived in group settings assisted by disability service staff, in both the Victorian and Queensland projects the majority of clients lived in the family home.

Most of the people who were in sheltered employment were clients of the ACT project. However, a small number of people were accessing sheltered employment in both Victoria and Queensland. In South Australia, however, clients were either still at school or were unemployed. In the Victorian project the majority of the clients were still at school.

There were marked variations in the types and levels of disabilities between the projects. In Victoria and the ACT the majority of clients had moderate levels of disability whilst in the other two projects the majority were reported as having a severe disability.

Whilst in all the projects the overwhelming majority of clients had an intellectual disability, in the South Australian and Queensland projects, in particular, large numbers of people also had physical and sensory disabilities.

Finally, in the South Australian and Queensland projects a large proportion of clients required considerable assistance with mobility, communication and personal care, whereas the clients in Victoria and the ACT were, as a group, far more mobile and able to communicate.

6.3 The Sample Population

We noted earlier that the sample of clients for the evaluation comprised approximately 40 per cent of each of the pilot populations. The samples were selected on a random basis wherever possible, controlling for living circumstances and level of disability. These two variables were used to stratify the sample because it is believed they have a significant impact on a person's support needs. We also interviewed, when possible, the informal carers of the clients in the sample.

Table 6.3: Selected Characteristics of the Sample Population and the Total Client Population

	Sample		Total client population
	No.	%	%
Total clients	34	100	100
Age			
0-10	3	9	6
11-20	8	24	24
21-30	12	35	37
31-40	6	18	21
41-50	3	9	7
50+	2	6	5
Sex			
Female	17	50	53
Male	17	50	47
Living circumstances			
Lives alone	6	18	11
Group living	10	29	43
Family home	10	29	34
Institution	8	24	12
People from non-English speaking backgrounds	4	12	10
Aboriginal and Torres Strait Islanders	2	6	3
Family support/contact			
Family contact	25	74	77
No family contact	9	27	23
Employment circumstances			
Sheltered employment	6	18	19
Open employment	2	6	2
School	10	29	34
Unemployed	16	47	45
Level of disability			
Mild	6	18	12
Moderate	9	27	44
Severe	19	56	44
Disability type (single response)			
Intellectual only	16	47	29
Physical only	1	3	7
Sensory only	-	-	
Psychiatric only	1	3	1
Behavioural only	-	-	
Multiple (not specified)	16	47	32
Area of support needed			
Mobility	16	47	47
Communication	23	68	56
Personal care	16	47	76

Unlike the information on the total client population which is based on the assessments of workers, the information we provide on the sample population is self-reported, that is, derived from interviews with clients and carers.

Table 6.3 provides a description of selected characteristics of the 34 clients included and compares these with those of the total client population. In comparing the aggregate sample group with the aggregate project population it should be borne in mind that the clients of each project constituted a different group with distinct characterisitics. In respect of their social characteristics that is, age, sex, ethnic backgound and living circumstances, the two populations compare reasonably well. However, as Table 6.3 illustrates, in terms of type and level of disability and the kind of support needed there are some differences. We attribute these, at least in part, to the effect of selecting substitutes for the clients who we were not able to interview and to the possible understatement by clients of their support needs. A more detailed account of the characteristics of the two populations and the differences between them as well as a description of the carers interviewed is given in Appendix Four.

7 Outcomes of the Pilot Project

7.1 Overview

In previous sections we looked at the approaches of the various pilot projects and the principles upon which these were based. In this section we are concerned with the **impact** of these approaches and principles on the clients of the projects themselves, on their carers and on the agencies which sponsored the projects.

This section discusses the outcomes of the work of the projects. By 'outcomes' we refer firstly to the extent to which the goals set for individuals by the projects were realised; secondly to the changes that occurred in the lives of individuals as a result of their involvement in the pilot project; and thirdly to the level of satisfaction experienced by clients and carers as a result of this involvement. Finally, it refers to the impact of the pilot project on the projects' workers and on the organisation of the projects themselves. This section deals with all these aspects of outcome.

We have noted earlier that the lack of information about the sample population prior to the implementation of the project makes it difficult to postulate causal links between the activities of the pilot projects and outcomes for clients and carers. In this context it is worth asking to what extent one can reasonably expect changes in a person's life as a result of their participation in a project whose primary purpose was simply to assess and plan for individuals. In addition, because a number of the projects, being sponsored by service delivery agencies, were already involved with many of the clients, it is impossible to judge whether the outcomes for clients would have occurred in any case. Moreover, whilst the evaluation would have benefited from a comparison of outcomes, the projects' diverse aims and methods, in large measure, prevent this.

Despite these difficulties our evaluation paid considerable attention to the question of outcome. A number of questions were asked which relate to the satisfaction of both clients and carers with the process with which they were involved, and to their perception of what they gained from this process. To some extent, we are also able to determine, by means of parallel sets of questions asked at the first and second stages of evaluation, whether these outcomes were maintained over time. Despite the inherent interest of these findings, it should always be borne in mind that the small size of the samples effectively decreases the ability to make statistically sound assertions about significant differences between projects and over time.

A significant problem associated with the interviews with clients was that most had an intellectual disability and a substantial number also had communication difficulties. Many were unable to rely on their memories to confirm points of fact, such as how often they saw the project worker or when they last went to the doctor. Nor were many of the clients able to discuss in any depth their attitudes or feelings. Some also found it difficult to tackle even simple issues on a conceptual level. For

people with these difficulties, who constituted the majority of clients, the interviewers found it necessary to move away from the formal questionnaire and to pose simple options with which the client could agree or disagree. Consequently the true feelings and attitudes of the respondent may not have been exposed and the basis upon which comparisons between clients could be made has been lost. However, as far as possible and with the agreement of the client, we attempted to clarify doubtful responses to questions with others close to the client, such as formal or informal carers.

7.2 Outcomes for Clients

Needs and Outcomes

In general the workers believed that the projects had had a positive impact on both clients and carers. Whilst in the ACT and South Australia progress was acknowledged to be slower than expected, workers, nevertheless, believed significant changes in the lives of their clients were occurring, and that this was due, at least in part, to the activities of the pilot project. A worker from the South Australian project commented:

> *There have been more opportunities for clients to make choices and decisions. Some people are moving to better accommodation and other people have broader life options. Bank accounts have been established for clients. Attitudes and approaches of staff are now more individually responsive. A number of social supports have been established. For families there has been a slow realisation of possibilities and options for their members with a disability.*

In the Victorian project the main outcomes for clients cited by workers were the development of individual plans based on needs, the dissemination of information, the empowerment of clients, the co-ordination of services, and in some cases the provision of services.

The manager of the Victorian project commented:

> *Outcomes have been varied but pretty positive......The project linked clients into appropriate services. It gave clients greater freedom, confidence and options.*

A worker from the same project said:

> *The majority of outcomes for clients have been positive and clients' ability to manage their own affairs has generally improved. Strategies and options have been developed also.*

Similar outcomes were reported for clients and carers in the Queensland project, but with an emphasis on the empowerment of the families of people with disabilities and the establishment of support networks. An increased level of social interaction and confidence was also believed to have resulted from clients' involvement in the project.

As the co-ordinator commented:

> *People now know what is available and what options are possible. They know someone is there for them and cares about what they want. The whole process has been empowering for families. They are following up on plans and making enormous strides. They are also getting involved in the development of support and are sitting on committees.*

In general, clients believed that their participation in the project had been helpful in a number of ways and that the benefits gained had, by and large, been sustained over time. It is important, however, to bear in mind, that the clients of services are highly dependent people who are more likely to respond positively than negatively to any help they are offered or receive.

Table 7.1 shows, for each client, the original needs identified by INA workers and the outcomes achieved at both stages of the evaluation. The names given to clients in this table are not the names of the people interviewed. The information in this table must be treated with some caution as workers provided their views on the original needs of clients towards the end of the life of the project and the information is therefore retrospective. The outcomes reported in this table derive from a combination of sources: clients and carers, workers and the observation of the evaluators. As far as possible, we link in this table the needs identified to the outcomes achieved.

The table shows that all clients obtained at least something from their participation in the project but that there was a wide variation in outcomes both between clients and projects. It appears that some of the greatest difficulties were experienced in moving towards preferred accommodation options for clients. Another difficulty to emerge was in the maintenance of relationships and friendships over time. It is of some interest that employment was rarely set as a goal by workers. This may be due to the considerable degree of disability experienced by this group of clients. On the other hand, it may reflect a realistic view of the possibilities for achieving employment-related goals.

Table 7.2 compares the situation of clients at the two stages of the evaluation in a number of different areas of life. It indicates whether the status of clients at the beginning of the evaluation had been sustained, or had regressed or progressed. There was little detectable progress for clients once funding of the project had ceased. On the other hand, the table suggests that, overall, the status of clients did not regress once the projects had ceased to be funded. The only area in which we

Table 7.1: The Extent to Which Needs Identified for Individual Clients in the Pilot Projects Were Matched by Outcomes

Needs Identified in Assessment	Outcomes - Stage 1[a]	Outcomes - Stage 2[a]
LINKS **Australian Capital Territory** **1 Michael** • Budgeting, social skills • Motivation • Friendships Friendship with neighbours • Independent community living • Hygiene, health, diet • Recreation	Improved living skills Friendship with support worker Independent community living Increased recreational opportunities	Increased social interaction Increased confidence and motivation Improved living conditions Improved health and diet Regular recreation
2 Patrick • Links with people with similar interests • Regular leisure and social activities • Individual support and friendship • Improved accommodation circumstances	Joined recreational club and attended regularly. Attended church. Friendship with support worker Changed living circumstances	Spasmodic social and recreational activities. Diminished contact with support worker Increased confidence and improved communication skills
3 Rob • Confidence and motivation • More suitable employment • Individual support and friendship • Improved accommodation • Regular leisure and social activities	Friendship and outings with support worker Advocacy through support worker	Continued, but decreased level of interaction with support worker Increased family contact
4 Cathy • Links with people with similar interests • Motivation • Social skills and personal development • Individual support and friendship • Community living	Attended church Improved social skills Friendship and outings with support worker Obtained employment	Intensified church activities Diminished contact with support worker Left employment
5 Toni • Friendship • Community interaction • Better living conditions • Confidence and assertiveness	Friendship with support worker Increased community interaction Changed living circumstances Greater assertiveness More open about feelings	Diminished contact with support worker Loss of confidence and motivation

Needs Identified in Assessment	Outcomes - Stage 1[a]	Outcomes - Stage 2[a]
6 Chris • Community interaction • Living skills • Individual support and friendship • Confidence	Regular outings Several friendships in community including support worker	Improved living skills Improved communication and confidence
7 Sol • Family contact • Connections with community • Friendships • Confidence • Health and personal care	Outings Friendship with support worker Increased lead in social interaction Improved health	Receiving home help Attendance at clubs Broader circle of friends Improved communication Improved personal care, presentation and health
8 Jenny • Community living • Supported employment • Social interaction • Respite	Friendship with support worker Outings with support worker Respite	Diminished contact with support worker Increased use of respite
DAS **Victoria** **1 Phil** • Justice issues • Behaviour modification • Social skills	Support with justice issues	Personal development training Vocational training Case management
2 John • Pension eligibility • Employment • Confidence, self esteem	Assistance with pension eligibility Access to supported employment Improved confidence	Obtained pension Obtained open employment Increased self esteem Individual plan
3 Morag • Move from institution • Independent living skills • Social skills • Motivation • Travel training • Health, hygiene and exercise	Moved to less institutional setting Attended personal development programs	Living training program in community Increased motivation and interest Travel training Swimming program Increased family contact Case management

Needs Identified in Assessment	Outcomes - Stage 1[a]	Outcomes - Stage 2[a]
4 Sheila • Anger management • Living skills • Change in living circumstances • Justice issues • Budgeting • Debt management	Improved confidence Change in living circumstances Assistance with justice issues Improved budgeting skills Assistance with debt management Increased family contact	Attending anger management program Change in living circumstances Case management
5 Natalie • OT assessment • New wheelchair • Day programs • Health issues • Assistance in home	OT assessment Wheelchair funding obtained Access to day programs	Wheelchair obtained Revised day program Improved health In home help Individual plan
6 Peter • Employment • Pre-vocational training • Day activities • Recreation • Social skills and motivation	Waiting list for workshop placement Attended cookery classes Information	Attending pre-vocational training program Improved motivation Individual plan
7 George • Community living • Motivation • Stimulation and recreation • Living skills • Personal development	Residential placement in community Toilet training, walking with assistance, eating skills, individual plan	Increased motivation Increased recreation Progress with living skills and personal development
8 Sarah • Community living • Living training • Employment • Appropriate day activities Individual plan	Plan for community living Plan for changed day activities	
9 Helen • Appropriate accommodation in community	Information	
10 Gloria • Appropriate accommodation in community	Information	

Needs Identified in Assessment	Outcomes - Stage 1[a]	Outcomes - Stage 2[a]
11 Angus • Appropriate accommodation in community	Information	
12 Ashley • Appropriate accommodation in community • Taxi access	Use of taxis Individual plan	
CHOICES **South Australia** **1 Rosemary** • Co-operative community living, living skills • Communication • Social skills • Control over finances	Increased choice and decision making Living skills training Increased assertiveness Key worker support Personal bank account	Moved to co-operative community living Improved relationships with others
2 Bruce • Co-operative community living • Choice and decision making • Community interaction and recreation • Anger management • Control over finances	Living skills training Increased choice and decision making Improved recreational opportunities Key worker support	Improved decision making skills Increased choice Improved anger management
3 Marina • Co-operative community living • Decision making and choice • Social and recreational experiences • Control over finances	Increased decision making skills Greater confidence Increased social interaction Key worker support	Regular one-to-one social outings Increased family contact
4 Anthony • Co-operative community living, • Communication • Recreation • Employment • Control over finances	Living skills training Improved communication Key worker support Recreational outings (one on one) Pre-vocational training Personal bank account	Co-operative community living

Needs Identified in Assessment	Outcomes - Stage 1[a]	Outcomes - Stage 2[a]
5 Steve • Co-operative community living • Social skills and personal development • Friendship • Living skills • Health and Hygiene • Control over finances	Individual support Joined club	Improved social and personal skills Key worker support Regular recreational and social activities Increased family contact
6 Judy • Co-operative community living • Behaviour management • Community interaction • Choice and decision making • Control over finances	Key worker support Personal bank account	Improved behaviour Increased decision making Improved communication
7 Greg • Co-operative community living • Individual support • Choice and decision making • Therapy • Health issues • Social and recreational opportunities • Control over finances	Key worker support Recreational outings	Improved choice and decision making Therapy aids Improved equipment/aids Joined clubs
Quality Lifestyles Queensland **1 Dennis** • In home/out of home respite • Equipment and aids • Access to mainstream schooling • Ramp • Path	In home/out of home respite Parent motivation Access to mainstream schooling Individual plan	Increased respite Arm supports Increased access to mainstream schooling S for bathroom modification
2 Lynda • Supported community living • Supported employment • Individual support • Self esteem • Personal presentation • Pre-vocational skills • Household tasks and budgeting • Community interaction • Respite for carer	Regular 'mentor' support Improved self esteem Improved personal presentation Improved household skills Regular outings in community Institution based respite Information Individual plan	Permanent placement in institution Decreased 'mentor' support Decreased self esteem Deterioration in social skills, behaviour and motivation

Needs Identified in Assessment	Outcomes - Stage 1[a]	Outcomes - Stage 2[a]
3 Mark • Hydraulic lift • Carer respite • Access to mainstream schooling • Exercise/recreation	Access to mainstream schooling Individual plan	Respite Increased access to mainstream schooling
4 Jackie • Employment • Individual support and friendship • Self esteem • Independent community living	Employed at workshop but subsequently left Regular 'mentor' support Independent community living Individual plan	Pre-vocational training Broader circle of friends Improved self esteem Joined clubs
5 Carol • Supported community living • Social outlets • Living skills and personal development • Behaviour management • Respite for carer	Limited 'mentor' support Individual plan Holiday respite	Permanent placement in institution
6 David • Basic stimulation • Supported community living • Individual support and friendship • Personal development • Family contact	Limited family contact Individual plan	Likely placement in institution
7 Julia • Personal development and hygiene • Individualised support and friendship • Supported community living • Social interaction and recreation	Limited personal development Limited individual support Individual plan	Likely placement in institution

Note: a) Based on interviews with clients, carers and workers, as well as observations made by the evaluation team.

Table 7.2: Comparisons of Selected Clients' Selected Life Circumstances: Stages One and Two

	All projects			
	Stage 1 (n=34)		Stage 2 (n=30)	
	No.	%	No.	%
Employed	8	24	7	23
Having vocational training	9	27	11	37
Happy with living arrangements	26	77	23	77
Relies on pension for main source of income	31	91	27	90
Has a special friend	24	71	22	73
Has a special friend who does not have a disability and was not a staff member	4	12	10	33
Taking medication	26	77	19	63
Has fun every week or more	28	82	21	70
Has fun with people without disabilities (not staff)	8	24	13	43
Doing a recreational course	19	56	20	67
Has contact with family every week or more	25	74	21	70
Needs more help	11	32	8	27

can detect a deterioration was in 'having fun every week or more'. In two of the projects this can be attributed to seasonal changes and the cessation of sporting activities associated with these.

We need to remember that INA funding was not intended to provide extra resources to purchase services. If the Department had hoped that this 'kick' start' funding would have a **incremental** effect, this did not seem to have occurred. It seems clear that to make continued progress in their lives, people, at the level of disability of this client group, will need ongoing supports that are, in many instances, likely to be resource intensive. As one worker commented:

> *To stop now would be like teaching a person to swim half way across a lake and just leaving them to sink.*

Satisfaction

Table 7.3 describes clients' level of satisfaction with particular aspects of the project at the two stages of the evaluation. Satisfaction here relates to whether clients:

- liked the worker (referred to as support worker) who undertook INA activities;

- thought the support worker listened to what they had to say;

- could talk to the support worker about the things that worried them;

- saw the support worker enough;

- thought there had been a positive change in their lives because of the help that the support worker had given them; and

- were happy with the help that the support worker had given them.

Not all the questions which relate to levels of satisfaction were repeated in the second stage interview as once the project had terminated some questions became irrelevant.

It will be observed from the table that a large number of the questions we asked sought the clients' opinion about their INA support worker. This was because, for many, the project was only recognisable in terms of their involvement with a support worker.

Overall, just under two thirds of the clients (65 per cent) said they were happy with the help that they received, whilst 17 per cent said they were not happy with the help. The remainder were not able to answer this question. Most of those who were unhappy with the assistance they received indicated that this was either because they had not been provided with the kinds of support they thought they needed or, because their involvement with the project had resulted in tension within their families. As one client endeavouring to move out of a psychiatric institution commented:

> *She* (the support worker) *helps me how she can but its very*
> *slow, too slow. I have moved from the wards to the hostel and*
> *its a bit better but its still a dump. I think the Government*
> *should do more so that people can have a better life.*

The level of client satisfaction was replicated in Stage Two of the evaluation when, overall, 73 per cent indicated that they were happy with the help they received. This was a small and probably insignificant increase in satisfaction between the two stages of the evaluation.

Client satisfaction varied considerably between the projects, being much higher in the ACT and South Australia than in the other two projects at the first interview.

Table 7.3. Level of Client Satisfaction: Stages One and Two

Areas of Satisfaction	ACT No	ACT %	Vic No	Vic %	SA No	SA %	Qld No	Qld %	All projects No	All projects %
Stage One	(n=8)		(n=12)		(n=7)		(n=7)		(n=34)	
Liked support worker	8	100	5	42	4	57	3	43	20	59
Non-response			5				3			24
Support worker listened	8	100	5	42	5	71	3	43	21	62
Non-response			2				4			18
Could talk with worker	8	100	5	42	6	86	1	14	20	59
Non-response			3				4			21
Saw support worker enough	6	75	5	42	6	86	4	57	21	62
Non-response			2				3			15
Was a positive change	8	100	6	50	6	86	2	29	22	65
Non-response					1		2			9
Happy with help	8	100	6	50	5	71	3	43	22	65
Non-response			2				4			18
Average satisfaction Stage One[a]		96		44		76		38		62
Non-response				20		2		48		17
Stage Two	(n=8)		(n=8)		(n=7)		(n=7)		(n=30)	
Positive changes since last visit	6	75	4	50	3	43	4	57	17	56.7
Happy with help	7	88	6	75	4	57	5	71	22	73.3
Average satisfaction Stage Two[a]		81		63		50		64		65.0

Note: a) Estimated as % average of all responses relating to levels of satisfaction.

Three explanations are suggested for the variation. First, the amount of interaction between workers and clients was greatest in the ACT and South Australia. Second, these two pilot projects provided day to day services to the clients and their response to questions about satisfaction may have been somewhat influenced by this dependency. Third, satisfaction was lowest where the resources available for services to meet client needs was the most limited. This was most obvious in the Queensland project where only 29 per cent indicated that participation in the project had brought about a positive change in their lives. By Stage Two, the level of satisfaction in the ACT and South Australia had considerably declined (in the ACT this perhaps reflects a lower level of interaction between workers and clients by this

stage) and had substantially risen in the other two projects. In these the increased satisfaction may have been due to a time lag in procuring supports which, only by the second stage of the evaluation, had materialised.

Changes

When clients were questioned, at Stage One of the evaluation, about what, if any, changes had taken place in their lives as a result of the help the support worker gave them:

- for 27 per cent the development of an individual plan was the main outcome of their involvement in the project;

- for 21 per cent the services obtained were the main outcome;

- for 18 per cent it was increased level of social interaction; and

- and for a further 18 cent it was being able to go out more.

Nine per cent felt that there had been no change as a result of their involvement in the project. The remainder were not able to answer this question.

At Stage Two of the evaluation clients were asked to identify whether or not there had been any further changes in their lives since the first interview and, if so, whether the support worker had been involved. Table 7.4 shows that further changes had taken place in the lives of about a quarter of the clients and that the support worker had been influential in many of these cases. That any changes in clients' circumstances occurred at all after the cessation of INA funding is no doubt due in most cases to the fact that people remained clients of the service. We need to point out that changes in activities (which Table 7.4 describes) are not necessarily accompanied by **increases** in activities nor that the changes are necessarily positive.

Forms of Assistance

Table 7.5 shows the main forms of assistance clients said they had received from the support worker as a result of their involvement in the project.

Four types of assistance were most commonly reported; assistance in planning their futures, being taken out by the support worker, accessing services and the friendship provided by the support worker. The forms of assistance received and the types of changes brought about by this seem to be directly related to the orientation of the individual projects. The table shows that clients of the Victorian project received the greatest range of services, reflecting perhaps, the multi-dimensional nature of this project's approach to assessment and case management.

Table 7.4: Changes in Selected Areas of Clients LIves and whether INA Worker was Invovled: Stage Two

Areas of Life	ACT (n=8)		Vic (n=8)		SA (n=7)		Qld (n=7)		All (n=30)	
	No.	%	No.	%	No.	%	No.	%	No.	%
Changed living circumstances	1	13	2	25	2	29	2	29	7	23
Support worker involved	1	100	2	100	2	100	-	0	5	71
Changed day activities	3	38	6	75	5	71	3	43	17	57
Support worker involved	3	100	5	83	3	60	3	100	14	82
New work training	1	13	3	38	3	43	1	14	8	27
Support worker involved	1	100	2	67	2	67	1	100	6	75
Need less help with daily living tasks	3	38	2	25	2	29	1	14	8	27
Support worker involved	3	100	2	100	1	50	1	100	7	88
Doing new things for fun	4	50	5	63	4	57	3	43	16	53
Support worker involved	4	100	1	20	3	75	1	33	9	56
Attending new recreation course	2	25	5	63	3	43	1	14	11	37
Support worker involved	1	50	3	60	3	100	1	100	8	73

Table 7.5: Types of Assistance Provided to Clients: Stage One

Assistance	ACT (n=8) %	Vic (n=12) %	SA (n=7) %	Qld (n=7) %	All (n=34) %
Went out together	75	8	43	14	32
Helped with recreation	25	17	-	-	12
Provided friendship	38	-	14	43	21
Helped access	-	33	14	43	24
Helped with accomm.	37.5	-	14	14	15
Helped get employment	-	8	-	-	3
Helped obtain aids/equip.	-	8	-	-	3
Helped plan future	13	8	71	72	35
Helped with budget	-	8	-	-	3
Provided information	-	-	29	-	6
Other	-	8	-	-	3
Nothing	-	25	-	-	6

We now examine outcomes for clients in the individual projects.

The ACT Project (8 clients in both stages of the evaluation)

In the ACT project, in the opinion of clients, the main form of support provided by the INA worker was going out with the client. All clients said there had been a positive change in their lives because of the help that the support worker gave them. Most said they had a better social life, some said their residential arrangements had improved and a couple indicated that they were more confident. While the changes for clients in the ACT project appeared to be small they were also often significant.

Clients said about their support workers:

> *Jack and I go out together. He helped me move into the flat and get furniture. I like being on my own, getting my own furniture and doing what I like when I like.*

> *Rene understands my problems and helps me. We go out and have fun...I think I'm growing up more and it's getting better at home now. And I like going to church and going to work.*

> *Al took me out every week - to the shops and bank. He got me a cupboard to put clothes in but he hasn't got me a desk yet.*

Workers said about their clients:

> *Initially, he's had a very isolated life. He was living in a bed sitter. He was very reluctant to join in. He didn't want to know anything about the world. You had to make him part of the world.*

> *From having nothing he now has something, every day virtually. It has been a very slow process and it was hard in the beginning but its been worth it for Sol. He's always had it inside him, his humour, and is now able to share that with more people, and he's more confident and relaxed. His rituals aren't so fierce now.*

For many clients, the recreational activities they undertook and their circle of friends broadened over the life of the project. For a number of others, however, strong links with the community were not established and the client remained dependent on the support worker to maintain the links formed. This was especially evident at Stage Two of the evaluation when the funding for the project had ceased. Whilst some informal links between workers and clients continued, this was at a much reduced level and, especially for those with a greater level of dependency, their community involvement waned.

The Victorian Project (12 clients at Stage One, 8 at Stage Two)

Only half the clients interviewed in the Victorian project reported that were happy with the help they received. Their satisfaction was in most cases a result of the provision or co-ordination of services, especially accommodation supports and equipment. As a direct result of the project two clients had moved to more suitable accommodation in the community and several clients indicated that they had gained considerable confidence as a result of their involvement with the project.

> *I moved in here with Ros's help. We have our names down to get a flat and we've done a deal to get my furniture out of storage. My budget is now going well and I'm paying my bills, which I wasn't before.*

> *Anton arranged interviews with the OT to get a wheelchair and I've now got a new wheelchair. He also tried to get us help with the ramp and the hospital has given us some money for it. I've had a GSP. It took a long time. We looked at hostel options but I wasn't really interested.*

> *Ros had a friendly attitude. She did enough for me. Helped me prepare for court and represented me there. I'm seeing Tom now. I don't care who I'm seeing, at least I'm getting help.*

> *Ros tried to get me motivated to get back into work. She introduced me to 'helpmates' and we did a plan together and set some goals. It was something to go for and my brother was all for it...Ros has done a lot for me in the time I've known her, built up my confidence and motivation to get on with things. She gave me a lot of options for work and took me to the doctor in the city to get the Disability Support Pension. Personally I'm very grateful to CSV for what they've done.*

Clients who were dissatisfied felt that the workers were not doing enough for them. Some said that their involvement with the project had caused family problems.

By Stage Two of the evaluation an additional two clients had moved to better living situations. Three clients were undertaking new vocational training which the INA worker had helped them to organise. Three clients commented that they needed less help than when we had visited before and that the INA worker had, in part, been responsible for this improvement. By this stage of the evaluation, a number of clients also had had a General Service Plan developed for them.

The South Australian Project (7 clients in both stages of the evaluation)

All but one client interviewed at Stage One believed that there had been a positive change in their life because of the project. For the most part, this change was

reported to be in the area of increased confidence and opportunities to exercise choice.

> *Marina has blossomed. She was very unhappy at 'resi' (the nursing home) and hardly smiled or talked and now she seems to be enjoying herself more. She's become very cheeky and vocal.*

Although, most were happy with the help they received some clients felt that their involvement in the project had resulted in difficulties with their families. One of the clients preparing to move into new accommodation also felt that there had not been enough preparatory work and this claim was repeated at Stage Two, after the move had taken place.

> *I don't think Shirley did a good job because of all the problems with Mum.....Things are worse with Mum because I've moved and its pretty hard living on my own. I haven't got as much money for myself as before. I like it, but the staff need a lot more training to assist us properly. It wasn't organised enough for me to move in really and I would have liked some more preparation before moving.*

By Stage Two the range of recreational activities undertaken by clients had increased, although most of these were facilitated by staff of the service. However, at this stage only three clients said that the project had led to a positive change in their lives. Two clients lamented the conflicts which had occurred between them, their parents, and the staff of the organisation, and another said that their views had not been given an adequate hearing.

One client who felt torn between his own wishes and those of the INA worker said:

> *I felt pushed a bit. Shirley wanted me to do more....I didn't want to disappoint Shirley so I went along with it.*

The Queensland Project (7 clients at both stages of the evaluation)

At Stage One of the evaluation clients were generally content with the assistance provided, and many were excited by the plans which had been developed for them.

> *We talked a lot about where I'd like to live and what I'd like to do. I've moved house, away from Mum which wasn't working out and I've stopped working at the workshop. I've started going to the Senior Citizens for craft.*

> *I had a talk with Lydia and she talked to my parents. We went to dinner and there was a meeting to talk about me moving into a flat.*

A number of clients also secured services such as respite, home help or education support, as a result of the project.

By Stage Two, however, some clients were disappointed about the lack of progress made towards the plans developed. Two clients for whom community accommodation had been planned were permanently placed in institutional settings and for another two, a nursing home placement was likely. A number of clients, however, indicated that there had been positive changes in their lives - that they had access to more services, that they were more socially active, or that they had more control over things that affected them. However, over a half of the clients remained unhappy because they recognised that the services they needed most were simply not available locally. Neither was there much confidence that the resources to obtain these services would become available in the future.

7.3 Outcomes for Carers

Fourteen carers were interviewed in Stage One and ten in Stage Two of the evaluation. About three quarters of these cared on a full time basis but all found aspects of caring worrying or difficult. The most difficult areas related to medical issues associated with the health and frailty of the client and the scarcity and quality of services. Most carers believed that caring had had a detrimental effect on their health, especially their mental health, as well as on their family and social life. Many of the carers were also concerned about what would happen to the client once they became old or could no longer care.

At Stage One of the evaluation, half of the carers interviewed believed that as a result of their involvement in the project they were able to cope better with some of the things about caring that worried them most. The majority said that this involved obtaining or being linked into a service. Some appreciated the help they received with identifying their own needs and making plans, and others were happy because the project worker had befriended the client.

At this stage, half of the carers interviewed said they were very satisfied with the help they received. The remainder were only fairly satisfied or dissatisfied and this was mainly because expectations had been raised but no outcomes had been achieved. Some said they would have liked to have been consulted more.

At the first stage about a third indicated that the assistance provided had made caring for the client easier. Most carers had been able to talk with the project workers, and felt that their opinions had been noted. Fifty seven per cent of carers believed the project had had a positive impact on the client, and many said that they personally had become more empowered through their involvement in the process. Table 7.6 shows the proportion of carers who were satisfied in a range of areas. This table does not, however, cover all points which are raised in our discussion of carers.

Table 7.6: Level of Carer Satisfaction: Stages One and Two

Area of Satisfaction	All Projects	
	No.	%
Stage One (n=14)		
Had say in whether client participated	7	50
Happy with help	7	50
Needs taken into account	6	43
Opinions taken into account	9	65
Could talk with support worker	10	71
Positive difference to client	8	57
Positive difference to carer	8	57
Positive change in relationship with client	4	29
Client worse off without INA	5	36
Average satisfaction Stage One[a]		51
Stage Two (n=10)		
INA had lasting positive impact	7	58
Positive change in relationship with client	3	25
Positive difference to client	9	75
Positive difference to carer	5	42
Average satisfaction Stage Two[a]		50

Note: a) Estimated as % average of all responses relating to levels of satisfaction.

From the table it is apparent that a relatively high proportion of carers were dissatisfied with various aspects of the project and, in the opinion of the evaluators, sceptical of its value. Extrapolating from the table, a large proportion (57 per cent) did not believe that their needs had been adequately taken into account. Well over a half did not think the project had made any difference at all. One carer believed that life was more difficult as a result of the project. Four carers said that the project had led to tension within the family.

At Stage Two of the evaluation the level of client satisfaction had increased in some areas. As Table 7.6 shows significantly more carers believed, at this stage, that the project had made a positive difference to the client.

Fifty per cent of carers reported that they were getting more help than when they were first interviewed, although a large number still required additional assistance in areas such as accommodation and respite, therapy, and day activities for clients. An important finding (not recorded in the table) is that a number of carers in the study had not only obtained increased access to respite care by the second round of

interviews, but now felt that the amount they were receiving was adequate for their needs.

By Stage Two of the evaluation carers also perceived some positive changes in their own health and welfare which they attributed to the assistance provided by the INA worker: five carers reported a positive change in their family life; three indicated that their social life had improved; one said their health had improved; one reported an improvement in their financial situation; and one said their work situation was better.

These figures suggest that the projects' greatest impact was felt in the social and emotional areas of the lives of carers rather than on more tangible aspects, such as their employment or financial situation.

We now discuss the attitudes of carers in the different pilot projects. These varied markedly and seemed to be related to the policy of the project in involving the carer, in giving the carer a role in the decision making process and in treating the client and carer, as far as their needs were concerned, as a single unit. Ultimately, however, their attitudes were related to the amount of assistance they received.

The ACT Project (2 carers)

At Stage One of the evaluation, the two carers in the ACT project expressed considerable satisfaction with the assistance they had received and reported that their involvement had had a positive impact on both them and the clients. Both the carers and their families were experiencing less stress than previously because the worker had befriended the client, although for one there had been some conflict in the family as a consequence.

> *Rene is a good outlet for Cathy and is like a sister - it's good for Cathy to have someone else to talk to. Cathy is more independent and stable.*

> *Cathy was confirmed as a Catholic recently. This was difficult for Cathy as she had to concentrate and learn a lot of things, but in the end she did it - but it was stressful leading up to it.*

Although both carers said they could talk easily with the INA worker, they, nevertheless, felt that their own needs had not really been taken into account. At the second stage of the evaluation the impact for clients, in the opinion of carers, had been maintained, but neither felt that the project had had a positive impact on them personally. Both indicated that they still needed more help with caring.

The Victorian Project (5 carers in Stage One and three carers in Stage Two)

In the Victorian project the overall findings are affected by the responses of two carers of Perse School pupils who were negatively predisposed towards the project.

However, the three other carers interviewed at Stage One indicated that the INA worker had helped them alleviate some of the problems that they had found particularly worrying or difficult, mostly by helping them to obtain services. For one carer the assistance had had a positive impact on their health, for another it had resulted in an improvement in their social life and for the third, in an improvement in their family life.

Only one carer said they had had a say in whether the client received INA help. Three carers, two of whom were associated with the Perse School, were dissatisfied with the project, either because there were no services available to meet identified needs or because they had not been consulted.

> *The school asked me to co-operate. Then I got a letter about Gloria's 'case'. They appointed a worker without my permission. I told them I didn't want to have anything to do with them. I told them I wanted records destroyed. I didn't want any more contact unless I contacted them.*

> *They were never there to talk to and I eventually got onto The Perse School about it. I was very angry. Then sometime later I got another letter from the same person. The case worker then sent a letter after doing a non-personal assessment, which had a number of options. It was incompetent, not professionally adequate. She never saw her, doesn't know her, doesn't know what Gloria needs.*

By Stage Two of the project, carers in the Victorian project were far more positive about it. Two carers reported that they had obtained additional help with caring, three indicated that the project had a positive impact on the client because of the supports that had been secured for them, and two carers said that the project had had a positive impact on them personally.

George's elderly parents said:

> *We were really worried until he was placed. It was getting harder and harder to look after him. We don't know what would have happened otherwise. He probably would have wound up in an institution....We were really impressed when Ros came out. She was very practical and her assessment was spot on.*

The South Australian Project (three carers)

Dissatisfaction was highest amongst carers in the South Australian project both at Stage One and Stage Two of the evaluation. Of the three carers interviewed none thought that the INA worker had assisted them with any of the things that they found

most worrying about being a carer. One carer did, however, admit that there had been an improvement in her emotional state.

On the whole carers had little good to say about the project. One carer said that its activities had made family life more difficult and another said that they were worse off financially as a result of the project. None of the carers said that they had been asked whether they would like the client to participate in the project and two carers indicated that it had caused them some difficulty because of family conflict and because they believed that the client had been put at risk.

> As a family we've been isolated. During CHOICES my relationship with Bruce was strained. He wanted to please everyone (at SCOSA and at home with me). It was important to me that he would do what pleased him. He told me he was uncomfortable with making a choice about living somewhere else but didn't convey this to them because he didn't want to be out of favour with them.

> Because I was still living in the country it was difficult to find out what was happening. Bruce seemed confused about wanting to go to the new house. At the same time when he talked to them he told them he did. I spoke to Denise and Shirley about wanting to be involved but got a 'don't call us, we'll call you' response. They never did and the wheels were in motion. It took two years before I was asked point blank what was Bruce's decision and I had to get an advocate to prove to them that Bruce didn't want to go and they still didn't believe me when I did that. I saw Ruth and Pete (management) about my concerns during the whole thing. Things came to a head with Bruce, he was going (to move) so I decided not to see him any more. I thought that this was best for both of us. We had no contact for two weeks.

By Stage Two, carers were somewhat more positive about the project and had come to recognise that it had had a small positive influence on such aspects as their social life, their work situation and their state of mental health. One carer even believed that the project had had a lasting impact on her son in terms of opportunities to take control of his own life. Another carer, however, said that the project had left a legacy of conflict and tension which had had a detrimental affect both on her son and on her relationship with him. Overall, carers were of the opinion that the expectations on the clients were too high and that the planned changes were happening in too short a time and without sufficient preparation. In addition, some felt that the choices being offered to the client were only those which had the ideological support of the project management.

> SCOSA'S idea of CHOICE is their choice- providing and selecting options for Rosemary. It's important to make people aware they are doing this. I think they are deceiving

themselves.......I'm determined that Rosemary has 'real' and 'informed' choice and to do that she needs to know what she is choosing from. ...The computer is a worry for her because she is forced to have it. What kind of choice is it when they take her Bliss board away from her and leave her only with a computer to communicate with?

The Queensland Project (four carers)

Three out of the four carers interviewed in the Queensland project were very satisfied with the assistance provided to them. Two said that they had received some services which they needed as a result of their involvement and another said that the project had provided her with an action plan for her son. All the carers said that they had asked whether they and the client wanted to be a part of the project. In this respect the Queensland project was unique in that it was the only one to have engaged, as a matter of policy, both clients and carers in the process of needs identification and planning.

Most carers said that the their involvement in the project had taken a load off their minds and that they were relieved to have someone looking out for them and the client. All carers said that there had been an improvement in their family life.

Three of the carers also believed that the project had made a positive difference to them in that they had become more energised and informed.

It (the process of assessment and planning) *helps you focus on how much further you could go in establishing links in the community. It puts things in perspective.*

Two carers, however, indicated that they had some difficulty with the process because no supports were available to realise the plans that had been developed.

It has energised me to do things. It's strengthened my resolve to argue for things, even if they don't ever exist. I think there are more people who think the same as us. That things could be better.

At Stage Two of the evaluation three of the four carers indicated that the project had had a lasting and positive impact. However, carers expressed the same types of reservations at this stage of the evaluation as they had done earlier.

There's probably lots of things she doesn't do for herself that she used to do. But I think Carol has been pushed enough and her happiness is more important than reaching her potential. Not everyone is going to benefit from schemes to maximise independence.

At least I know she is protected where she is. I'm not really interested in a follow up on plans now for Carol. I'd rather leave her where she is. I've got no faith in government funding or society really. Even if something came up I don't think I'd do anything about it now.

7.4 Organisational Outcomes

In the implementation of the pilot projects, the agencies involved learnt a number of lessons and began a process of self examination. These organisational impacts are dealt with in more detail in other parts of the report but are briefly summarised here.

FOCUS, the sponsoring body for the ACT pilot project, in recognition of the part which services play in fostering client dependency, has begun to examine critically its future role as an accommodation service. The view is now held that FOCUS may have a more important role to play in helping to foster natural networks rather than in the provision of traditional forms of accommodation support. In addition, the goals of the LINKS project (that is, attending to the social needs of individuals) are now being extended to all of the agency's clients.

As the manager of this project commented:

> *For me, it's absolutely re-inforced the importance of developing relationships and personalising the supports in people's lives. Personal relationships are more important than human services which should, I believe, gradually be replaced by natural supports. We are starting to develop structural changes in FOCUS to facilitate this.*

Because it was overtaken by an alternative system of assessment and case management, the Victorian project made little difference to the sponsor organisation, CSV, in the longer term. Workers, however, while somewhat demoralised by their experience in the project, gained considerable skills in the area of assessment and have found the transition to the new system, which combines assessment and case management, relatively easy.

The manager said:

> *I've had to reassess my views about a separate assessment model which I had previously supported. It's expanded my understanding of assessment and it's also made me rethink the value of pilots. I think you've got to go into a pilot as if you were keeping it going and monitor it in that way or it won't be of as much value to you or the organisation.*

The experience gained through the South Australian pilot project has led its sponsor, SCOSA, to recognise that it was inappropriate to confine the CHOICES initiative to

one group of clients and also that this was difficult to justify. The management of SCOSA came to believe that it was both inequitable and unworkable to devote a great deal of energy to one particular group of clients who were living and interacting with those who were not receiving special treatment. Consequently, at the time of the evaluation, the concepts contained in CHOICES had started to flow through to all parts of the organisation and its clients. SCOSA has also recognised the need to make radical structural changes within its own organisation in order to enable meaningful improvements in the quality of life of its clients to take place.

> *It has had a major impact on the impending restructuring of SCOSA, as we have decided to build in as much of the CHOICES model as possible within the new organisation and make it a fundamental part of its policy.*

Finally, for workers in the Queensland project, the lack of resources to put plans into place has been a dispiriting aspect of the pilot project. Consequently, it is believed that further resources should be put towards the project to test the model developed and the agency will continue to seek these.

> *Looking back, I would have liked to have a clearer picture of what funding would or would not be available to do the plans.....I felt really awful in Jackie's case, about leaving her again like everyone else had in her life. Its a big issue, coming in, delving so deeply, making value judgements and then leaving. But you're seen as facilitator, not the centre pin...If the plans are done with the expectation of funding it can raise so many false hopes. I think each case should be assessed as to how far it would be realistic to go with planning.*

> *In practice, not having any resources to call on was soul destroying for a lot of clients and consultants. It (the project) should have either been financed or not had anything to do with additional resources.*

8 Summary and Recommendations

The evaluation of the Individual Needs Analysis pilot projects has proved to be both an interesting and rewarding exercise. The projects have attempted to develop and introduce innovative initiatives to improve the lives of people with disabilities, and their experiences in these endeavours have the potential to make a significant contribution to the process of policy and program development.

The loose conceptualisation of INA, resulting as it did in a diversity of aims and methods between projects, has made the evaluation task difficult. While we have attempted to draw some comparisons between the projects, it has not been possible to comment on which of the approaches provides the best model of INA, for three main reasons:

- the projects were not formulated within an evaluative framework;

- the projects were set up to achieve different goals; and

- the lack of specificity of the aims of the individual projects made it difficult to assess whether these had been achieved.

Despite these constraints, we believe that we have been able to provide a description of the various pilot projects, and, in very broad terms, assess the exent to which each has been able to achieve its aims. Most signficantly, the evaluation has provided many lessons for 'good practice' in the provision of supports for people with disabilities.

8.1 Summaries of the Four Pilot Projects

The ACT Project

The LINKS project achieved many of its aims. However, it did not address one of its original objectives - to look at ways of attaching funds to individuals. It also moved away from a structured and holistic approach to needs identification and planning to more individually focused and less formal methods which explored the social needs and emotional needs of clients.

Over the period of the project 21 people with disabilities were assisted by 23 workers to establish links within the community. From the sample studied, a number of genuine and possibly enduring friendships were formed between workers and clients and, in a few cases, other external self-sustaining relationships were facilitated. Our perception as evaluators was that the friendship of the support workers was generally appreciated by the people being assisted and that, through this friendship, opportunities for personal development were enhanced. In many cases,

the relationships that developed were significant, not just for the person receiving support but for the LINKS workers, too.

There was a strong ideological commitment to the principles of social role valorisation within the project team and this was reflected in its approach to the people it supported. The majority of LINKS workers demonstrated a very considerable personal commitment to the people whom they were assisting, and many spent additional unpaid time with them. Some of the workers commented that it was difficult to delineate between 'work' and 'friend' time and some expressed feelings of guilt about receiving money for what they were doing. An issue for a number of LINKS workers was where to go next within the relationships they had developed, perhaps reflecting the relative inexerience of the workers involved. Some were keen to sustain their relationship with the person. For others, there were potential problems in easing out of what had become a very significant and intense relationship both for the person with a disability and the worker. For many workers an additional issue was the continuing status of their relationship with the people they were assisting once the funding for the project had ceased.

Some important consequences of the pilot project for the organisation and the people receiving support can be identified. The damaging role service agencies can play was confirmed for FOCUS management, despite their good intentions, in inhibiting a person's life experiences and opportunities to form natural links in the community. As a result of getting to know people on a personal level through the project and developing relationships of trust with them, they were impressed with the considerable potential for greater development displayed by those who participated as clients in the project. They believed that these were people who, because of their long term and dependent relationships with the service sector, had lacked the motivation and skills to form valued social relationships but that through the project had been given the opportunity to reveal their capacities and interests.

Our evaluation was not able to provide supporting evidence for these views and whilst appreciative of the individualised attention, it was also difficult to know whether the people they were supporting shared these views.

A second consequence was that the types of personalised assistance provided by workers in the project were now being incorporated within the general activities of the organisation and extended to all people served by the agency. The project highlighted for FOCUS the potential value of the LINKS approach for all people with disabilities, and also the ethical problems of undertaking a project such as this with only a proportion of their clients. As a result all FOCUS accommodation workers are now being encouraged to spend more **discrete** time in social interaction with individuals and in activities that promote the development of relationships within the community.

Whilst the ACT project adhered to many of the principles of Individual Needs Analysis, the main aims of the project were not, it appeared, centred on the development of assessment and planning tools for people with disabilities. Because of this, the results of the project have limited capacity to inform the development of

an Individual Needs Analysis framework and make comparisons with the other projects somewhat irrelevant.

The Victorian Project

The Victorian project, which was sponsored by a large government agency, was highly ambitious, incorporating a multiplicity of aims within a tight time-frame. Nevertheless, it went a long way towards meeting its aims. In particular, it succeeded in developing and testing a new approach to assessment and planning. A comprehensive assessment tool, which provided a framework for the identification of individual needs, was constructed and applied. Over the period of the project a great many assessments were conducted in an efficient and professional manner and, apart from the Perse School project, were welcomed and generally well received by clients. Although frustrated by a lack of services, it was the view of both staff and clients that at least clients felt themselves better informed about the kinds of options and strategies available to them. In addition, many said they gained a good deal of self confidence and greater self reliance as a result of the assessment and planning process.

Within the project there was a strong commitment to individual choice and control for people with disabilities. Staff took pains to encourage clients to explore and develop their own interests and, as far as possible, to take an active role in the process of planning for their own needs. Considerable effort and resources were expended in attempting to put in place a system of assessment and planning which better met the needs of individuals, was actively driven by them, and which covered the range of life areas which are important to all people.

However, during the period of the project, the concept of seperate assessment and case management being trialled was overtaken by a new statewide integrated system. This differed from the previous structure because it provided a discrete and standard assessment role for Client Services Team members who would then also take on the case management of clients.

One of the most interesting questions to arise from the Victorian project is the extent to which large government bureaucracies are able to establish and maintain the kinds of personal relationships with clients and their families which are necessary to develop assessments and plans reflecting individual needs and interests. The barriers to the development of trusting relationships between government agencies and the community have been emphasised throughout our evaluation of this project. An associated aspect, which differentiates the Victorian project from some of the other projects, was the recognition of the need for a clear and standardised approach to case work at all stages of the process, of which the client was also fully aware. These structures, it was believed, served to clarify the expectations for both parties and avoid the fostering of client dependency. The notion of client dependency is perhaps particularly problematic within an organisation such as CSV where specific client/worker relationships are unlikely to be consistent or maintained over long periods of time.

In re-examining the original objectives of the INA pilot the evaluation team felt that there was a need to question the contribution that large government agencies, of the type we were evaluating in Victoria, can make to the implementation of initiatives which are highly personalised in effort and outcome. One might ask whether smaller community-based models are not more likely to have greater success. To what extent can a government agency, for instance, come to understand the multi-dimensional aspects of a person within the context of their community, be flexible and responsive to changing needs and be seen to be independent from the source of funding? This is a complex issue to which we do not have a ready answer. However, our evaluation of the Victorian project has enabled us to raise these as issues for consideration.

The South Australian Project

Despite a number of obstacles, the South Australian project went, at least, part way towards achieving many of its original aims. The experiences of the project have heightened the resolve of those management staff involved in pursuing the concepts embraced in the project with even greater vigour, albeit with more emphasis on the strategic aspects.

Most significantly, the unexpected resistance to client independence and self management in areas relating to finance, accommodation and leisure has brought SCOSA management to a recognition that these particular areas are critical to the improvement of the quality of life of people with disabilities. To overcome the difficulties encountered, management has begun to adopt strategies which incorporate more modest aims for each individual, and which have been formulated and introduced within a staged approach. These include programs which prepare individuals for independent living and social interaction and integration. In this way, the developmental needs of different individuals within the context of their particular circumstances, are now being taken into account to a greater extent than before.

Whilst it has been slow, some progress has been made in securing greater financial independence for clients in the pilot. Over three quarters of the group now have their own bank accounts and a significant number are making choices about how to spend their residual incomes. Four clients have moved new houses and although experiencing some difficulties with the transition have established themselves on a shared living basis.

Generally, staff (and to some extent families) have acknowledged the project's positive impact on clients. These have included improved relations between staff and clients and improved decision-making skills, greater assertiveness and more effective communication skills on the part of clients. For some staff their involvement in the project has resulted, we were told, in an increase in the motivation and energy through the recognition of the types of options which might become available.

Structural and organisational problems were particularly highlighted in the evaluation. A large part of the CHOICES philosophy and focus on individual needs could not, it appeared, be easily accommodated within the existing organisation, concerned as it was with service delivery and employee issues. At the same time, the need for broader intra- and inter-organisational changes has been recognised. Much of this work has already begun with the establishment of the Community Links project, the location of appropriate advocacy supports, and the impending changes to the way SCOSA provides its accommodation services are now part of the new business (or corporate) plan.

The Queensland Project

The Queensland pilot project was successful in achieving what it set out to do, that is, in meeting the original aims of the pilot project. It attempted, with some success, to translate a number of complex concepts and ideas into a practical framework. Moreover, a range of innovative tools were developed and applied with a view to assisting people with disabilities to achieve a better quality of life.

Over the life of the project 25 clients were assisted with assessment and planning using the tools developed for the project. These tools were based, in the main, on *Framework for Accomplishment* (O'Brien and Lyall, 1987) material. In general, both clients and carers were satisfied by the activities of the pilot and the expertise of those involved.

Many clients, and more particularly, their parents, indicated that had they found the process of comprehensive needs identification and planning to be, in itself, an energising and empowering experience because they gained more knowledge and understanding of their situation and of the possibilities available to them. The process provided some with the hope that they would not just have to settle for what was doled out to them as they had done in the past, but that there might be some opportunity to obtain the kinds of individualised supports that actually met their needs. On the whole, they valued simply having the chance to talk, in a non-patronising environment, about those things they felt they needed.

The extent of community networking by consultants was a particular feature of the Queensland project. It could be that there is greater likelihood that such networks will develop within small rural communities than in urban settings. Further, the particular group of individuals working on the project may have significantly contributed to the outcomes of the pilot in this respect. It could be argued that this grouping and configuration of expertise, personality and energy could not easily be replicated elsewhere.

One frustration associated with the pilot project was the unavailability of many of the supports needed to meet the assessed needs of individuals. In this respect, the project had much in common with the Victorian project. Both in that project and this, expectations may have been raised through discrete assessment (that is,

assessment which is separate from service provision) which were unlikely to be realised for some time to come, if at all.

In the Queensland pilot project, considerable effort was made to ensure that clients and their families understood that the project was being conducted as a pilot only. For the clients and their families, it was emphasised that the outcomes of the project were assessment, lifestyle plans and costings only, and that securing services and supports would be part of a different process. Nevertheless, from our observations many families were primarily motivated to participate in the pilot project because of the chance, however remote, of obtaining some assistance out of it.

In the development of its 'hypothetical' approach to individualised funding (brokerage), the project has raised a number of interesting issues. For example, it has demonstrated that without funds/and or services to match those requirements specified in plans there is no real way of knowing whether what has been costed is actually sufficient for an individual.

Other more probing questions emerge when we begin to look more closely at the proposed system of brokerage or these resources. What are the advantages and disadvantages of overlaying additional tiers of administration and co-ordination, that is, of separating assessment and planning from co-ordination and service delivery? Would the clients actually be empowered under this system, or would power simply shift to other parts of the non-government sector, for example from services to brokers? What safeguards can be put in place to protect the clients' interests under such a system? Is equity of support possible for all people with disabilities within a brokerage model of the kind proposed by the Queensland project given that it will necessarily target particular individuals?

8.2 Lessons

There were a number of unexpected barriers encountered in meeting the goals of the projects from which some important lessons have been learnt. These can be summarised as follows.

Equity and Access

The underlying intention of INA is to better match the assessed needs of people with disabilities with the support they receive. The principles of access and equity imply that support should be provided according to the level of physical and social needs. Thus, equity implies that people should not be disadvantaged by any feature of their circumstances and that they should have an equal chance of having their needs met. Principles of equity are particularly important for people with an intellectual disability who may not be able to represent themselves fully. Within this pilot scheme, assessment and the services received on the basis of this assessment, were provided to people who were already linked into the service system. However, even for those people linked into the service system, prioritisation was not equitable

because rigorous criteria for the allocation of services were neither articulated nor applied. Unless these problems are recognised and addressed in the setting up of such schemes, there is always a danger that they will be inequitable.

Stakeholder Resistance

Unexpected resistance was encountered, especially to client independence and self management in areas relating to finance and accommodation and leisure. This resistance was located with staff and family members and proved a major barrier to the development and implementation of plans involving change. This points to the need for improved understanding and greater involvement of key stakeholders in the development of programs which are likely to impact on them.

Needs for Experiential Development

All projects recognised that the high level of social isolation experienced by their clients had played a significant part in inhibiting their development and access to opportunities in a range of life areas. In particular, the need for greater experience and strengthened ties with the mainstream community were identified as a vital part of the transition to community based living and self reliance. Phased programs to facilitate social and decision making skills through practical experience were therefore seen as an important element in the development and implementation of individual plans which are intended to be user driven.

Limits to Community Responsiveness

Whilst the projects emphasised the need for increasing the level of interaction with mainstream community activities as a means of personal and social development, many barriers to this type of endeavour have emerged from our evaluation. These for the most part relate to the limitations of existing networks within a community, negative community attitudes and lack of time and resources to enable ongoing access by people with disabilities to these networks.

Structural and Organisational Barriers

It became clear in the course of the evaluation that INA can only operate effectively within a structural and organisational environment which is sympathetic to its aims. The evaluation has demonstrated that the relationships between sponsoring bodies and the projects can have a major impact on the implementation of INA.

Where projects were sponsored by agencies which already provided services to people with disabilities there tended to be a confusion between the INA activities of the pilot project and the day-to-day work of the sponsor. In South Australia this was exacerbated by a lack of understanding by direct care staff of their role in the project.

On the other hand, where projects were poorly co-ordinated with the work of their sponsor body, INA can be perceived as somewhat irrelevant and consequently easy to undermine. It is perhaps the very absence of a sponsor organisation operating as a service provider in Queensland which enabled this project to meet its stated aims.

8.3 Recommendations

The experiences of the INA pilot projects have led the evaluation team to make a number of observations and recommendations. It will be appreciated that given the somewhat descriptive nature of the evaluation of the INA pilot projects, it is difficult to make recommendations which are derived from evidence that is conclusive. For this reason the judgements of the members of the evaluation team have played a large part in linking the data collected in the course of the evaluation to the conclusions reached in this section.

The Establishment, Conduct and Evaluation of the Pilot Projects: the Departmental Role

The evaluation team believes that the pilots were not conceived with the rigour, structure and purpose required to allow effective evaluative comparisons between them or to make a significant contribution to the development of a universal INA policy and framework. The pilot projects lacked common goals and understanding of the policy objectives behind them, and were insufficiently monitored to ensure that they met their aims. **It is important that the Department provides clear direction and works in partnership with the service sector in setting up similar projects in the future so that they contribute to the maximum extent possible to policy reform or program development.**

The overall design of the INA approach piloted lacked an adequate operational framework and did not take into account the Department's evaluative needs. **In order to achieve useful outcomes from resource outlays for pilot projects, evaluation frameworks must be developed, utilising appropriate expertise, at the project design stage.**

However, the model of INA cannot be fully developed or tested unless it is trialled on an ongoing basis and linked to available resources.

For example, the Queensland pilot project assessed and costed the needs of their clients but did not have the capacity to implement the costed plans. What is suggested is that earmarked funds are injected into a range of schemes, in a variety of service settings and locations in order to meet the totality of assessed needs of a small number of clients in each scheme.

The impact of these funds would be carefully monitored over time to assess:

- the adequacy of the plans themselves ;

- the adequacy of the resources believed to have been needed to meet the assessed needs and the changing needs of the clients;

- the effect of the different levels of service provision in the different localities on the implementation of individual plans;

- the extent to which the injected funds act as an impetus to the development of new services; and

- the improvement in the quality of the lives of the individuals concerned.

The INA Model: a Strategic Framework

A number of general princples have emerged from the evaluation which should be taken into account.

- The quality of assessment is enhanced by its separation from the case management function.

- Thorough assessment is inherently valuable for the identification of needs. However,the benefits of assesment are diminished if resources are not adequate to meet needs.

- Publicly articulated systems of prioritisation at both the cliient recruitment and service allocation phases are needed to increase the likelihood of equitable access.

- Brokerage and case management when separated from service delivery systems operate with fewer constraints which are associated with exisitng systems of resource allocation.

- Client access to independent advocacy is desirable.

- Grievance and complaints procedures provide essential safeguards for clients.

On the experience of the pilots it is recommended that the scheme should be introduced gradually with maximum involvement of the players, and in such a way that takes into account the complex power dynamics surrounding a person with a disability, and the prepatory needs of many people with disabilities required to make successful changes in their lives.

In the development of new initiatives, particularly those likely to result in changed living or service arrangements, the protective concerns of stakeholders need to be

taken into account. To this end, **the benefits and purpose of the INA scheme need to be widely promoted and understood by all stakeholders prior to its implementation.**

Although the value of the pilot projects is self evident, it would be misleading to suggest that the outcome of the evaluation points to the application of one or other or even a combination of approaches trialled through the pilot. However, some lessons have been learnt and elements of a preferred approach have emerged. Given this, limited implementation of an INA model with a view to its further development is recommended, utilising the structural and organisational elements of the assessment and planning mechanisms described in the framework above.

Appendix One: Individual Needs Analysis Project Brief

Background

The Handicapped Programs Review in 1983 and 1984 identified individual self-determination as a critical issue for people with a disability. Since that time Commonwealth disability services policy has been directed towards enhancing the empowerment of individuals, with a greater focus on individual outcomes.

Current funding practice under the Disability Services Program (DSP) entails the provision of block grants to agencies, which then deliver services to people with disabilities. The Commonwealth has very little knowledge of these services; in particular, to whom services are provided, on what basis, the level of support required, and whether the appropriate levels of support are received by these individuals.

There have been a number of calls from disability groups in recent years for funding to be directed to individuals. The commonly sought model of these groups is for funds to be allocated directly to individuals, or alternatively to a 'brokerage' agency, who then assists the person concerned to purchase the supports required. Such a model separates the funding source, assessment, service selection and service provider functions.

While that approach is attractive from a consumer empowerment perspective, it would be an ambitious change for the Program in the short-term.

Consumer Focused Funding Approach (previously Individualised Funding Approach)

The Consumer Focused Funding Approach (CFFA) is being introduced within the DSP as a necessary first step along that path, establishing the concept that public moneys are being used to purchase specific assistance from agencies to meet the assessed support needs of identified individuals, and that such moneys move with the person, rather than belonging to the agency.

Because of parallel discussion in the context of Commonwealth State rationalisation across disability services a meeting with State and Territory Government representatives was held on 18 February, 1991. The response was very positive, and State/Territory Governments have expressed a desire for CFFA to be implemented as a joint initiative.

On 20 February, 1991, the Minister endorsed a strategy for the introduction of CFFA through which, from 1 July 1991, all **new** Accommodation Support and Supported Employment services will be funded to provided an agreed type and level of support to identified people with disabilities.

- That strategy also proposed that in 1992 the Program will work with **existing** service agencies to apportion their funding among their existing clients, on the basis of agency knowledge of client needs and current support levels, and that in 1993 these allocations will be confirmed, with all funds allocated to agencies on the basis of identified and assessed individuals.

- This timing is subject to successful introduction of Stage One, and will be confirmed at a later date.

An initial discussion with peak disability councils was held on 4 March, 1991 where there were strong indications of support for the concept of CFFA.

CFFA was also discussed at the October and March ASM meetings. As a result of the latter, a Working Group comprising officers from the Disability Planning and Development Branch, the Disability Services Management Branch and the Queensland and Victorian offices was established to assist in the resolution of a number of administrative issues. The recommendations of the Working Party have been incorporated in draft CFFA Guidelines for Project Officers.

Further consultations are planned over the coming months with consumers and their families and service organisations. Discussions are currently taking place with State Offices about the plans for consultations in each State. The national consultation process is expected to commence in Queensland in June, and be completed by the end of 1991.

Individual Needs Analysis (previously Uniform Assessment)

The policy question of controlling appropriate entry into accommodation and other services for people with high support needs has been a subject of debate for some time. More recently the need for a more equitable way of determining funding support for a given level of individual need has become a parallel concern. Following the provision of funds in the last Budget work was able to progress on the development of a more uniform approach to assessment within disability services.

This work culminated in a 2 day 'think tank' on 18 and 19 April where a possible approach to assessment and service entry through Individual Needs Assessment (INA) was examined, based on the Local Co-ordination approach developed in Western Australia by the State Government Authority for Intellectually Handicapped Persons (Irrabeena).

This INA is multidimensional in approach and takes account of all formal and informal supports currently and potentially available to each person eligible for

assistance from Disability Services. It also encourages a greater sharing of responsibility across the community and assists in directing funded services towards those with the highest need.

An adaptation of the WA INA is now being considered for its applicability within the broader disability services area, and several pilot programs will be funded from 1 July 1991 to test INA in a number of locations around Australia. Subject to the success of these pilots and further work on processes for training and accreditation of co-ordinators and monitoring and evaluation methods, INA could be introduced on an incremental basis into two or three States from January 1992.

The broad principles of the adapted INA are:

• It would be seen to stand outside current service provider networks. Implementation in each State and Territory would vary according to local conditions, but it is possible that the work could be done by a trained and accredited person employed by a NGO or State or Commonwealth Government.

• It would be conducted by trained and peer-accredited co-ordinators.

• It would be locally based.

• It would focus on individuals, their families and their community.

• It would take a multidimensional approach to needs analysis.

• It would have the flexibility to cover informal, immediate or short term needs, would identify and pursue non-DSP sources of support to meet these needs, and a costing of ongoing individual needs to enable a bid (through CFFA) from the Disability Services Program, based on current Priority of Access Guidelines.

Interim Guidelines

INA is working on a slightly different time frame from CFFA and interim guidelines are suggested for those places which will proceed under CFFA from 1 July 1991.

• No immediate change in the method of funding is anticipated except that service providers will receive funding under contract for the provision of support for specified individuals on the basis of the agency's identification of each individual's level of need for that particular service.

• Services will determine (often in conjunction with Project Officers) the relative priority of individuals for that service, taking into account current Priority of Access Guidelines.

• Until INA is in place the initial assessment of those individuals will remain the province of service providers. Such assessment will need to be expressed in

finance Strategy terms (i.e. support hours). Where assistance is required Project Officers may, subject to available funds from within the State allocation or the Uniform Assessment Project operated from Central Office, assist in the purchasing of independent assessment of support needs.

• Where Project Officers are unable to determine the appropriateness or accuracy of an agency's assessment, Project Officers may (subject to available funds) support the agency in referring individuals for an independent assessment from another independent/private agency or a State or Commonwealth agency (such as CRS).

Appendix Two: Sample Selection Procedures for Individual Pilot Projects

The ACT Sample

The five managerial staff associated with the project were interviewed, including the project manager, as well as the eight LINKS workers associated with the clients selected for interview.

Eight clients were randomly selected. Two of these were not interviewed because the project management felt that given their circumstances at the time, this would not be appropriate. Two other clients were selected, as substitutes.

Amongst the eight clients that were selected for interview only two unpaid carers were identified. Both were interviewed after obtaining agreement from the clients. In both cases the clients lived in the family home.

The Victorian Sample

The project manager, the team leader, and two assessors were interviewed. In order to gain the views of those that were not part of the pilot project but whose work might be affected by it, the leaders of two case management teams within the Regional Office where the project was managed were also interviewed. In addition two case managers from another region, whose clients had previously been part of the pilot projects, were interviewed.

Discussions were also held with the Principal of the School (the Perse school) which was attended by a number of clients in the pilot population.

A sample of four clients from each of the three stages associated with the pilot (twelve clients in all) was randomly selected. In the event, a number of clients could not be contacted or did not wish to participate. In two other cases we were advised against interviewing the client because of the specific problems they were experiencing at the time. To obtain a sufficient sample 4 substitute clients were selected as well as two clients from the caseload of another case manager who had also worked as an assessor in the pilot project.

Five carers were identified, three being parents of students at the Perse School. Two of these were not part of the original sample but were suggested by the Principal at the school. In both of these cases the client lived in the family home. Of the remaining eight clients in the sample only three had an identifiable family carer and only two of these agreed to be interviewed.

The South Australian Sample

The CHOICES manager, three co-ordinators and a number of direct care workers associated with the clients in the sample were interviewed.

Six clients were randomly selected for interview. However, one of the clients did not wish to participate and to obtain a sufficient sample substitute clients were randomly selected. A final sample of five clients and four carers was selected from the total client population of 20. Three additional clients in particularly interesting circumstances, first because they had been recipients of spin off activities from the pilot project, and second, because they represented somewhat different types of client (they did not strictly comply with the original eligibility criteria of the project but were nonetheless part of it) were also invited to participate. One of these declined to be interviewed.

The Queensland Sample

The project co-ordinator, five consultants associated with the clients in the sample, some members of the Board's Executive, and workers in other local services affected by the project were interviewed.

Initially, eight clients were randomly selected for interview. One of the clients did not wish to participate and in two other cases we were advised against interviewing the client because of problems that they were experiencing. To obtain a sufficient sample, substitute clients were selected. However, it was not possible to interview one of these clients or their carer because they were unexpectedly out of town for the entire period of the evaluation. In all, seven clients and four families in a caring role were interviewed.

Appendix Three: Selected Characteristics of the Populations of the Four Pilot Projects

A3.1 The ACT Pilot Population

Over the period of the project, 21 people with disabilities receiving FOCUS accommodation support services were involved in the pilot project, and at the time of our visit there were 19 clients being assisted through the scheme. The people were selected for the project because they were considered by the organisation to be particularly isolated within their communities.

Although the severity of disability amongst the clients varied in level, nearly all had an intellectual disability. According to the workers in this project less than a quarter required assistance with personal care which leads one to question what function this agency performed for a number of these clients. Most people did not have a close family carer and, because FOCUS is an accommodation agency, most of the people did not live with their families but in grouped or single accommodation.

Clients ranged in age from between 17 and 66 years, the majority being between 25 and 35 years. The average age for the group was 37 years and as such, on average, were older than the clients of the other three projects.

Just under half of the group had a job, in many cases in a sheltered workshop environment. Only one person was from a non-English speaking background. One person left FOCUS during the period of the pilot to live in a different area, and another had died.

A3.2 The Victorian Pilot Population

The Victorian project involved 39 clients. All had an intellectual disability as this was a condition of eligibility. Some clients had additional disabilities. This group of clients was less severely disabled than the clients generally. Only 10 per cent were assessed as having a severe disability, 64 per cent of clients had a moderate level of disability and 26 per cent had a mild disability. Assistance with personal care was considered necessary for 82 per cent of the pilot population.

The clients of this project were relatively young, the majority being aged between 21 and 30 years. Most clients still lived with their families and a large number of these were attending school. Most of the older age group were unemployed and while a small number worked in sheltered employment, only two had a job in open

employment, these being the only two clients in open employment amongst the entire client population.

Three separate pilot populations were identified in the course of the Victorian project:

- particular students attending the Perse school for children with disabilities;

- clients assessed by the Disability Assessment Service (DAS) from September 1991 to May 1992; and

- clients assessed by the Client Services Team from May to July 1992.

Our account of the Victorian client population looks separately at the clients based at the school and all other clients.

The School Population

The project targetted those students who were considered to be inappropriately accommodated in the school because they were using the respite facility as residential accommodation. Others were targetted because they were close to or above school age and plans needed to be made for their futures. All of the pupils had multiple physical, sensory and intellectual disabilities and required a great deal of support. There were communication limitations in all cases.

Of the six students included in the client population, three were in their early twenties and three were under twelve years of age. Four of the students were female. Three students lived at the school, two with their families and one had recently moved into a CSV group house.

The DAS Population and Client Services Population

For this group, the client population consisted of all people who self-referred or were referred to the service by another agency, between July 1991 and the time of the evaluation. Thirty three clients were assessed through the INA project during this period and all were assessed as having an intellectual disability, the majority at the mild or moderate level. A small percentage had additional physical or sensory difficulties. Two clients were reported as having a psychiatric disability and two others were classified as having challenging behaviours. Although most were mobile, 76 per cent were considered to require assistance with personal care and just under half had difficulty communicating. The ages of clients ranged between seven and 40 years of age, the average age being 26 years.

Almost half of the clients lived with their families, three others lived in an institutional setting, 11 lived in group homes and four people lived on their own. A quarter of the clients were from non-English speaking backgrounds. Over two thirds

were in employment, (mostly in sheltered employment) or attended school or day programs.

A3.3 The South Australian Pilot Population

The project targeted adult people who would meet current criteria for eligibility for SCOSA services, that is, people with severe and multiple disabilities requiring constant support and assistance in all areas. The project population originally consisted of 20 of SCOSA's existing clients. They lived in four SCOSA-sponsored residences within the community. All had high support needs and were considered to have a history of limited opportunities to exercise control over their lives.

The clients ranged in age from 18 to 56 years. The average age was 28 years. Men and women were equally represented in the pilot population. Three quarters of the group attended community access services during the day, while the remainder attended a special school. A large number had relatively close family ties.

During the development of the project three additional clients were targeted for this project. Two of these were reported as having artistic ability and had been invited to move into an artist's colony. This was being established with the philosophy of including people from all sections of the community. The third client was selected because, although he did not meet the original selection criteria for the project, it was felt that he would benefit from the CHOICES model.

A3.4 The Queensland Pilot Population

This project had a deliberate policy of recruiting as broad a group as possible in terms of disability type and level of support needed. Many of the clients selected for the pilot project were already known to the workers in the project or to its Board of Management. Some were also clients of the accommodation service or waiting for respite care supports. Other clients were referred by word of mouth from other individuals (such as health and welfare professionals), agencies (such as the CRS or a private domiciliary care service) or community groups (such as a church group). A group of nine clients were accepted from a Home for children (many of whom are now adults) with severe and multiple disabilities.

Twenty five clients had received a service from this project by the time of our evaluation. The majority of these were reported to have physical or 'cognitive' disabilities, and it is likely that a substantial proportion also had some form of intellectual disability. Just under a half had demonstrated difficult or challenging behaviours. Eighty per cent of the clients had disabilities (and associated life impediments) which were considered to be severe. All but three were considered to require full time support, approximately 90 per cent with personal care tasks and 70 per cent with mobility related needs. Well over half of those selected had difficulties with communication. Although the project had a policy of recruiting a broad

spectrum of disability and dependency, they did not, in fact, enlist any clients with a mild disability.

The youngest client of this project was five and the oldest, 45 years old. The average age was 24 years. Four clients were under 18 years of age. The group of clients from the Home for children were all aged between 18 and 20 years. Of all clients, two lived on their own, 12 with their families and eleven in an institutional setting. The residential pattern of this group perhaps reflects the absence of suitable alternatives for people with disabilities living in this area.

Appendix Four: Selected Characteristics of the Clients and Carers in the Sample Population

A4.1 Clients in the Sample

The sample population contained an equal proportion of clients assessed as having intellectual and multiple disabilities, although the majority of the latter were also thought to have an intellectual disability. When the sample is compared with the total client population we find that these groups are somewhat over-represented and the remaining groups with other disabilities are under-represented.(see Table 4.3) This bias is probably due to the effect of selecting substitutes for clients who were originally selected but who we were not able to interview.

The proportion of people with a mild or severe level of disability was higher in the sample population than in the client population overall. A lower proportion of the sample population than of the client population had a moderate level of disability.

Almost half the sample population reported that they required assistance with mobility and personal care tasks. The proportion of people in the sample who said they required assistance with mobility was similar for the two populations but the need for personal care was lower in the sample than for clients generally. We suggest that this disparity might be due to different perceptions on the part of clients and workers and that clients tended to understate their need for assistance in certain areas. In contrast those needing help with communication were over represented in the sample population.

The high dependency of the clients included in the sample is illustrated in other ways. Over three quarters were taking some form of medication and 82 per cent said they had a bad illness or condition that 'stopped them doing things'.

People residing in group homes and living with their families were equally represented in the sample. However, a slightly lower proportion lived in these circumstances amongst members of the sample than amongst clients as a whole. Conversely a higher proportion of people were living independently and in institutions than for the total client population.

Six clients in the sample lived on their own. Of clients living with others, 24 per cent lived in large purpose built dwellings of ten or more people and 41 per cent lived with between four and nine others. Only 34 per cent of the sample group lived with one to three others, the majority of these in family groups.

The age range of the sample population reflected that of the total client population. The greatest proportion of people (35 per cent) were aged between 21 and 30 years. The mean age of the sample population was 27 years compared with 26 years for total population. The sample population comprised a slightly higher proportion of people below the age of 21 than did the total client group.

Almost half of the sample population was unemployed, just under one third attended school and of those who were employed most were in sheltered employment. The employment circumstances of people included in the study generally corresponded to that of the total client population.

Women and men were equally represented in the sample population. People form non-English speaking backgrounds and Aboriginals and Torres Strait Islanders accounted for 12 per cent and six per cent respectively of the sample population. In these respects the sample population compares well with the total client population.

A4.2 Carers in the Sample

All but one of the 14 carers interviewed were mothers of clients. The remaining carer was the client's sister. The age of carers ranged between 35 and 67 years of age, the average age being 44. This reflects the relative youth of the clients.

Seventy one per cent of carers interviewed lived with the client. Over half of the carers provided support on a full-time basis. About a third supported the client between about one and three days per week and the remainder for a couple of days each month. Only 42 per cent of carers said they had had a break from caring in the last year, and nearly half of these had only had a break once or twice over that period. Most carers received some form of external help, generally from a government department or community agency but indicated that the level of assistance was inadequate.

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