ACT Health
Review of the Flexible Family Support Pilot

FINAL REPORT

the
Nucleus
group

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1 Introduction

1.1 Background

The Flexible Family Support (FFS) Pilot was developed as part of the ACT Government's Respite Budget Initiative in 2002-2003. The Initiative allocated funds to pilot innovative models of respite care including emergency respite and respite care for carers of people with challenging behaviours across the areas of mental health, aged care, younger children with high medical needs, and disability. Carers ACT, Community Options and Community Connections were approached and agreed to develop pilot projects based on the model of FFS.

The FFS pilot aims to deliver flexible personal support to the caring unit, including the purchase of goods and services, aimed at supporting or improving their caring relationship. The role of the coordinator includes advocacy and administration, and an educative role in changing the nature of respite service provision. The target groups are caring units who require innovative support and are willing to utilise a FFS model, and whom services or funding would assist in sustaining or strengthening their caring relationship.

1.2 Purpose of the Evaluation

The aim of the evaluation is to undertake an initial evaluation of the FFS pilot, and to develop criteria to assess the effectiveness of the FFS pilot in providing a new approach to respite service provision. It is proposed this be followed by an further evaluation of the FFS pilot approximately six months after the development of the criteria.

The evaluation included an examination of the following issues.

1. How the FFS pilot differs from traditional respite service provision programs?

2. Has the experience of being part of the FFS pilot been a positive one for families?

3. Would families consider continuing using an FFS approach to respite in the future?

4. Has being a part of the FFS pilot encouraged families to approach or view their particular situation in a different manner?

5. Has there been a general shift in perception on respite within the families and also the service providers?

1.3 Evaluation Framework

An expanded set of key evaluation questions were used to guide data collection and analysis. The key evaluation questions are outlined in the following section.

How FFS differs from traditional respite service provision programs including:

- differences in theoretical underpinnings

- differences in approach to support planning

- engagement and utilisation of the broader family or caring network

- differences in client outcomes

- key enabling factors for client control of the support and planning process

- impact of the training, background and orientation of staff on client outcomes.

Has the experience of being part of the FFS pilot been a positive one for families including:

- impact on family quality/carer quality of life
- satisfaction levels with 'customer service'
- carer/family control over the planning process
- responsiveness to cultural and linguistic differences
- carer/family views on program improvement or changes.

Would families consider continuing using a FFS approach in the future including:

- match between the service provided and carer/family needs
- reasons why carers/families would to continue with the program
- comparisons with traditional respite services.

Has being a part of the FFS pilot encouraged families to approach or view their particular situation in a different way including:

- changes in carer sense of empowerment and control
- changes in usage (patterns, frequency) of natural supports such as extended family and friends
- impact of the program coordinators on changing carer/family perceptions on respite.

Has there been a shift in perception on respite within the families and service providers including:

- impact of the program coordinators on changing carer/family perceptions on respite
- strategies used to optimise client empowerment and control
- engagement and utilisation of the broader family or caring network.

Are there differences between the three pilot programs and does this impact on client outcomes including:

- congruence among the roles of agencies and personnel
- methods for measuring client outcomes
- the sustainability of client outcomes
- characteristics of a successful client/ support personnel relationship
- information provision to clients.

Is there evidence of the initiative influencing other sectors/organisations eg traditional respite providers including:

- integration with related initiatives
- emergence of program champions
- response of local communities
- support and resistance to the initiative.

2   Methodology

The methodology for the project involved five key elements:

1. scoping of the services and client groups across the three FFS providers

2. interviews with FFS coordinators and or program managers

3. interviews with 25 FFS clients

4. interviews with a selection of traditional respite service providers and other referrers

5. analysis and reporting.

2.1   Agency Scoping

A data collection proforma was developed and circulated to each of the agencies. This was followed by an individual interview with each agency to collect and clarify data relevant to the evaluation. Agency data collection focused on:

▪   program focus and orientation

▪   characteristics of the client group

▪   intake and assessment processes

▪   service demand

▪   type and scope of services provided

▪   client outcomes

▪   difference between FFS and traditional respite care

▪   program staffing

▪   views on service system strengths and weaknesses

2.2   Client Interviews

Each of the agencies was asked to send an invitation to all clients in the program to attend and an individual semi-structured interview of one-hour duration with the consultants. Interview rounds were conducted in December 2004 and January 2005. Clients were offered interview times time during the day and out of hours. Interviews were conducted at the agencies or in the client's homes.

25 client interviews were conducted in total representing 34% of the total number of client current in the program across the three agencies.

Interviews followed a semi-structured format. Clients were asked to briefly describe their situation eg: age and type of disability of the person being cared for and their general family situation. Clients were also asked to describe how they were referred to the program and their understanding of FFS at the time of referral.

Clients were asked to discuss and rate:

- the impact that being part of the FFS Pilot has had on the family/carer

- the impact that being part of the FFS Pilot has had on the person being cared for

- satisfaction with the service

- the levels of control clients perceived that they had over their program

- service responsiveness to cultural and language needs

- general opinion of the program and its impact

- other information clients thought was pertinent to the review.

2.3   Limitations of the Data

The agencies in the project were using differing internal systems to collect and report on program data. However all agencies were reporting data to the department in a common formats. The project attempted to collect a common data set however there are several limitations to the data that should be noted:

- Clients self selected for the interview process so this may have potentially skewed the client sample towards those client predisposed to participate or with certain perspectives such as positive or negative appraisals of the program. The relatively large sample size (in relation to the total program numbers) would minimise the impact of such effects.

- There was some variation between the agencies in relation to the definitions of the target group and how client characteristics, needs and presenting issues were defined and recorded.

- There may have been some skewing of client responses because the clients wanted to secure the future of the program.

3 Findings Part 1 - Program Scoping

3.1 Program Focus

ACT Health initially developed the following goal statement and operating principles for the FFS:

FFS strives to achieve the goal of helping families, friends and community networks to stay together through:

- developing the families' natural capacity to meet the needs of family members
- enhancing the capacity of communities to value and support older people and people with disabilities and their families
- offering additional supports such as staff, goods and services, and financial resources.

Operating principles that guide FFS activities include:

- individuals and their families are recognised as the primary decision makers about their lives and supports
- FFS focuses on the whole family and recognises that benefits to the whole family also benefit the older person and/or the person with a disability
- FFS requires flexible, timely options that are responsive to families' unique needs, strengths and cultural values
- families are offered opportunities for increasing control in the planning, implementation, management, and evaluation of resources
- families are encouraged and supported to develop their natural capacities for innovation, initiative and leadership
- family support operates in ways that individuals with disabilities and their families are perceived and respected as valued members of their communities
- family support is pro-active and not only crisis intervention
- family support builds on existing natural and community supports and maximises the use of generic resources.

Over the past 12 months the agencies have been meeting as a group to further define the FFS goals and issues associated with program operation. Over this time there has been a shift in emphasis away from alternative respite towards a more holistic focus on family/carer support. The review considers this to be a positive shift that should be further encouraged and endorsed by the department.

The shift in focus has caused some confusion amongst referrers and clients. There would be benefit in developing and distributing new information about the program to referrers and clients.

3.2   Developing program focus

The three agencies meeting as a group (referred to in this report as the FFS Network) have undertaken further work to develop; the program focus; concepts than underpin the program; role of the program coordinators; and how the program is utilised. The work of the group to date has included:

- work on the definition of FFS

- identifying concepts that underpin FFS

- articulating the operating principles for FFS

- defining the role of the program coordinators

- identifying what FFS offers

- developing examples of allowable expenditure.

The definition of FFS that has been currently adopted by the FFS Network is;

"To work proactively with families to deeply explore possibilities, options and choices that strengthen the families capacity to support each person to grow and develop and to enrich the life of all family members and the broader community"

Recommendation 1

- ***The department and the three provider agencies should work collaboratively to further develop and refine the definition and operating guidelines for the FFS program. The revised definition and operational guidelines for the program should be ratified by the department and articulated to referrers and the broader sector.***

Recommendation 2

- ***A common information brochure should be developed for prospective clients and be available in alternative formats and languages as required.***

3.3 Program Capacity

The following table provides information on the number of clients receiving service by each program between November 2003 and November 2004. The data indicates that the client group is relatively stable with an average client throughput of 12% per annum.

Agency	Carers ACT	Community Connections	Community Options	Total
Total number of client receiving a service in the 12-month period.	21	29	32	81
Average number of clients in receipt of services at any one time.	21	23	28	72

Table 1. Total and average numbers of client receiving service between November 2003 and November 2004

A total of 11 clients exited the program in the above period. The main reasons for service exit were:

- services were no longer required as family/carer needs were meet
- the needs were of a short term nature and further assistance was not required
- clients moved from the ACT.

3.4 Characteristics of the Client Group

The agencies were asked to describe the general characteristics of the client group including type of disability of the person being cared for, socio economic status of the family/caring unit and level of need and use of other services. The following table provides details of the number of clients across nine client descriptors. It should be noted that clients might appear in more than one category. These descriptors relate to the target group for FFS as defined by the department.

Descriptor	Carers ACT	Community Connections	Community Options	Total
1. Families supporting children with disabilities.	14	17	22	53
2. Families supporting a young person with a disability leaving school and seeking to access work, social activities and vocational opportunities.	11	3	3	17
3. A person in a supportive relationship who due to incapacity now requires support	1	3	4	8
4. Ageing parents who require increasing support from their children	0	2	2	4
5. People experiencing an unexpected or traumatic event, eg, acquired disability, death of a carer, major illness leading to incapacity to continue in the supportive relationship, family breakdown.	1	2	6	9
6. Clients who identify as indigenous.	0	0	1	1
7. Client s who identify from CALD backgrounds.	1	6	6	13
8. Clients on income support.	4	5	16	25
9. Clients from single parent or carer households.	6	4	16	26

Table 2. Client distribution across primary client descriptors by agency

Disability Type

The following table provides information on the ranked frequency of the disability of the person being cared for (where this information was available) across the three programs with 1 being the most common.

Disability	Rank
Autism Spectrum Disorder	1
Intellectual disability including: global developmental delay, Down Syndrome, Fragile X.	2
Physical disability including; Cerebral Palsy and Spina Bifida	3
Medical Conditions including: arthritis	4
Attention Deficit Disorders	5
Degenerative or neurological conditions including: Muscular Dystrophy and Multiple Sclerosis.	5
Acquired Brain Injury	6
Alzheimer's Disease	6
Sensory disability including; visual impairment	7
Mental illness	8

Table 3. Ranked disability types of the client group.

Socio-economic Status

The agencies reported that clients come from a range of socio economic backgrounds/situations. Approximately 35 % of clients in the program receive some form of income support and 36 % of clients are single parent or carer households.

Level of Need

The agencies describe the client group as having varying levels of need. The majority of clients were described as having high or moderate to high support need. Client needs ranged from families who cope relatively well but require support at times of high stress to families who are chronically under stress and require ongoing support.

Approximately 19 % of families or carer units were defined as having more than one family member with a disability. The majority of these cases were families with more that one child with a disability.

Use of Other Services

The agencies reported that majority of clients are using other services either as a direct result of brokerage from FFS or in addition to FFS. These services typically included:

- respite care eg: Fabric and Carers ACT
- community health
- disability supports eg: Therapy ACT and Disability ACT
- specific support groups eg: Alzheimer's Association, Epilepsy Association. Autism Association, Downs Syndrome Association
- housing eg: TAS Housing.

3.5   Referral and Intake

The main referral sources to the program include:

- internal with the agency
- self/family
- FaBRIC
- Therapy ACT
- Alzheimer's Association
- Carers ACT
- family services
- hospital/medical.

The referral and intake processes are handled differently by each agency and generally reflect the size and focus of the agency including other agency wide referral processes. All agencies reported that:

- referrers are notified of the outcome of the referral usually by phone
- clients are notified of the outcome of the referral usually by telephone and or a face to face visit
- if clients are ineligible for services from FFS then they are notified (usually verbally) and referred onto other services as appropriate
- a dispute resolution process is in place if a client disputes the decision regarding eligibly for services or for other grievances. However generally these processes are generic to the agency and not the FFS program.

The intake and assessment processes in use falls into two main categories.

1. Individual practitioner approach

The individual practitioner approach centres on the use of individual professional judgement and practice knowledge applied to the information provided by the referrer and or client. The decision to accept the client and determine level of priority is made solely by the program coordinator. The decision usually involves face-to-face contact with the client.

2. Team-based approach

The team-based approach involves some form of case discussion and conferencing involving the program coordinator and other members of the agency staff. These processes may be part of a broader agency intake process. The decision to accept the client and determine level of priority is made at a team level or by the coordinator after team consultation.

None of the agencies use a formalised tool for initial needs assessment. Each agency uses a different tool for the collection of individual client information upon referral. Some agencies use tools from other programs such as the HACC - CIARR.
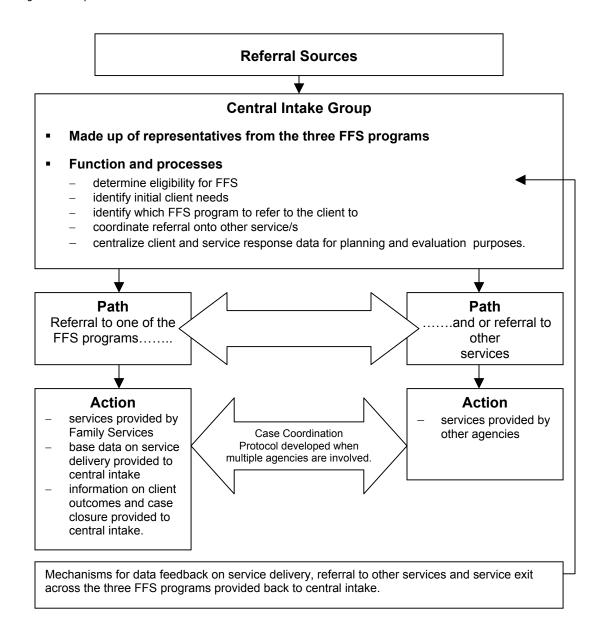
The review considers that a team base approach is the most desirable mechanism for intake and initial assessment.

The advantages of this approach are;

- opportunity for case discussion regarding intake and assessment issues (particularly useful in the formative stages of the program);

- improved consistency in program targeting; and

- improved quality as there are checks and balances in relation to potential practitioner bias or orientation.

There would be benefit in the three agencies developing a central intake process particularly as the program is still in the developmental stages. This process could be managed by the FFS Network and would ensure consistent application of program eligibility criteria, access based upon relative need (across the whole program) and distribution of service delivery matched to known geographical/social indicators of high need.

The diagram on the following page outlines a proposed structure and function of central intake for FFS.

Diagram 1. Proposed Model for Coordinated Intake

Referral Sources

Central Intake Group

- **Made up of representatives from the three FFS programs**

- **Function and processes**
  - determine eligibility for FFS
  - identify initial client needs
  - identify which FFS program to refer to the client to
  - coordinate referral onto other service/s
  - centralize client and service response data for planning and evaluation purposes.

Path
Referral to one of the FFS programs……..

Path
…….and or referral to other services

Action
- services provided by Family Services
- base data on service delivery provided to central intake
- information on client outcomes and case closure provided to central intake.

Case Coordination Protocol developed when multiple agencies are involved.

Action
- services provided by other agencies

Mechanisms for data feedback on service delivery, referral to other services and service exit across the three FFS programs provided back to central intake.

Recommendation 3

▪ *There is scope to improve current referral processes by adapting a common proforma for collecting client information upon referral to FFS.*

Recommendation 4

▪ *Some referral and service delivery data should be collated centrally in order that the program as a whole builds a picture of service demand and client characteristics over time to inform service planning.*

Recommendation 5

▪ *The three FFS programs should adopt a central intake model as described. This would ensure;*

    – *a team based approach to initial assessment;*

    – *consistent application of program eligibility criteria;*

    – *service access based upon relative need across the three programs; and*

    – *distribution of service delivery matched to known geographical social indicators of high need.*

Recommendation 6

▪ *There would be benefit in the three programs developing a consistent dispute resolution process. This process could be used for decisions relating to eligibility and other complaints or disputes that arise in the program.*

3.6 Demand Management

The following table shows the average demand for FFS in 2004 including the percentage of referrals that were not provided with FFS but referred on in most cases to other services.

Referrals	Number/ %
Number of client referred to the FFS program in 2004.	80
Average percentage of clients provided with FFS of the total number of referrals.	71%

Table 4. Referral and intake percentage data for 2004.

FFS generally endeavours to provide services as quickly as possible in response to the presenting needs of clients. Most agencies reported that they would give clients with urgent needs access to services as quickly as possible, typically by juggling the current case load/work. Times from initial referral/enquiry to service intake ranged from two days to three weeks with an average of approximately one week.

None of the agencies keeps a waiting list for FFS. This is primarily due to the relatively high or immediate needs of the client group. Referrers are notified of service capacity status at referral or as vacancies become available. If FFS cannot provide a service or if FFS is not the most appropriate service then clients are referred on to other services.

In general, FFS lacks a common approach to managing demand, hence service access is dependent on the type of intake systems operating in each agency and the varying approaches used for defining and allocating supports. The use of a common more structured intake and assessment processes across FFS may contribute to more effective demand management for the service as a whole.

The client source (location and type of clients) for each of the agencies is partly determined by agency location and historical client base. This approach may not ensure that the service achieves optimal geographic coverage of Canberra or representation of the sub categories in the target group.

Recommendation 7

- *There would be benefit in the FFS Network and the department determining the feasibility of the three FFS programs identifying geographical boundaries to maximise the geographical coverage of the program as a whole.*

Recommendation 8

- *The three programs should collate data on clients across the target group sub categories and compare this with population statistics to ensure that the program is representative of all sub target groups having accounted for client need.*

Recommendation 9

- *There would be benefit in moving towards a common approach to demand management to ensure that service access is consistent across the ACT. This could include the development of a central intake process under the auspices of the FFS Network. (See recommendation 5)*

3.7   Changes in Demand

It is difficult to determine any underlying changes in demand patterns over the relatively short period the program has been in operation. The agencies reported that the demand for the service was initially very strong. However, as programs have now generally reached capacity referral rates have decreased.

Recommendation 10

- *There would be benefit in collating demand data for the three programs over time to build a clearer picture of changing demand patterns including: referral sources and the needs and characteristics of the clients referred to the program.*

Recommendation 11

- *There is scope to strengthen collaborative planning between the three agencies focused at the service system level to manage changing demand patterns and the systemic impact of the introduction of other new programs and funding.*

Recommendation 12

- *Future resource allocation to FFS should incorporate known demographic information about geographical areas of high need to ensure an appropriate distribution of resources to identified areas of need.*

3.8   Needs Assessment and Service Planning

Once a client has been deemed eligible for the program each agency conducts some form of assessment of the needs of the client in order to develop a package of support. The process of assessing needs is generally informal and involves the coordinator working with the family or carer to identify needs and develop a support response and plan. The variations in need identification/assessment processes are in part influenced by factors such as individual practitioner experience/interest, agency focus, orientation and philosophy.

The understanding and application of contemporary person or family centred approaches varies between the agencies and in general requires strengthening. Some agencies are considering the use of contemporary person centred planning mechanisms such as Circles of Support or Path[1] and are undertaking staff training and development in this area.

Recommendation 13

- ***There would be benefit in developing a common needs assessment framework that could be applied across the three FFS programs to optimise service targeting and access.***

Recommendation 14

- ***There would be benefit in the development of coordinated training strategy for FFS agencies about contemporary ecological approaches to assessment and support for vulnerable families/carers and family and person centred planning approaches.***

3.9 Service Provision

The three agencies were asked to describe the services that were provided to families/carers by the FFS program. The services provided by the program can be grouped into three main categories:

1. Case Management/Service Coordination

This category includes full case management/service coordination where the FFS program provides the primary case management role for the client. This role includes coordinating services that families are involved with, providing information about services and assisting clients to navigate the service system. It may also include assisting families/carers forge natural supports such as links with the community and other families. Although this role is seen to provide some leadership for families/carers the focus of this role is upon empowering families to become more self-sufficient in the longer term.

2. Advocacy and Community Development

This role differs slightly from the above in that the focus is on working on behalf of the client to gain or support access to other series. One agency described this role as a client ally. Work under this category might include working with other services such as schools to support access by a child or assist people to gain access to leisure/recreational interests in the community.

Part of this work can also be considered to be community development as it involves working with other services or community facilities to make these facilities more accessible to the client group

3. Brokerage

This category includes the purchasing of a range of practical supports such as: respite care, counselling specialized therapy services, home modifications and equipment.

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[1] Information about person centred planning approached including can be found at http://www.valuingpeople.gov.uk/pcp.htm

Allocation of Services to Clients

The review sought information on how the programs make decisions about the amount and type of services it provides to clients. Decisions about amount and type of service are made on a needs basis. Although none of the agencies uses a formal needs assessment mechanism to do this. The range and amount of service provided to client varies considerably and the length of time clients are involved in the program also varies widely across the program as shown in the following tables.

Range of hours provided to client per year across the three programs	Average hours of service provided to client per client per year across the three programs
10 – 140	43.5

Table 5. Average amount of services provided to clients in any year[2]

Range of involvement - number of weeks	Average number of weeks per year[3]
3- 52	24

Table 6. Range and average length of engagement in the program[3]

Service Capping

None of the agencies reported setting a cap on the amount of services that can be allocated any one client. The approach is one of balancing the needs of the total group against available resources and monitoring the resource usage and needs of the client group.

Recommendation 15

▪ *There may be benefit is establishing a notional cap on individual client expenditure to ensure that the program can respond to an appropriate number of clients and a range of client needs. This could include the establishment of a trigger level above which where any additional expenditure required approval from higher levels in the organisation or through the Department and or the FFS Network.*

Recommendation 16

▪ *Data collection for the FFS programs should include; amount and type of services provided; and individual levels of expenditure .*

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[2] Data only available from 2 agencies.
[3] As above

3.10   Client Outcomes

Agencies were asked to describe the client outcomes that the program has achieved. The outcomes attributed to FFS as identified by the agencies included:

- improved quality of family life

- reduction in carer burden and stress

- improved health and metal wellbeing

- improved carer/family functioning and coping

- greater family/carer control authority over their lives

- improved self management of the family/carer situation

- increased awareness of rights/entitlements and access to other funding supports

- increased inclusion of people with disabilities in their local communities

- improved access to universal and specialist services for families/carers

- self-development through improved access to education and training

- increasing or maintaining employment situation

- linkage with other relevant services and support networks

- increased mobility and independence.

Measurement of Client Outcomes

Client outcomes are generally measured through a qualitative assessment process by examining the changes that have occurred for the family/carer in relation to their initial and ongoing needs. The criteria applied includes:

- strengthened family/carer to maintain their caring role within the family/caring unit

- improved quality of life for families/carers

- reduced family/carer burden and stress

- increased participation by people with disabilities in their community

- increased community capacity and understanding to value and support client participation

- increased client independence.

The process for determining and documenting client outcomes is largely anecdotal and is done through individual casework and notes.

Recommendation 17

- ***The three programs should work towards the development of a common definition of client outcomes in order to measure program performance over time. Once developed a standardised format should be used across the three programs to document client outcomes over time.***

Recommendation 18

- ***There is scope to use standardised measures of impact on carer/family functioning to measure program impact over time.*** *(See section 6.6)*

3.11   Cultural Responsiveness

The data on clients from Culturally and Linguistically Diverse (CALD) backgrounds was incongruent. There was a discrepancy between agency and client reported data in this regard. None of the 25 clients surveyed, representing 34% of the total client group, identified as being from CALD backgrounds, however agency data indicates that 13 out of 81 clients or 16% are from CALD backgrounds. Part of the explanation for the difference is that some of the clients interviewed did not identify themselves as being part from a CALD background although they may have come from other countries/cultures.

One client in the three programs was identified as indigenous or 1.25 % of the total client group. According to the 2001 Census[4] 1.2% of the population in the ACT identified as indigenous. This indicates that the program has a representative percentage of indigenous clients compared to the general population. Given the small numbers involved this should not be considered to be a highly reliable indicator of the program's representation of indigenous persons. Other factors such as higher unemployment rates and increased health issues in the indigenous population would indicate that this group may have a higher need for support than other sections of the population.

Recommendation 19

- *FFS should develop a consistent definition of CALD clients, capture this information at intake, and compare the percentage of CALD clients in the program with that of the local population.*

Recommendation 20

- *There is scope to develop an integrated strategy across the three FFS programs region to enhance the responsiveness of FFS to persons from indigenous backgrounds. This might include the FFS Network forging stronger ties with indigenous groups and exploring the development of new service models that are more culturally appropriate to the indigenous population.*

 Recommendation 21

- *All FFS programs should be required to develop a CALD and indigenous responsiveness strategy. This requirement should be included in the Funding and Service Agreement with the Department.*

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[4] Australian Bureau of Statistics 2001 Population Census

3.12 Program Cost Structures

The range of services and hence the costs per client vary widely and are linked to client needs.

Range of costs per client per year	Average cost per client per year
$ 280 - $14,000	$ 3,570

Table 7. Range and average cost per client per year

Information on costs structure varies across the agencies and not all agencies were able to provide detailed cost breakdowns. The average cost breakdown for the programs where data was available is show in the following table. It should be noted that it is not possible to draw firm conclusion form these data in relation to the comparative costs structures of each program. This would be possible once common definitions of cost components were developed and applied.

Program component	Agency 1	Agency 2	Agency 3
Corporate overheads	6%	Not identified	12%
Program management	Not identified	Not identified	0.5%
Coordination	51%	34%	54%
Purchased services	43%	66%	25%
Other	Not identified	Not identified	8.5%

Table 8. Cost breakdowns

Recommendation 22

▪ *A common financial reporting format for FFS should be developed by the department to build an accurate picture of cost structures including all corporate and administrative overheads. This would to enable a proper analysis of program expenditure patterns to be undertaken and inform the future development of funding models for FFS.*

3.13 Staff and Intervention Models

The review sought information on the qualifications and background of program staff in order to determined what characteristics related to staff (coordinators) qualifications and background contributed to program success.

Qualifications of the Coordinators vary and include differing level qualifications in areas such as: welfare, disability, education, counselling, medicine, social science, and psychology. Formal qualifications in relevant human service fields were seen as important elements in program success. Of greater importance is the understanding and application of contemporary approaches to working with vulnerable families and carers.

Work in other jurisdictions has identified service models that are most effective for vulnerable families. For example the Strategic Framework for Family Service, Department of Human Services, (2002)[5] considers that the model of service delivery for vulnerable families should include:

▪ A family focused approach that builds on family strengths and recognises the crucial significance of the family in achieving positive outcomes for children and young people.

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[5] Department of Human Services, 2002, *A Strategic Framework for Family Services,* Melbourne.

- An ecological approach that analyses the problems at the level of the individual, the family, the family's support system and the community and responds to both the risk and protective factors in these multiple contexts.

The Pathways to Prevention Report Attorney General's Department, (1999) [6] places emphasis on pathways and transition points. This approach allows for Family Services workers to plan ahead for critical transition points. This developmental approach allows for services to be provided to families in a non-linear manner, with the families utilising services when they need them and at different times.

The Evaluation of Strengthening Families Initiative in Victoria[7] concluded that the main components of the Strengthening Families Initiative model (assertive outreach, case management, in-home support and brokerage) were found to be highly successful in the achievement of positive family outcomes.

- Assertive outreach is most successful when the family has an awareness of the reasons and source of the referral and involvement in planning the first contact. (There was a variation found in services' interpretation of assertive outreach, which ranged from giving clients information to proactive home visits)

- Case management needs to fulfil the role of direct service delivery in order to achieve positive outcomes, not simply to assess and refer. In-home support appears to be a vital adjunct to case management.

- Brokerage worked exceptionally well as a means of engaging families and addressing practical goals for the family.

- There appears to be a direct correlation between the greater amount of time spent with families and greater goal attainment, worker satisfaction and a greater chance of engagement with services.

In 2003 the Department of Human Services Victoria[8], described a process undertaken by the department and Family Service agencies on the Eastern Metropolitan Region to; enhance the services to families by strengthening relationships between the agencies; developing a continuum of services within one service model; and develop relationships between Family Services and other service systems.

The Project asked clients for feedback on the service/s they had received. Clients spoke positively about their experience of 'active engagement' and emphasised that this resulted in interventions before they would have been possible if the clients had had to self refer. However, it was also found that clients who self referred received a less timely intervention that families where a professional had referred.

The most helpful aspects of service delivery from a clients' perspective were found to be:

- the outreach nature of services

- the provision of services within the home

- flexibility of appointment times

- availability of workers by phone

- ability of workers to engage the whole family and the willingness of workers to be practically involved.

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[6] Attorney General's Department, 1999, Pathways to Prevention: Developmental and Early Intervention Approaches to Crime in Australia, Canberra.

[7] Department of Human Services, 2001, *Evaluation of the Strengthening Families Initiative,* Volume 1, Main Report.

[8] Department of Human Services, Eastern Metropolitan Region, 2003, *Family Service System Redevelopment Research Project.*

Barriers regarding access included the fact that services may not be well known, that they may be church based, they may charge fees and concerns that they may have to tell their story more than once if they are involved with multiple services.

The knowledge and application of contemporary approaches to working with vulnerable families and carers varies across and within the three FFS agencies. The agencies have invested in work that is assisting each agency and practitioners to identify best practice approaches to working with vulnerable families and carers.

There is scope to expand on this work and further develop best practice principles at both policy and practice levels.

Recommendation 23

- *That FFS continues to develop and adopt best practice evidence based principles in relation to working with vulnerable carers and families including:*

  – *the use of family/carer strengths focus that is ecological, recognises life stages and enhances family/carer problem solving, self-efficacy and self-management*

  – *approaches that are collaborative, non-judgmental, flexible, holistic with a focus on goal setting*

  – *a culture of reflection which values participant feedback.*

Recommendation 24

- *There would be benefit in the three agencies pooling resources for the provision of joint training to program staff in contemporary approaches to working with vulnerable families to ensure evidence based practice is applied across the three programs.*

4   Findings Part 2 - Client Interviews

4.1   Profile of the Clients Participating in Interviews

Number of Interviews

A total of 25 client interviews were conducted across the three programs as shown below. Interviews were conduced at the agencies and in client's homes to suit client needs where possible. Interview times were offered during the day and in the evening. It is worth noting that many of the clients were quite emotional during the interview. This is an indicator that the program is correctly targeting those families and cares that are most vulnerable.

Community Connections	Community Options	Carers ACT
N = 9	n = 9	n = 7

Table 9. Client interview agency breakdown.

Ages of Clients Being Cared For

Of those interviewed the ages of people being cared for are show in the following table. These groupings were chosen to reflect developmental issues. Note there is no data for the age group 41 – 69 as no clients in this category responded to the interview invitation. Total n = 28 - there are more people being cared for than respondents because several carers are caring for more than one person. Over 50% of respondents were caring for children 0 – 12 years of age.

0-2	3-5	6-12	13-18	19-40	70+
2	10	4	5	6	3

Table 10. Age distribution of the person being cared for by interview respondents.

Gender

Of those being cared for 22 were male and 6 female. It is interesting to note that the vast majority of people being cared for are male. While there is a slight preponderance of females with disabilities in the general population (19.8% males and 20.1% females[9]), there are many more males receiving care than would be expected. Further research needs to be conducted to clarify this issue.

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[9] Australian Bureau of Statistics, Disability, Aging and Carers Summary of findings, 2002, 4430.0

Disability

Many of the people with disabilities had several issues. The following table is based on the primary disability reported by the respondents. The ranked frequency of respondents caring for people with a particular disability is similar to those reported across the three agencies.

Disability	Number	Rank
Acquired Brain Injury	2	5
Alzheimer's Disease	1	6
Attention Deficit Disorders	0	-
Autism Spectrum Disorder	6	2
Degenerative or neurological conditions including: Muscular Dystrophy and Multiple Sclerosis	1	6
Intellectual Disability including: Downs Syndrome, global developmental delay	7	1
Mental Illness	4	4
Medical conditions	2	5
Multiple disabilities	1	6
Physical Disability including: Cerebral Palsy, Spina Bifida	5	3
Sensory disability including: visual and hearing impairment	1	6

Table 11. Ranked disability types of the person being cared for by interview respondents.

Family Situation

The following table shows the family situation of the respondents. Several of the respondents were divorced but identified themselves as single. This seemed to reflect their experience as a single parent. It is interesting to note that 15 out of 25 respondents were married. This could indicate a skew in the data since this does not reflect the community rates of divorce (40%) (ACT figures are higher) and higher rates in the families with a child with a disability.

Family/Carer situation	Number
Married	15
Married uninvolved	1
Single/widowed	7
Divorced/separated	2
No family support	7
Employed – P/F	9
Unemployed	1

Table 12. Family status of interview respondents

Recommendation 6 should be noted in relation to client gender and family situation.

Intake and Referral

The majority of clients (68%) were referred to FFS from service agencies including internal referral within the FFS provider agency. The percentage of carers who were referred to FFS through agencies is of concern for those carers who are not already engaged in the service system. Navigating the service system was a source of frustration and concern for many of the carers. The following table shows respondent referral sources.

In agency	Other agency	Network/ Conference	Other carers	Media	Self/friend
6	11	1	1	1	5

Table 13. Referral sources for interview respondents to FFS

Respondent comments included;

> *"There is no place to get information. You see GPs and they don't know. I thought there was nothing."*

> *"Information outside of the medical network was completely lacking. I only found out about the carers' network after 10 years."*

> *"The program helps people outside the system who have fallen through the cracks."*

Although it is likely that carers with high needs are in contact with the service system, more use could be made of events including Disability Week and various media such as community newspapers to bring services to the attention of carer's who are not involved with the service system.

Recommendation 25

▪ *There would be benefit in utilising existing avenues for promoting the FFS program so that information about the program is available to the widest possible group of potential clients.*

The following table shows families response to: what they understand FFS could provide at the time of referral; what service they are receive; and for how long clients think they will be in receipt of services.

Question	Not sure	Respite	Something to make life easier
What did you understand was being offered by FFS?	12	5	7
What service/s did you receive from FFS?		6	Advocacy by worker, air-conditioning, appliances repaired, case conferences, consultant fees, counselling, a house extension, getting child to day care, help with incontinence training, holiday, hoist, house maintenance, housekeeper during crisis, piano lessons for sibling, public speaking, safety issues dealt with, school holiday program, tuition, tyres, wheel chair top up.
How long will the services last?	23		

Table 14. Respondent initial perceptions of FFS scope and services provided.

The lack of clarity about what was being offered stems in part from the flexibility inherent in the program and that the guidelines have been developed through experience. Although they understood that the program would help them, the respondents reported some discomfort with the lack of information and certainty. This compounds the difficulties that people have in asking for help and using resources. Also the majority of respondents were unclear about how long the services might last.

Respondent comments included:

> "Asking for help leaves you feeling dependent, selfish, a burden."

> "I feel guilty because there are others worse of than me."

> "They ask you what you want, but I don't know what's possible. If you don't know, you don't know."

> "It feels like being in the world of the unknown."

Recommendation 26

- ***A communication strategy including a clear easy to understand pathway through the service system be developed to inform carers about FFS and other services.***

Recommendation 27

- ***There would be benefit in the three programs developing a common program description for clients upon referral and entry into the service.***

Impact (Carer/family)

Respondents were asked to rate the impact that being part of the FFS Pilot has had on them (carer/family). The respondents had the opportunity of indicating a negative impact. None of them chose to. The following table shows program impact ratings of respondents across nine key domains.

	Not applicable [10]	Not much	A bit	Quite a bit	A lot	% rated as quite a bit and a lot [11]
1. Stress levels			4	11	10	84%
2. Coping		2	5	8	11	76%
3. Connection with others	5	5	3	10	2	60%
4. Family relationships	1	6	3	5	9	58%
5. Feeling in control	2	6	3	6	8	60%
6. Managing time	4	7	3	7	4	62%
7. Confidence	2	6	3	9	5	60%
8. Access to other services	4	2	4	8	7	71%
9. Learning new skills	4	6	2	6	7	62%

Table 15. Respondent rating of program impact

The majority of respondents felt that the program had made a very positive impact on their life. The greatest impact was in:

- reducing stress levels

- improved coping

- enabling access to other services.

Respondent comments included:

"A weight is off me, there is some back-up."

"The effect ripples out."

"If I didn't get this support, my child would have to be in supported accommodation."

"It has given me a life."

"It has allowed me to keep employed."

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[10] Not applicable responses indicated that this was not an issue at the time of involvement in the program.
[11] Excludes not applicable responses

Many respondents also expressed concern that they felt the task of caring was overwhelming and that even this support, which focuses on the specifics of what they need, does not enable them to live a life that approaches "normal".

Respondent comments included:

"The support network is zilch."

"Having people in my home all of the time is stressful. All of my life is exposed."

"It is positive someone helps, even if nothing changes."

"The program meets some needs, but the major stress isn't being addressed."

Impact on the Person Being Cared For

Respondents were asked to rate the impact that being part of the FFS Pilot has had on the person they care for. The following table shows program impact ratings on those being cared for across five key domains. The responses were heavily weighted towards the positive in that FFS made a valued difference in the lives of the people they care for.

	Not applicable [12]	Not much	A bit	Quite a bit	A lot	% rated as quite a bit and a lot
1. Learning new skills	1	1	3	8	12	83%
2. Access to the community	5	3	2	5	10	75%
3. Connection with others	3	4	1	10	7	77%
4. Family relationships	2		8	10	4	63%
5. Confidence and self esteem	5		1	11	8	95%

Table 16. Respondent rating of program impact on those being cared for.

The greatest impact was in:

▪ improved confidence and self-esteem

▪ learning new skills

▪ developing connections with others

▪ improved access to the community

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[12] Not applicable responses reflect that for these people with disabilities these things are unlikely or that they were not an issue at the time.

Respondent comments included:

> *"This program has helped to maintain the person I care for in a job which has had a very big impact on self esteem. A dramatic difference!"*

> *"We are aiming for our daughter to use the skills she has learnt in a broader way."*

> *"The hugest difference to our quality of life and impact on others in childcare."*

> *"Can't say enough about this crowd."*

> *"The kids are somebody at day care. Usually they are nobody, nowhere."*

Satisfaction

Respondents were asked to rate their satisfaction with the service they received. The following table shows respondent ratings across six domains.

	Not applicable	Not very satisfied	A bit satisfied	Quite a bit satisfied	Very satisfied	% rated as quite a bit and very satisfied
1. Being told what's happening.				8	17	100%
2. Having access to information I want.	2	1		7	15	96%
3. Service is available when I need it.		3	2	6	14	80%
4. Staff respond to what I need.				5	20	100%
5. Staff follow through on things I raise.				5	20	100%
6. The organisation deals with complaints or grievances I have.	17			1	7	88%

Table 17. Respondent satisfaction ratings.

Overall the respondents were very satisfied with the service they received. The greatest degree of satisfaction related to:

- the responsiveness of staff

- having information and being kept informed.

32 % of respondents reported having dealt with a complaint or grievance with the program they were using. Of these 88% were "very satisfied" with the way in which the complaint or grievance was dealt with by the agency.

Respondent comments included:

> *"My relationship with the carer is central and important and excellent."*

> *"I can ask, I don't have to beg."*

> *"All staff are united in helping. It makes my job so much easier."*

> *"Flexibility is fabulous."*

Areas where respondents were not satisfied with the services they received included;

- difficulty in services being available when needed (having to wait for services); and

- general dissatisfaction with the service system such as frustration navigating the system.

Respondent comments included:

> *"It is very frustrating waiting for services- if it is going to take six months."*

> *"Learning to navigate the service system is very difficult."*

> *"There is a lot of unfairness with the squeaky wheel, even when it is me getting the service, it is unfair."*

Recommendation 28

- ***Further work should be undertaken to identify the critical factors in this program that produce the positive outcomes for carers and the people they are caring for and how these could be applied more broadly.***

Control

Respondents were asked to rate how much control they felt they had in relation to service provision and planning. The following table shows respondent ratings across six domains.

	Not applicable[13]	Not much	A bit	Quite a bit	A lot	% rated as quite a bit and a lot
1. I was in control of planning what service I received.	1	2		4	18	91%
2. I had a choice of what sort of service was provided to me.	4		1	5	15	95%
3. I had choices about the timing of getting services.	4	2		4	15	90%
4. My opinion was listened to.	1			4	20	96%
5. I got what I expected/needed.	1	1	3	3	17	83%
6. I could get changes to what was happening.	1		1	6	17	96%

Table 18. Respondent rating of degree of control over planning and service delivery.

Respondents felt most in control in relation to:

- their opinions were valued and central to the process

- planning for service provision and support

- choice of the type of services they received.

Respondent comments included:

"When hours of support were cut, I was nervous and apprehensive, but they were gentle and in fact it has increased my confidence."

"One of the staff wasn't suitable –we worked through that together."

"I was asked what would help me."

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[13] Not applicable responses indicated that there was a focus on a particular need and choice was not relevant. There were high reported levels of feelings of control. This does not necessarily reflect actual control of services, but rather that the consultative approach used by the workers encouraged feelings of control.

Some respondents felt that they did not receive adequate information about FFS and what it could offer. Provision of more accessible information about services would enhance feelings of control.

Respondent comments included:

"Not knowing how much I was allowed to spend was difficult. If I had an amount I could plan."

"The guidelines could be clearer."

Respect for Cultural, Linguistic and Communication Differences

Respondents were asked to rate how respectful the service was to culture and language needs. The following table shows respondent ratings across five domains.

		Not applicable	Not very	A bit	Quite a bit	Very
1.	Information was provided in the language I am comfortable with.	25				
2.	If I needed help with English it was available.	25				
3.	The information provided was easy to understand.				6	19
4.	The service was happy to change things to suit my culture.	25				
5.	I was asked about my culture when services were being planned.	25				

Table 19. Respondent rating of cultural and language responsiveness.

None of the respondents identified themselves as being from a culturally and linguistically diverse background. 76% of all respondents reported that the information provided to them was very easy to understand.

Respondent Views About FFS

Respondents were asked to rate what they though of FFS in terms of its impact and general value to themselves and potentially others. The following table shows respondent ratings across five domains.

	Not applicable	Probably	Yes	Absolutely	Total % rated Yes or Absolutely
1. I'm better off in this program.		1	3	21	96%
2. I would tell other people to use this way of getting services.	*Comment		3	21	96%
3. It is an improvement on what was happening before.			4	21	100%
4. I'm more positive about my family situation and myself after being in FFS.		4	3	18	84%
5. The program is a good use of the available money.			4	21	100%

Table 20. Respondent ratings of the general impact of FFS.

There was a very high degree of positive sentiment about the program's impact on the lives of respondents and strong endorsement of the program to others.

Respondent comments included:

" The worker has been very important. Other services are difficult to deal with. It provides co-ordination. It is goal orientated and the advocacy is important. It isn't just flopping about."

"They have been there to pick up the pieces."

"It allowed me to keep my family together."

*" This is tricky because there are only so many dollars and we don't want to risk our share. Funding and staffing are hopelessly inadequate for the need that is in the community. It is like Departments don't want you to know what is available so that they can limit expenditure."

There were a few expressions of disappointment.

"We talked about a lot off things, but nothing much eventuated."

"There is not enough money in the system. Some families are getting nothing."

Perception of Family/Carer Situation

Respondents were asked if being part of FFS had changed the way they thought about their family situation. In particular: had involvement the program lead to more positive outlook on their family/carer situation and hence enhanced resilience? 88% of respondents indicated that FFS had lead to them developing a positive or very positive perception of their family/carer situation.

Very negative	Negative	Neutral	Positive	Very Positive
0	0	3	14	8

Table 21. Program impact on respondent outlook on their family/carer situation.

Respondent comments included:

"I had a plan and this is making it happen."

"It is helping me realise I could do it myself and me and my kids would be fine."

Perception of Respite Care

Respondents were asked if being part of FFS had changed the way they think about or use respite care. 68% of respondents indicated that FFS had lead to them developing a more positive view of respite care that was expressed in feelings of more power, an expectation of better services and in some cases using less respite services.

Very negative	Negative	Neutral	Positive	Very Positive
O	O	8	12	5

Table 22. Program impact on respondent outlook on respite care.

Respondent comments included:

"I expect more from my co-ordinator – services (from another agency) were getting cancelled, and now that is seen as not OK."

""We are using the respite service less because we are getting on better."

"We are getting more focussed care and so we are using respite less."

The Most Positive Aspects of FFS

Respondents were asked to describe the most positive aspects of being part of FFS in terms of the areas and issues the program covers. Ranked responses are provided in the following table.

Service type	Rank
Personal connection	1
Short term emergency support (back-up)	2
Benefits to family members other than person with a disability	3
Access to resources	4
Respite	4
Therapeutic service	4
Advocacy	5
Carer strength development	5
Family focus	5

Table 23. Respondent ranking of the most positive program aspects.

Least Positive Aspects of FFS

Respondents were asked to describe the least positive aspects of being part of FFS in terms of the areas and issues the program covers. Ranked responses are provided in the following table.

Issue	Rank
Asking for help – feeling guilty	1
Not knowing what's available, uncertainty	1
Competing for services	2
Accessing services or resources	2
Short –term duration of support	3
Loneliness	4
Exposure of life/intrusion	4
Arrangements not working	4

Table 24. Respondent ranking of the least positive program aspects.

Recommendation 29

- *Other strategies to support carers to develop and maintain personal networks and connections be developed and implemented.*

5 Findings Part 3 - Consultation With Other Services

The purpose of consulting external stakeholders was to identify the influence and impact that the introduction of FFS has had on other agencies providing services to people caring for people with disabilities. The definition of respite care needs clarification. In some agencies it is taken to mean any service that supports the family's care for the person with a disability; in FaBRIC it is taken to mean only direct care of the person with a disability. This has lead to some confusion. There is a need for a clearer definition and understanding of the roles and provision of respite care, emergency respite and support services.

5.1 Agencies

A mix of staff and management from Therapy ACT, FaBRIC, Carers ACT and Centacare were consulted using questions to guide conversation. The questions centred on:

- relationships that the workers and agencies have developed with FFS providers
- champions for the program
- valued aspects of the program
- community knowledge of and engagement with the program
- factors influencing the long term integrity and viability of the program.

5.2 Relationships

Respondents all agreed that the program had required them to strengthen and build on existing relationships. Consistent with information from carers, there are many cross referrals and some brokerage between agencies. FaBRIC reported that between 40-50% of the families they provide respite for have been referred to FFS for equipment, case management and broader family support.

FFS has highlighted the lack of co-ordination of intake, assessment and provision of services between agencies in the respite area. The current level of emergency and ongoing respite care respite was also cited as a reason that this program has been well utilised.

The need for a more formal network across the disability sector was identified. There have been networks and meetings in the past and a HACC network that is functioning at the moment. While the information sharing that is a central function of that network was valued, its strategic function was questioned. Sector development requires that resources are allocated to building networks and developing consistent procedures for intake and assessment and provision of services.

5.3 Champions

Each agency reported strong champions for the program in staff and management. Support was shown by:

- sharing information about the program as part of new worker induction, with families and in other forums
- arguing for the integrity of the program with management and Boards
- working with other agencies to creatively generate options to meet families' needs.

5.4 Valued Aspects

The aspects of the program that were highly valued include:

- short-term goal orientation
- flexibility
- being able to meet needs that have always existed but have fallen outside of the funding guidelines
- supporting carers so that they feel able to continue caring
- creatively opening up options
- the responsiveness of the program to the families' needs that has meant that the focus of the program has changed over time
- the respectful way of working with carers that empowers them.

The workers reported that part of their commitment to the program came out of the feedback that they received from families.

5.5 Community Knowledge and Engagement

Every respondent reported that they did not want too many people to know about the program. It was not seen as appropriate for the general public to know about the program and there were concerns about too many people wanting services. It was reported by Centacare that when they did advertise they received many enquiries from the public and referrals from other agencies. It was also thought that other agencies provided more appropriate referrals and 'genuine need' had been established. All of the agencies appear to be controlling information about the program as a means of demand management.

It was acknowledged that there were contradictions in this practice. In some cases, practitioners outside of the disability sector such as teachers and welfare workers in schools and social workers in the hospitals did not know about the program and some families who could have benefited from the program were not alerted to its existence. The other area of discomfort was in the family centred, strengths based approach of the program being undermined by the agencies acting as gatekeepers. This was acknowledged and the educative possibilities in the program were understood to ameliorate this contradiction.

5.6 Threats to Long-Term Viability and Integrity

Threats to the long-term viability of the program were understood to be:

- the confusion of having multiple auspice agencies
- unclear guidelines, benchmarks and expected outcomes
- issues about where it 'sits' in ACT Health. Is there a more suitable area of Government for such a program?
- lack of co-ordination of intake and common assessment and protocols for provision of services
- some confusion, tensions and conflicts of interests over roles for provision of emergency respite, respite care, support services and case management
- a particular threat was understood to lie in the program filling up some of the worse gaps in the service system and masking an inadequate level of funding for emergency and ongoing respite care.

It was noted that most of these exist because it is a new program and that it was considered that as the program matures there will be increasing sophistication and clarity in all of these areas.

5.7   Opportunities for Long-Term Viability

The features that indicate some of the opportunities for long-term viability of the program are:

▪ Flexibility underpins the strengths based family focus of the program. This was understood to be its main strength.

▪ The change in work practices has meant that as staff have worked with the possibilities in the program they are becoming more comfortable with developing creative options and 'taking it slow and getting to know.'

▪ The development of well-informed, capable families who have cared for a person with a disability who can mentor and provide information and companionship to others.

▪ Over time, if patterns of use emerge, the focussed short-term interventions might open up the possibility of some corporate sponsorship e.g. several people have been supported to obtain their drivers license and a driving school could be approached to sponsor this area of training.

6   Findings Part 4 - Service System Issues

The project identified a number of service system issues that impact on program effectives and potentially on further development.

6.1   Person and Family Centred Approaches

Agencies reported that there is a general lack of understanding across the sector about person and family centred approaches to service planning and delivery. This can create issues where FFS interfaces with other services that do not adopt the same degree of flexibly in client planning and service delivery.

6.2   Service System Integration

Many of the clients interviewed spoke of a lack of readily accessible information on what services are available in the ACT and did not have a clear sense of how to access services. A significant proportion of the FFS coordinator role is applied to assisting clients to navigate the service system. In some cases there is a lack of clarity around the case management role when multiple agencies are involved.

6.3   Complexity of Cases

Generally the agencies noted that there was an increase in the complexity of client presenting issues for the agency as a whole and to some extent to the FFS. It is not possible to determine if there are any trends relating to client presenting issues for FFS given that it is a relatively new program. However changes for the general client group are consistent with that reported elsewhere[14] and include:

- an increase in clients with mental health issues and in combination with other issues

- a greater proportion of clients with intergenerational poverty and abuse

- an increase in clients with substance abuse issues

- an increase in clients with family violence issues

- an increase in single parent households in particular single mothers

- an increase in issues/difficulties managing child and adolescent behaviour

- an increase in clients where the parent/s carers have a disability.

In general there is a need for the services that work with vulnerable families/carers to be involved for longer and for more complex interventions to be applied. Some agencies noted that where clients were involved with multiple agencies/services case management was problematic. Issues related to case management included lack of clarity about which agencies had responsibility for case management. In some cases multiple case planning/ coordination mechanisms were reported to be in place.

Recommendation 30

- ***The FFS in conjunction with other relevant sectors such as disability and mental health should develop a case management protocol for the effective management and coordination of complex cases.***

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[14] Department of Human Services, 2004, *Protecting Children: ten priorities for children's wellbeing and safety in Victoria, Technical options paper,* Community Care Division, Victorian Government, Melbourne.

6.4   FFS Governance

Analysis of the strengths, weakness and opportunities confronting the FFS indicates a case for strengthening of FFS service system governance. Significant work has already been undertaken by the three agencies in this regard and is continuing.

The need for more integrated service systems is described in the research literature. For example Glisson and Hemelgarn (1998)[15] undertook research that found outcomes for children are better where agencies have clearly defined structural arrangements between them to enable collaboration. They also found that where the collaboration resulted in an abdication of responsibility, outcomes for children were not improved.

Protecting Children: The Child Protection Outcomes Project[16] discusses integrated governance as an aspect of community partnership. Integrated governance is described as the merging of service organisations, both government and non-government, into an integrated system that is managed as a system and held accountable for effective service provision in the context of local needs and conditions. Integrated governance arrangements permit, support and facilitate cooperation and collaboration among different agencies.

Integrated governance begins with a shared vision and purpose, the tasks to achieve them and development of the indicators for success. It may include protocols, common assessment frameworks, the pooling of funding and resources and co-located services.

There is potential for FFS to take a leadership role in developing more flexible person centred approaches to family and carer support in the ACT

Recommendation 31

- *The role of the current FFS Network could be enhanced in order to provide a more robust and influential mechanism to govern future program development.*

   This could include:

   – *formalising the partnership between the three FFS agencies through an instrument such as a Memorandum of Understanding at agency governance level*

   – *developing terms of reference and a mandate for the FFS Network related to service system governance and development that is supported by the department.*

   – *establishing practitioner level networks to support the services system development and share best practice across both the FFS and other respite programs*

   – *developing stronger and more formal partnerships with other service systems such as mental heath and disability services.*

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[15] Glisson, C. and Hemelgarn, A., 1998, The effects of organisational climate and intereorganisational coordination on the quality outcomes of children's services systems. *Child Abuse and Neglect,* 22 (5), pp 401-421.

[16] Protecting Children: The Child Protection Outcomes Project, 2003, Allen Consulting Group.

6. Future Evaluation Framework

It is necessary to accurately demonstrate performance against the agreed expectations for the outcomes of any program. This is particularly difficult in human service programs such as FFS which have many factors impacting on its implementation and outcomes.

A useful framework for monitoring and evaluation should provide a rationale for gathering information to:

- demonstrate how the program is performing

- identify the critical factors influencing the functioning of a program

- include information on both processes and outcomes

- include opportunities for gathering quantitative and qualitative information

- be a valuable source of information for learning and program development.

The following framework which is based on the Targeting Outcomes of Programs (TOP) framework, some aspects of Bennett's Hierarchy[17] and the Most Significant Change (MSC)[18] approach is suggested.

Some of the criteria need information that already exists within the agencies managing the program, some information will need to be collected for the first time and in some cases new tools to collect the information will need to be developed. The items in **bold** will need to be developed.

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[17] Information about both TOP and Bennett' Heirarchys is at Http://citnews.unl.edu/TOP/english/synopsis.html
[18] Evaluation Journal of Australasia, Vol. 2 (new series), No. 1, August 2002. Peter Sigaard "Monitoring without indicators

6.5   Process Monitoring Framework

To monitor and evaluate **processes** for FFS the following areas should be considered:

AREA	CRITERIA	POSSIBLE TOOLS

1. Resources	▪ What resources are currently in the system?
	  – Staff – EFT, qualifications
	  – Volunteers – EFT, qualifications
	  – Written resources
	  – Organisational resources (buildings, cars, IT, training)
	▪ How sustainable are resources?
	  – future funding by Government
	  – other funding opportunities
	  – organisational commitment to program
		▪ Audit information
		▪ Equipment register
		▪ Staff and volunteer records
		▪ Document control records
		
		▪ Staff turnover
		▪ Identification of other sources of funding by Boards of management
		▪ Strategic plans of organisations

2. Participants	▪ Demographics of clients ▪ The duration and intensity of service provision and resources allocated	▪ Intake forms ▪ Participants' records ▪ File notes ▪ **Common client data template for intake and initial needs assessment (See Recommendation 3)**
3. Activities	▪ Program information to clients and sector ▪ Contacts with clients – type and purpose ▪ Contacts with organisations – type and purpose ▪ Network meeting attendance ▪ Administration tasks – type and time ▪ Travel including time and costs ▪ Information sharing ▪ Direct service delivery	▪ **Timesheets at the agency level** with activities noted either exemplar (an agreed series of weeks chosen to reflect different demand patterns) or ongoing ▪ **Common client data template for service provision (See Recommendation 3)**

4. Practices	▪ Staff and volunteers knowledge and application of:
	  – fundamental research in areas such as: person centered planning, family centered practice, family protective factors and resilience
	  – program frameworks, such as family focused strength based practice
	
	▪ Processes of:
	  – Initial referral to program
	  – Intake
	  – Assessment and client plan
	  – Service delivery
	  – Referral for services
	  – Brokerage
	  – Case management
	  – Advocacy
	  – Review
	  – Feedback to referrers
	  – Service exit
	  – Grievance procedure
		▪ Count and description of training episodes
		▪ Staff development plans
		▪ **Count and description of information sharing episodes**
		▪ **Assessment of knowledge**
		
		▪ **Audit of processes**

Table 25. Process monitoring framework.

6.6 Outcome Monitoring Framework

To monitor and evaluate the **outcomes** of FFS the following areas should be considered:

AREA	CRITERIA	POSSIBLE TOOLS
1. Reactions	Reactions to the program by: ▪ participants ▪ staff ▪ organisation ▪ external stakeholders	▪ **Survey/questionnaires** ▪ **Interviews** ▪ **Focus groups**

2. Changes in:
– knowledge
– attitudes
– skills
– aspirations.
	How does the following change during the course of the program?
	▪ Staff, volunteer and participants' knowledge about agreed core areas.
	▪ The attitudes of staff, volunteers and participants about core area.
	▪ What skills of staff, volunteers and participants are evident or needed.
	▪ What aspirations are they expressing.
		▪ **Focus groups of staff and clients to develop agreed core knowledge, attitudes, skills and aspirations. (MSC)**
		▪ Pre and post testing either through:
		  – interview as part of intake and service exit interviews
		  – questionnaire
		  – (this is done in some agencies)
		▪ **Staff and volunteer questionnaires or focus groups**

3. Client outcomes including: – family functioning – social – economic – service usage.	What has changed in family/carer protective factors and impact for example: ▪ the development of family/carer networks ▪ clear family rules and roles ▪ strengthened family/carer/couple relationships ▪ strength and use of informal supports ▪ personal development of the carer ▪ self security and self esteem ▪ stress and coping ▪ sibling support and well-being ▪ employment ▪ patterns of respite use ▪ need for emergency respite ▪ life satisfaction ▪ general health ▪ practical supports.	▪ **Family strength assessments** that could be built upon the initial needs assessment (as part of the intake assessment) and could be reviewed as part of the service exit process. This could include the use of standardised tools such as the CADI, CAMI and CASi[19], CAWB[20] to give a quantitative measure of family functioning variables pre and post service provision. ▪ Program statistics to identify patterns and changes in respite and emergency respite use.

Table 26. Outcomes monitoring framework.

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[19] Nolan, M., Grant, G., & Keady, J., 1998 *Assessing the needs of family carers. A guide for practitioners.* Brighton: Pavilion Publishing (Brighton) Ltd.

[20] Tebb, S., 1995, An aid to empowerment: A caregiver well-being scale. *Health & Social Work, 20*(2), 87-.

6.7   Implementation of the Monitoring Framework

The framework provides a comprehensive plan of program monitoring and evaluation. It could be introduced in a staged way that would facilitate development and maturing of FFS at the same time.

As each area is addressed there should be time for reflection on the implications for the development of the program. At a staff level, this could be included as part of regular performance discussion with management. At a sector level, reflection on the information that has been gathered could be included as part of regular network meetings.

The first area for development could be the **practice** area with:

- a FFS processes document (Procedure Manual) that captures the processes that are used and sets out standards for these processes
- sharing the understanding that the coordinators have about the core research and program frameworks and developing an agreed theory and practice framework standard.

The next area could be the **activities** area with:

- a process for information capture about activities being developed by the coordinators using a timesheet format that includes relevant categories which is filled in each day or in exemplar weeks as a starting strategy
- focusing on this area can also reveal activities that are not included and should be or that are included and shouldn't be - work in this area should be alert for these.

The **resources** and **participants** areas already have information collection tools in place and information is being collected and reported on. Given that decisions are made in the light of this information an audit may be required to ensure that it is suitably robust.

Some of the information about the final three areas (reactions, changes in knowledge, attitudes, skills and aspirations and social, economic and environmental changes) needs to be gathered continuously, including:

- pre and post testing as part of intake and service exit
- family strength assessments
- program statistics.

Other information about reactions to the program and changes in knowledge, attitudes, skills and aspirations and social, economic and environmental changes should be collected twice a year. If the same instruments were used each time a comprehensive body of information would be developed. This information would be extremely valuable for planning, projecting outcomes, service demand management, training and budget management.

Appendix 1- Summary of Recommendations

Recommendation 1

- *The department and the three provider agencies should work collaboratively to further develop and refine the definition and operating guidelines for the FFS program. The revised definition and operational guidelines for the program should be ratified by the department and articulated to referrers and the broader sector.*

Recommendation 2

- *A common information brochure should be developed for prospective clients and be available in alternative formats and languages as required.*

Recommendation 3

- *There is scope to improve current referral processes by adapting a common proforma for collecting client information upon referral to FFS.*

Recommendation 4

- *Some referral and service delivery data should be collated centrally in order that the program as a whole builds a picture of service demand and client characteristics over time to inform service planning.*

Recommendation 5

- *The three FFS programs should adopt a central intake model as described. This would ensure;*

  - *team base approach to initial assessment;*

  - *consistent application of program eligibility criteria;*

  - *service access based upon relative need across the three programs; and*

  - *distribution of service delivery matched to known geographical social indicators of high need.*

Recommendation 6

- *There would be benefit in the three programs developing a consistent dispute resolution process. This process could be used for decisions relating to eligibility and other complaints or disputes that arise in the program.*

Recommendation 7

- *There would be benefit in the FFS Network and the department determining the feasibility of the three programs identifying geographical boundaries to maximise the geographical coverage of the program as a whole.*

Recommendation 8

- *The three programs should collate data on clients across the target group sub categories and compare this with population statistics to ensure that the program is representative of all sub target groups having accounted for client need.*

Recommendation 9

- *There would be benefit in moving towards a common approach to demand management to ensure that service access is consistent across the ACT. This could include the development of a central intake process under the auspices of the FFS Network.*

Recommendation 10

- *There would be benefit in collating demand data for the three programs over time to build a clearer picture of changing demand patterns including: referral sources and the needs and characteristics of the clients referred to the program.*

Recommendation 11

- *There is scope to strengthen collaborative planning between the three agencies focused at the service system level to manage changing demand patterns and the systemic impact of the introduction of other new programs and funding.*

Recommendation 12

- *Future resource allocation to FFS should incorporate known demographic information about geographical areas of high need to ensure an appropriate distribution of resources to identified areas of need.*

Recommendation 13

- *There would be benefit in developing a common needs assessment framework that could be applied across the three FFS programs to optimise service targeting and access.*

Recommendation 14

- *There would be benefit in the development of coordinated training strategy for FFS agencies about contemporary ecological approaches to assessment and support for vulnerable families/carers and family and person centred planning approaches.*

Recommendation 15

- *There may be benefit is establishing a notional cap on individual client expenditure to ensure that the program can respond to an appropriate number of clients and a range of client needs. This could include the establishment of a trigger level above which where any additional expenditure required approval from higher levels in the organisation or through the Department and or the FFS Network.*

Recommendation 16

- *Data collection for the FFS programs should include; amount and type of services provided; and individual levels of expenditure.*

Recommendation 17

- *The three programs should work towards the development of a common definition of client outcomes in order to measure program performance over time. Once developed a standardised format should be used across the three programs to document client outcomes over time.*

Recommendation 18

- *There is scope to use standardised measures of impact on carer family functioning to measure program impact over time. (See section 6.6)*

Recommendation 19

- *FFS should develop a consistent definition of CALD clients, capture this information at intake, and compare the percentage of CALD clients in the program with that of the local population.*

Recommendation 20

- *There is scope to develop an integrated strategy across the three FFS programs region to enhance the responsiveness of FFS to persons from indigenous backgrounds. This might include the FFS Network forging stronger ties with indigenous groups and exploring the development of new service models that are more culturally appropriate to the indigenous population.*

Recommendation 21

- *All FFS programs should be required to develop a CALD and indigenous responsiveness strategy. This requirement should be included in the Funding and Service Agreement with the Department. .*

Recommendation 22

- *A common financial reporting format for FFS should be developed by the department to build an accurate picture of cost structures including all corporate and administrative overheads. This would to enable a proper analysis of program expenditure patterns to be undertaken and inform the future development of funding models for FFS.*

Recommendation 23

- *That FFS continues to develop and adopt best practice evidence based principles in relation to working with vulnerable carers and families including.*

  - *the use of family/carer strengths focus that is ecological, recognises life stages and enhances family/ carer problem solving, self-efficacy and self-management;*

  - *approaches that are collaborative, non-judgmental, flexible, holistic with a focus on goal setting;*

  - *a culture of reflection which values participant feedback..*

Recommendation 24

- *There would be benefit in the three agencies pooling resources for the provision of joint training to program staff in contemporary approaches to working with vulnerable families to ensure evidence based practice is applied across the three programs.*

Recommendation 25

- *There would be benefit in utilising existing avenues for promoting the FFS program so that information about the program is available to the widest possible group of potential clients.*

Recommendation 26

- *A communication strategy including a clear easy to understand pathway through the service system be developed to inform carers about FFS and other services.*

Recommendation 27

- *There would be benefit in the three programs developing a common program description for clients upon referral and entry into the service.*

Recommendation 28

- *Further research should be undertaken to identify the critical factors in this program that produce the positive outcomes for carers and the people they are caring for and how these could be applied more broadly.*

Recommendation 29

- *Other strategies to support carers to develop and maintain personal networks and connections be developed and implemented.*

Recommendation 30

- *The FFS in conjunction with other relevant sectors such as disability and mental health should develop a case management protocol for the effective management and coordination of more complex cases.*

Recommendation 31

- *The role of the current FFS Network could be enhanced in order to provide a more robust and influential mechanism to govern future program development. This could include:*

  - *formalising the partnership between the three FFS agencies through an instrument such as a Memorandum of Understanding at agency governance level*

  - *developing terms of reference and a mandate for the FFS Network related to service system governance and development. That is supported by the department*

  - *establishing practitioner level networks to support the services system development and share best practice across both the FFS and other respite programs*

  - *developing stronger and more formal partnerships with other service systems such as mental heath and disability services.*

Appendix 2 – Case Studies

The following case studies indicate the scope and range of client and service reposes provided by FFS.

Case Study 1

Client 1 is a 40-year-old woman who resides alone in her own home. She has multiple sclerosis her condition deteriorating considerably over the past few years. She is now unable to weight bear, verbally communicate, or care for herself independently. Her mother lives in NSW and is her carer and only natural support.   The mother spends each Friday with the daughter arriving early morning and leaving late evening. She spend this time cleaning, shopping, preparing meals for the week and attending any appointments leaving minimal time to for social interaction. The mother who is in her sixties works part time and is in poor health. She takes her daughter home once per month but has recently injured her back by lifting her up the stairs. She has established a temporary arrangement downstairs to enable these visits to continue.

Two agencies share care of the client six days per week, three times per day with shifts allowing minimum time for extra contact, other than the required support, leaving the client with no social contact other than a volunteer who visits two hours per week. Her day consisted of being positioned in front of TV after the morning routine. Her only contact being support workers hourly visits for care, and then assisted to bed early evening. Through the FFS program both the client and the carer has been assisted with the following:

- arranging a three day holiday with a long time support person

- supply of a hoist

- linking the carer with continence support program, a massage therapist and the Community Nurses to assist with bowel management

- liaising with both service providers to extend support time each shift and add Friday evening support, enabling Mum to leave earlier

- organised three hours of weekly social support enabling the client to have quality community participation

- arranged for an album of activities and venues to allow the client to choose outings

- established two evenings per week with unpaid support, enabling a more appropriate bedtime and increased social contact

- arrange for the client to attend the theatre in Sydney with unpaid support and her mother.

The program has been able to support the client to have a far more inclusive and valuable lifestyle and encouraged the traditional services to be more pro-active with support.

Case Study 2

FFS assisted a family in collaboration with Therapy ACT to develop and implement a bedtime program for their six-year-old son who has autism.

The family had been experiencing difficulties with getting their son to bed for a number of years. As a result, the pattern was established whereby the child was going to bed at midnight and requiring one of the parents to lie down with him until he was asleep (which often resulted in the parent falling asleep on the child's bed). Consequently, the child was regularly falling asleep at school, and both parents were extremely exhausted, which in turn placed enormous stress on their marital relationship.

After discussions with the parents, social worker and psychologist from Therapy ACT, the family identified that they would like to work towards a bedtime routine that did not require one of them to stay with their child to get him to sleep, and to initiate an earlier bedtime. The family also identified that they would support each other in implementing the new bedtime program, but believed they also needed support (in home) during this time. The psychologist from Therapy ACT continued to meet with the family and developed an intervention plan (bedtime program).

The 'bedtime program' focused on establishing strict routines before bedtime (which meant considerable changes to the current routines) and gradually moving the bedtime back by 30 minutes every three nights until a bedtime of 8.30pm had been reached. The plan also included a support person to model/guide/support the family over the four week period.

In partnership with the family, social worker and psychologist, a support person was identified and selected. The support person met with the family on several occasions prior to the commencement of the program, given the sensitive nature of their role, and the intrusiveness of the support. Once it was established that all parties were comfortable with the program, it was implemented over a four-week period. During this period the family and support worker had regular contact with the FFS Coordinator, the social worker and psychologist, and adjustments were made as required.

At the end of the four weeks the family managed to successfully establish a new bedtime routine, with their son going to bed at 8.30pm and no longer requiring one of them to lie with him. The family has also received feedback from the school indicating that their son is now not falling asleep in class, and as such appears to be enjoying his time at school and is making a valuable contribution to his class.

As a result the family unit has been strengthened by the provision of support through the FFS Program. FFS will continue to maintain contact with the family and make available 'top up' support should the need arise.

Case Study 3

Mrs B is a single mother with two sons aged nine and 11 years. Following family breakdown the two boys resided with their father, as Mrs B was no longer able to cope with the demands of caring for them.
Mrs B is now in a new relationship and the boys reside with her and her partner. Mrs B is not in the work force and is in receipt of government income support. She has no close relatives in Canberra and few friends. She is under considerable stress due to the demands of caring for her two sons.

The older boy has an intellectual disability and epilepsy as a result of encephalitis in infancy. He requires 24 hour monitoring and care including PEC feeding and oxygen dependency/monitoring. This is provided in home by nursing staff. The younger son does not have a disability by is emotionally affected by the impact of his older brother and the past family situation.

The family were refereed to Flexible Family Support from a government department concerned about the impact of the situation on the mother and children. Assistance sought included counselling sessions for the younger boy and support in the management of the behaviour of the older boy. Mrs B required financial assistance to continue the counselling secessions provided by two psychologists. Later the relationship with her partner broke down and she also required assistance with emergency housing.

The FFS program has:

- arranged a case conference including all organisations involved in providing formal and informal support to the family to plan for how assistance would be provided to the family and by whom

- provided financial support for psychological counselling for Mrs B and her partner

- arranged a holiday for both boys including medial and attendant care support

- provided assistance with domestic duties to relieve the pressure on Mrs B

- assisted and advocated for Mrs B in relation to government housing.