Intensive Family Support Programs

KEEPING CHILDREN WITH A DISABILITY SAFELY IN THEIR FAMILIES

By

Dr Jan Breckenridge
Dr Sarit Huppert

Centre for Gender-Related Violence Studies, UNSW

Report released June 2010

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The Context for the Study

Introduction

This report ‘Keeping Children with a Disability Safely in their Family’ presents the findings of a research project examining the effectiveness of Intensive family Support (IFS) programs, funded by the Department of Ageing, Disability and Home Care DADHC and offered by The Spastic Centre of NSW (TSC), Northcott Disability Services and UnitingCare Burnside. The specific aim of the research is to determine whether the families referred to an Intensive Family Support (IFS) program experience an increase in confidence and competence in managing their particular situations as a result of involvement in that IFS program; and, if the IFS program (including program elements) significantly contributes to maintaining child safety within the family.

The current research project builds on a previous collaboration between TSC, Northcott Disability Services and Autism Spectrum Australia (ASPECT) and the University of New South Wales (UNSW). The results of this original study suggest that there is cause for optimism in the field of children with disabilities being kept safely with their families. In particular, the authors argue that while certain aspects of the intervention stood out for different carers, the combination of both program elements and therapeutic interventions was recognised as being integral to the positive outcomes achieved (Baldry, Bratel, Dunsire and Durrant 2005, 153). It was envisaged that the data from the original ARC research would allow comparisons to be made at a later date if so desired.

1.1 Background to the Current Research

The current project design was commissioned by The Spastic Centre of NSW (TSC) in 2007 and was originally intended to more broadly evaluate not only the effectiveness of the Intensive Family Support Services (IFS) but also the development and process of establishment of the newly funded IFS services in 2006. The evaluation had the following specific objectives:

1. To document team formation and development
2. Examine the referral process and service exit
3. To explore, measure and analyse the effectiveness of the range of support options offered to project participants during and after their participation in the IFS Program
4. To investigate the effectiveness of Intensive Family Support (IFS) Programs for different client groups, particularly in relation to Culturally and Linguistically Diverse (CALD) and Indigenous families and families where the primary caregiver has an intellectual disability.

1 The NSW Department of Ageing, Disability and Home Care (DADHC) recently changed its name to ADHC – Ageing Disability and Home Care. As all data was collected when the Department was known as DADHC and both workers and families have referred to DADHC in the qualitative data, this acronym has been retained and used throughout the Report to avoid confusion.
Objectives 1 and 2 were examined in Phase 1 of the current project, and were comprehensively presented in the Interim Report submitted to TSC in November 2008. Accordingly these results will only be briefly summarised and not substantially included in this Report. However any select issues pertinent to the program elements of the IFS services will be included in the discussion in Section Five.

Phase 2 of the project commenced in late 2008, when Northcott Disability Service and UnitingCare Burnside (both of whom offer an IFS service) formed a consortium with TSC. Hence the aggregate qualitative and quantitative data presented in this Report are collected from workers, managers and client families from all three organisations in the consortium. Data collection was finally completed in March 2010 after the project was extended by 6 months in an attempt to increase the number of families who participated in data collection at commencement and completion of the IFS intervention and again at the three month follow up.

1.2 IFS Services offered by The Spastic Centre, UnitingCare Burnside and Northcott Disability Services

In 2006 DADHC announced a comprehensive funding package to establish Intensive Family Support programs across the state for families with a child with a disability that have complex needs and are in crisis. The Spastic Centre of NSW already had two IFSO services (at Allambie Heights and Parramatta) and successfully tendered for a number of these new services. TSC received funding to establish an additional IFS service at Penshurst, a CALD specific team at Parramatta, two Regional teams in the Upper Hunter and Central Coast. A joint proposal was successfully tendered by TSC and UnitingCare Burnside to develop a partnership in South West Sydney, prioritising the intersection of Care and Protection and Disability. Northcott Disability Services successfully tendered for their service Northcott Intensive Family Support (NIFS) established in the Nepean District of Sydney, NSW. A budgetary allocation for evaluation was included in each tender.

1.3 About the Participating Agencies

All three participating agencies are independent not-for-profit organisations that receive some Government funding but rely also on public donation and philanthropy. TSC and Northcott Disability Services offer services to adults and children with disabilities and their families. UnitingCare Burnside offers a range of services for children, young people, families and communities. All three organisations provide a range of services throughout the Sydney Metropolitan Area and also in rural locations across NSW.

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2 The two original TSC services were usually referred to as Intensive Family Support Options (IFSO) services. The newly established services have been referred to as IFS. The acronym IFSO has been used in this Report to clearly identify the original services.
**UnitingCare Burnside** - Burnside is committed to working with children, young people and families who are living with disadvantage. They have developed a range of services that provide a full continuum of care and support. The type of services offered depends on the needs and situations of each child and family. Programs that support families and communities are open to everyone in the area, not just the families who are in crisis. This is aimed at creating the capacity to build a strong and safe community for all its members. ([http://www.burnside.org.au/](http://www.burnside.org.au/) accessed 09/04/2010)

**Northcott Disability Services** – Northcott provides support to 8,000 people with a broad range of disabilities and their families and carers across NSW and the ACT by providing a range of services which promote a genuinely inclusive society. A broad range of programs is provided, from support in the initial diagnosis period and early intervention, through to early childhood development and assisting adults gain employment and independent living skills. Support and services are not only directly provided to people with a disability, but their carers, siblings and the entire family. ([http://www.northcott.com.au/](http://www.northcott.com.au/) accessed 09/04/2010)

**The Spastic Centre of New South Wales** – TSC provides services to children and adults with cerebral palsy and other disabilities and their families across NSW and the ACT. The Spastic Centre aims to provide holistic service models that foster community participation and skill development and which improve the well-being of parents and carers. ([http://www.thespasticcentre.org.au/services/about_tsc/index.htm](http://www.thespasticcentre.org.au/services/about_tsc/index.htm) accessed 09/04/2010)

1.4** The Centre for Gender-Related Violence Studies (CGRVS)

This research has been undertaken by researchers from the Centre for Gender-Related Violence Studies, UNSW. Located in the School of Social Sciences and International Studies, the Centre aims to contribute to the outreach and community engagement of UNSW by prioritising projects that specifically focus on engagement with ‘communities’, service providers and service users. CGRVS believes that research should contribute to the important goal of community engagement, encapsulated in the recursive relationship between practice and research expressed in the concepts - ‘practice-informed research’ and ‘research-informed practice’. As such it is an approach to research that extends and enables participation in the research process beyond UNSW researchers.

The project advisory team included:

**Researchers from CGRVS:**

- Dr Jan Breckenridge - Principal Researcher – Director CGRVS, Discipline Convener, Social Work Programs, School of Social Sciences and International Studies, UNSW.
- Dr Sarit Huppert: Senior Researcher, CGRVS, UNSW.
Colleagues from TSC:

- Joan Bratel: Senior Consultant - Service Development and Communication TSC, Adjunct Senior Lecturer, School of Social Sciences and International Studies, UNSW
- Don Coles: Senior Practitioner, Community Links TSC, Adjunct Lecturer, School of Social Sciences and International Studies, UNSW
- Ros Crowe-Mai, Jenny Drayton and Martin Pearce: Family Therapists and Research Associates of CGRVS.

The project team met regularly for the duration of the research, jointly planned the research process, assisted in both the collection and the analysis of data. Throughout the course of the research, the researchers have regularly provided feedback to all IFS staff at the TSC at cross-regional staff development meetings. In addition a half-day seminar for managers and workers from all three organisations was provided in 2009, presenting all preliminary results and seeking one last round of feedback prior to the completion of this Report.

1.5 The Expected Benefits Arising from the Research

The expected benefits from the research include:

- Supporting evidence based practice
- Gaining knowledge about the effectiveness of the current IFS programs
- Identifying areas of need in relation to the improvement of service delivery
- Providing information that enhances the quality of service delivery offered to IFS clients
- Contributing to the wider body of knowledge in relation to effective intervention and support programs for families in crisis who have a child with a disability under 18 years of age
- Meeting evaluation requirements attached to the DADHC funding of the IFS programs

1.6 The Structure of this Report

‘Keeping Children with a Disability Safely in their Family’ is structured in the following way:

Section Two - What the literature tell us about Intensive Family Support Programs
Section Three - Methodology
Section Four - What Changed? – Outcomes of the IFS Programs
Section Five - Client and Worker Perceptions and Experiences Understanding the ‘How’ and ‘Why’ of Effectiveness
Section Six - Discussion of Results and Recommendations for Future Practice

Section Two of this Report will now briefly present the literature supporting key program elements of IFS programs and select therapeutic frameworks and interventions.
Section Two
What the Literature Tells Us About Intensive Family Support Programs

Intensive Family Preservation Services were first established in the USA in the mid 1970s. The very term ‘family preservation’ was invented specifically to apply to this type of program, which has a better track record for safety than foster care (Kirk, Reed-Ashcraft and Pecora 2003). The first such program, ‘Homebuilders’, has significantly influenced the development of intensive family services in child protection generally across Australia and specifically in non-government organisations such as UnitingCare Burnside. This model of service provision has been extended to underpin the growing philosophical trend to maintain children with a disability safely within their families. Section 2 will provide a brief overview of the literature including the introduction of IFS services in NSW, and research discussing the core program elements and therapeutic strategies.

2.1 The Introduction of Intensive Family Support Programs

In 1997, The Spastic Centre of NSW established a family–centred program designed to work with families in a highly flexible, responsive but short term way to help keep children with a disability safely in their families – Intensive Family Support Options or IFSO. This service was conceptually influenced by UnitingCare Burnside’s implementation of the ‘Homebuilders’ model. Families were eligible to receive this service where there was a risk of family breakdown and possible placement of the child with a disability in alternative care. An inherent bias in the program was (and still remains) the belief that children with a disability are better cared for within their family than in respite services and that supporting families to keep children safe is a priority (Baldry, Bratel, Dunsire and Durrant 2005). The establishment of the IFSO program also reflected the pragmatic realisation of the scarcity of respite options for children with disabilities.

The key and innovative elements of the original program were:

- It was family rather than child focussed underpinned by a systems perspective in which a family is not seen in isolation but as part of a wider network of systems
- It was intensive – workers worked with a maximum of two families for a limited period of time providing out of hours support and availability by phone 24/7 ensuring maximum flexibility.
- It was underpinned by a commitment to intervening early when a family entered a crisis.
- It utilised a Solution-Focused Brief Therapy approach (Berg 1994, Cade and O’Hanlon, 1993) which seeks to build on and enhance the strengths and abilities of family members. Such an approach was seen to be consistent with the Principles of the NSW Disability Services Act (1993) and the NSW Disability Services Standards (1993).
• A second tier of the IFSO model used a component of the grant to broker less intensive services and practical support so that the families could maintain an acceptable level of functioning.

After the initial establishment and development of the program, The Spastic Centre in partnership with UNSW, undertook research funded by an ARC (SPIRT) Grant between 1999 -2002. This research sought to discover:

1. Whether programmes for children with a disability that emphasised brief and varied forms of support for children’s families (i.e. IFS models) influenced outcomes for the child and family; and,

2. Which strategies and program elements contributed to those outcomes

Select results from this study were published in the Journal of the British Association of Social Workers (Vol17; 3 September 2005). However to summarise, the results of this study provide cause for optimism in the field of children with disabilities being kept safely with their families. In particular, while certain aspects of the intervention stood out for different carers, the combination of both program elements and therapeutic interventions was recognised as being integral to the positive outcomes. Importantly, this led the research team to conclude that programme elements as well as workers' therapeutic strategies were important and indispensible ingredients of an overall package contributing to the significant outcomes reported (Baldry et.al. 2005, 153).

2.2 The Literature Supporting the IFS ‘Package’ of Care

The idea of an overall intervention ‘package’ for families with a child with a disability has gained currency in recent times. King and Meyer (2005) discuss coordinated and comprehensive care as being associated with higher satisfaction with services, reduced stress and better emotional wellbeing on the part of parents. The study also suggests developing specialist teams to maintain the integrity of such programs, to better ensure consistency. Singer, Ethridge and Aldana (2007), similarly provide evidence that multiple component interventions were significantly more effective than single focus interventions. When more complex intervention methods were presented to parents over a relatively longer period of time than in the single component interventions, there were substantial reductions in parental distress. The IFS interventions are based on the concept of a comprehensive package with multiple components of care to ensure that children with a disability are maintained safely in their home.

The idea of adaptable and flexible service provision to families with complex needs, including a child with a disability is evident in the literature. Hudson, Matthews, Gavidia-Payne, Cameron, Mildon, Radler, Nankervis (2003) present an example of flexible service provision in their discussion of the ‘Signposts’ program for families of children with a developmental disability. Davis and Susana (2009) suggest that positive outcomes are obtained with a family – focused intervention that provides support tailored to the unique needs of each individual family. In the IFS intervention, flexibility is enhanced by the intensive nature of service provision which allows workers the time to negotiate partnerships with families that enhance the development of individualised intervention goals and therapeutic responses.
The following discussion will, for ease of reading, artificially separate the program elements and therapeutic strategies which combine to produce the intervention package known as the Intensive Family Support (IFS) service. There is no attempt to present a comprehensive review of the literature discussing these separate areas. Instead a brief selection of key articles and reports will be outlined to provide greater understanding of the conceptual underpinnings of the IFS program development.

2.3 The Importance of Family Centred Services

The importance of providing family-centred services for families who have children with a disability clearly emerged in the 1980s. In a family-centred approach, professionals collaborate or partner with families to select and implement early intervention services. The aim is to make services more accessible, flexible and individualised to meet family needs and priorities. One of the earliest studies, Derevensky (1991), found that the effectiveness of the family-focused intervention model resulted in high levels of parental satisfaction, accelerated rates of progress by children with moderate or severe disabilities, and enhanced the acquisition of functional skills by families. Bailey et al. (1990) provided a rationale for and description of the family-focused interview, a collaborative mechanism for family assessment and goal-setting in early intervention with special needs children.

Hastings and Taunt (2002) built on this early work arguing that a family-centred perspective should permeate all aspects of service provision including establishing a program philosophy, screening, child assessment, team meetings and program planning, intervention activities and service coordination. Importantly this research argues that the family-centred perspective should not be limited to counselling or therapeutic intervention alone – a point which has underpinned the development of both IFSO and IFS services. Law, Hanna, King, Hurley, King, Kertoy and Rosenbaum (2003) also found that a family-centred culture within the organization and parental perceptions of family-centred services mostly determined parent satisfaction with services, as well as decreasing parental stress and increasing positive child outcomes.

Dempsey and Keen (2008) suggest that the importance of therapists being truly family centred when providing services to children with a disability and their families continues to gain currency in the research and practice literature. Brown and Remine (2008) provide evidence of professionals’ strong beliefs in most aspects of family-centred practice. In this study workers reported that they believed in practice that fostered partnerships and that intervention was most effective when therapists worked with parents rather than directly (and only) providing therapy to the child with a disability. Davis and Susana (2009) findings provide further evidence for the importance of a family-focused approach to intervention that acknowledges and provides support that is tailored to the unique needs of each individual family.
2.4 Strengths-Based Approaches and Therapeutic Strategies

There is a plethora of literature detailing therapeutic skills and strategies across a number of professional disciplines and intervention contexts. This review will not cover this literature but has instead selected a small number of key studies which support the IFS therapeutic approach more generally. Therapeutic strategies and skills utilised in the IFS intervention are provided within a strengths-based framework. There is ample evidence in the therapeutic and professional literature of the efficacy and effectiveness of strengths-based approaches in a range of therapeutic contexts (Bailey, McWilliam, Darkes, Hebbeler, Simeonsson, Spiker and Wagner 1998). A strengths-based 'lens' re-focuses interventions towards family strength and resilience rather than exclusively managing pathologies and problems. There is considerable appeal in this approach in the disability arena which previously has been accused of concentrating on the difficulties experienced by people living with disabilities rather than on the ways they have coped and achieved their goals. Trivatt and Dunst (2000) claim that family support and resource programs are efforts appropriately directed at reforming existing policies and practices in ways that enable, and empower people. The intended outcome of such practice aims to enhance and promote individual and family capabilities which might further support and strengthen family functioning. Hastings and Taunt (2002) support the importance of asking more positive questions about the perceptions and experiences of families of children with developmental disabilities. They further hypothesise that positive perceptions function as strategies that help families adapt to or cope with the experiences of raising a child with disabilities.

Lloyd and Dallos (2008) trialled the use of a particular strengths-based approach - solution-focused brief therapy (SFBT) – in first session interviews with mothers who have a child with intellectual disabilities. They contend that previous studies present little about the knowledge and use of SFBT with families who have a child with a severe intellectual disability. Results of this study suggest that SFBT is a useful structure for first sessions particularly as it seems to build a useful therapeutic relationship, highlights self-efficacy and may encourage helpful coping styles. The effectiveness of SFBT has been clearly demonstrated in Baldry, Bratel, Dunsire and Durrant (2005) in the evaluation of the IFSO program. They argue that it is crucial to partner with the family to explore what they would like to be different in their life and on the strengths that they bring to the change process. This study claims that a strengths-based approach is fundamental to IFS intervention and complements a family-focused approach in service provision.

2.5 Intervening Early

Early intervention is an important principle underpinning service provision in many health and welfare contexts. Early intervention is intended both to respond to a current crisis but equally it is hoped that the intervention will prevent the crisis becoming entrenched or chronic. Prevention in this context is cost effective, potentially avoiding the need for extra resources due to the family's difficulty worsening. More important however is the explicit aim to ensure that the family's capacity to use help remains at an optimal level.
Cowen, Perle and Reed (2002) argue that early intervention services, including respite care, are a critical component of any service and necessary to promote healthy family functioning and prevent child maltreatment. Canary (2008) and King and Meyer (2005) argue that raising a child with disabilities involves balancing a number of challenges, including seeking and gaining support. They also point out that lack of access to existing services is one of the major reasons for dissatisfaction with health and disability services. A consequence of this is that these families have to wait for a service and can spiral further into crisis while they wait. IFS services are necessarily early intervention services. Intervening early, before a family’s crisis worsens, necessarily facilitates strengths-based interventions.

2.6 Intensive Services

Intensive service provision allows for an individualised approach to a family’s situation. Forming partnerships with families and developing goals and processes is best achieved with ample time and contact between family and worker. Flexibility is enhanced by intensive contact which allows for visiting after hours, phone contact 24/7 (Hudson, Matthews, Gavidia-Payne, Cameron, Mildon, Radler, Nankervis 2003) and visits from the worker when a problem is actually occurring. Bailey, Mcwilliam, Darkes, Hebbeler, Simeonsson, Spiker and Wagner (1998) argue that an individualised and intensive approach is needed to forge, recognise, value and support the partnership between a professional and the family. This is particularly the case for families who have a child with a disability and who may not have received a therapeutic service previously or have experienced intervention(s) provided only for their child.

The effectiveness of intensive and comprehensive services has been established by Law, Hanna, King, Hurley, King, Kertoy and Rosenbaum (2003) who highlight the benefit of an intense family-centred service for a period of time is that it avoids a number of different service providers all trying to intervene. Dellve, Samuelsson, Tallborn, Fasth & Hallberg (2006) report that stress, well-being and supportive resources experienced by mothers and fathers of children with rare disabilities were positively affected by an intensive family competence intervention. Intensive services are enhanced by both a family-focused and strengths-based approach.

2.7 Financial Assistance and Practical Help

A second tier of the IFSO model used a component of the grant to broker less intensive services and practical support so that the families could maintain an acceptable level of functioning (Baldry, Bratel, Dunsire and Durrant 2005). The importance of financial assistance cannot be over-estimated. Smith, Oliver & Innocenti (2001) suggest that factors such as income, time available for interaction with the child, and social support predict parenting stress, much better than do aspects of child functioning. Owen, Frederico, Copper, Gordon & Jones (2001) similarly note the importance of financial assistance as a crucial issue when dealing with the cost of equipment, home modification, transport and away-from home accommodation for assisting a child with disability.
The provision of practical assistance, in combination with therapeutic support was recognised as being extremely beneficial to families. Singer, Ethridge and Aldana (2007) found the combination of counselling and practical behavioural management strategies to be the most effective intervention for families in crisis. Freedman and Boyer (2000) suggest that social workers and health care professionals can improve the well-being of people with developmental disabilities and their families by addressing the needs of the entire family, facilitating family choice and control of supports and practical assistance, and by helping families navigate the complex service system. Financial assistance and practical help are clearly beneficial to families in addition to, not instead of therapeutic interventions.

Conclusion

The unique combination of program elements and choice of therapeutic strategies provide an excellent foundation for the provision of IFS services. The IFSO evaluation provides clear evidence of the effectiveness of this particular package (Baldry, Bratel, Dunsire and Durrant 2005). Further, this unique combination is supported in the literature prior to the IFSO research as well as in subsequent research studies. The inter-connectedness of program elements and therapeutic strategies and the ways in which they complement, inform and enhance one another, is striking.

Section Three will comprehensively discuss the methodology chosen for the current study - ‘Keeping Children with a Disability Safely in their Family’ and detail both quantitative and qualitative methods used to collect and analyse the data.
The IFS research project utilised a mixed methods approach with both qualitative and quantitative methodologies combined to address the core research questions:

- Do families referred to an IFS program experience an increase in confidence and competence in managing their particular situations as a result of involvement in that IFS program; and,
- Does the IFS program (including program elements) significantly contribute to maintaining child safety within their family.

Quantitative methodology provides means by which to measure and compare data from standardised and validated measures pre- and post-intervention and provides rates of change across time (Grinnell 2001). The qualitative aspects of the study provide information on the nature of participants’ experiences with a phenomenon, in this case both worker and client experiences of the IFS programs, as well as offering explanations for the quantitative findings (Strauss and Corbin 1990).

### 3.1 Choice of Methods

Both qualitative and quantitative data were collected from families, workers, managers and key informants at different points of time. Measures of client behaviour and attitudes were administered at regular intervals providing the means to measure change. The particular scales and surveys used in the original project were found to appropriately measure the effectiveness of the intensive family focused approach and have therefore provided both a theoretical and practical framework for this project.

### 3.2 Participation

#### 3.2.1 Sampling

IFS workers from all organisations routinely participate in service provision evaluations. It is the expected practice of all participating organisations to evaluate their programs in relation to their ongoing mission to provide relevant, effective service provision. It was therefore anticipated that all relevant staff would participate in the research although there was no set requirement for workers to ensure that a fixed number of families would participate.

Agency worker participants were recruited using non-probability convenience sampling (Grinnell, 2001). Participating workers acted as gatekeepers, introducing the research to the family member participants. The recruitment process was comprehensively documented in a Research Protocol distributed to all IFS workers (see Appendix 1). Briefly, once a referral was accepted and at the commencement of service provision, service users were asked if they wished to participate in the research project. Workers explained to client families, both verbally and in writing the purpose of the research, that participation was voluntary and that ongoing service provision would not be affected or dependent on participation in the evaluation process (see Appendix 2 for Participant Information Sheets).
### 3.2.2 The Sample

The eligibility criteria for a family to participate in this study included:

- They must be eligible for and receiving an IFS service
- The family has a child (0-17 years of age) with a disability living at home;
- The family must be in crisis and the child with a disability at risk of out of home placement.

It is important to note that referrals to the Intake referral and Information Service (IRI) panels in every DADHC region have different policies and procedures. This effectively meant that there are different referral procedures and inclusion criteria for each region.

In total, 76 participants took part in this study comprised of twenty one workers (only 6 workers took part in the original ARC research) from disciplines such as social work and psychology. All family members wishing to participate were included and of the 46 participating families there were 55 parents/carers who participated in both the qualitative and quantitative data collection. Forty six participants were primary caregivers of a child with a disability and nine parents were secondary caregivers. Secondary caregivers have not been included in the quantitative analysis because the scales are designed to measure change in each family situation but the qualitative data from their interviews have been included in the discussion. The predominant diagnosis for the child was autism spectrum disorder (43%), after that intellectual disability (33%), then cerebral palsy (17%) and last physical disability (7%). Of the primary caregivers, 87% of the participants were female and 13% were male. Single parent families comprised 37% of participating families and 26% of families had more than one child with a disability.

Families were referred from a range of agencies, with DADHC referring the most families participating in the research (37%), followed by non-government child welfare services (29%), Health (15%) and Education services (12%). Interestingly 37% of families were not receiving an active service prior to commencement in the IFS services although they were obviously known to services. This is explained by 60% of the families identifying as ‘DADHC families’. Twenty per cent of families were also known to Department of Community Services (DoCS)\(^3\) prior to the IFS intervention although only 2% of families were referred by DoCS.

Ten families (23%) were from a CALD background and 6 families (11%) required an interpreter. Four families had caregivers with a disability (3 with an intellectual disability and one with autism). Two of these families’ caregivers were not included in the quantitative data collection because they found the measures difficult to answer, but were still included in the qualitative interviews.

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\(^3\) The NSW Department of Community Services (DoCs) recently changed its name to Community Services. As all data was collected when the Department was known as DoCS and both workers and families have referred to DoCS in the qualitative data, this acronym has been retained and used throughout the Report to avoid confusion.
Only 2 Indigenous families were recruited in part because the Indigenous IFS service at Burnside had only recently commenced and workers felt that they did not have adequate experience to participate. However, the two participating Indigenous families provided scant data as one of the families withdrew from the research after commencement and the other withdrew from the IFS program before completion after their worker left the service. The relatively low numbers of CALD and Indigenous families as well as families with a carer with an intellectual disability have meant that the research was not able to adequately address Objective 4 – the effectiveness of the IFS services for these particular families. The qualitative data however does illuminate the particular experiences of these families and provides an opportunity to consider future directions in the provision of services in these circumstances.

3.3 Participation and Withdrawal Rates

A total of 46 families were included in the quantitative data collection at the commencement of the IFS service. Of these families, 32 participated in the data collection at the completion of the intervention, and a further 26 families participated in the 3 month follow-up.

3.3.1 The Spastic Centre

A total of 34 families participated in the first (commencement) interview, 25 families participated in the second (completion) interview and 22 families participated in the third (3 month follow-up) interview. Nine families from TSC were from a CALD background reflecting the establishment of a CALD specific service at Parramatta IFS. One Indigenous family was recruited and 3 families with one or more parents with a disability (intellectual disability and autism) took part in the research.

Nine families either withdrew before the completion of the service or were not able to continue in the research. In two cases the researcher was not aware that the families had finished with the program and so missed the nominated time frames for the completion and follow-up interviews. In two cases the primary caregiver (the mother) suffered from depression and did not wish to continue with the research. In another three cases medical difficulties affected the families’ capacity to participate. One family’s participation in the IFS program was suspended because the child was removed by DoCS and the Indigenous family left the program when their worker left TSC.

A further 3 families withdrew before the three month follow-up interview. It is difficult to ascertain why they withdrew at this stage. It is possible that the families were coping well and did not want to be reminded of periods when they did not cope as well. Alternatively it could mean that these families were not coping as well as they had been during their time in the IFS program.

In summary, TSC
- Commencement: 34
- Completion: 25
- Follow-up: 22
3.3.2 Northcott Disability Services

A total of four families participated in the first interview from Northcott Intensive Family Support. Two families withdrew after the first interview and the other two families participated in the second interview and the third interview. One of the families that withdrew from the research after the first interview was an Indigenous family. The mother and primary carer in this family gained employment and did not have the time to continue in the research. The other family who withdrew from the research travelled back to New Zealand for an extended period and suspended their participation in the program.

In summary,  

**Northcott Intensive Family Support**
- Commencement: 4
- Completion: 2
- Follow-up: 2

3.3.3 UnitingCare Burnside

A total of eight families participated in the first interview from UnitingCare Burnside. Six families participated in the second interview and two families participated in the third interview. Of the two families who withdrew after the first interview one was a single mother with six children who did not remember two interview appointments and finally requested to withdraw from the research due to stress and exhaustion. The other family that withdrew after the first interview expressed dissatisfaction with the service because the program was unable to change the family’s living conditions.

Of the four families who withdrew after the second (service completion) interview, one was from a CALD background and there were difficulties securing a suitable interpreter for the final interview – affecting the agreed time frame for the completion interview. One family had a parent with an intellectual disability who was unable to remember appointments post-intervention. The remaining two families were single parent families who were unable to make appointments due to part-time employment commitments.

In summary,  

**UnitingCare Burnside**
- Commencement: 8
- Completion: 6
- Follow-up: 2

3.4 Materials - Scales and Measures

Baldry, et al. (2005) argue that research regarding therapy outcomes for families with a child with a disability has generally focused on the child’s improvement measured by achievement of treatment goals. However recent child and family literature suggests that measuring client improvement should include a number of other dimensions. Hubble, Duncan and Miller (1999) similarly argue that factors such as what the client brings, the therapist-client alliance, expectancy and techniques should also be studied.
The original IFS study utilised the Bailey, McWilliam, Winton, Simeonsson (1992) Child/Family Program Evaluation Framework which includes and extends the previously listed four factors and also provides indicators of improvement for families. This framework was adapted by Baldry et.al. (2005) and provided a guide to the selection of quantitative instruments for the initial ARC research and the current research project that would best indicate any changes in these factors.

The following surveys/scales were administered to families at the data collection points previously specified:

- The Child Abuse Potential Inventory (Milner 1986)
- McMaster Family Assessment Device – general functioning subscale (Epstein et al 1983)
- Outcome Questionnaire (Lambert et al 1998)
- State Hope Scale (Snyder et al 1996)
- Happiness Measure (Fordyce 1988)

At the completion of the intervention and follow-up only:
- Working Alliance Inventory - therapist and client version (Horvath & Greenberg 1989).

These scales were administered as part of the original ARC research project and were chosen for their reliability and validity and their proven sensitivity to change over short time frames. When measurements are made repeatedly, definitions and procedures within an organisation or program may change. In this project care was taken to see that time series were free of definitional and measurement changes, because these can be mistaken for program effects (Forehand 1982 and McCleary and Hay 1980). Appendix Three contains detailed descriptions of each scale and measure and their validity and reliability. Where one or more parents/carers had an intellectual disability, scales and questions were either not administered or modified to collect qualitative information only.

3.5 Research Design

The quantitative component of the study is a pre-experimental (pre-post) design, field experiment. The dependent variables are child abuse potential, family functioning, psychological disorders, hope and happiness. The independent variable was time: the scales and measures were administered at three points - pre-intervention, post intervention and three months post intervention – over a six month time period. The simple pre- post design was chosen as it is appropriate for short time frame impact assessment of programs attempting to affect conditions that are unlikely to change much on their own (Rossi, Lipsey and Freeman, 2003). The quantitative component of the research was undertaken in Phase Two of the research process.

Qualitative methods were utilised in Phases One and Two of the research project and included semi-structured interviews, focus groups, an audit of select agency documentation and thematic analysis of select information from client files. Phase One of the project analysed a selection of historical and program documents from websites, strategic plans, tender documents and contracts, memorandums of agreement (MOA) between services, IFSO program manuals and intake and referral guidelines and procedures.
A selection of the document analysis from Phase One and the thematic analysis of worker focus groups and managerial interviews addressing objectives 1 and 2, discussed in the Interim Report, are summarised later in this Report – Section 5.1. In Phase Two, qualitative methods (interviews and thematic analysis of case notes) were used alongside the implementation of scales and measures to gather data about worker and family experiences of the intervention process and their perceptions of the ‘helpfulness’ of the IFS program model.

3.6 Procedure

In this Report data collection methods are documented in relation to Objectives 3 and 4 however data/information pertaining to more than one objective has been collected at the same time.

Objective 3: Explore and measure family and worker experience of the spectrum of support offered to research participants over time

Objective 4: To investigate the effectiveness of Intensive Family Support (IFS) Programs for different client groups, particularly in relation to CALD and Indigenous families and families where the primary care-giver has an intellectual disability.

Data was collected at the following points:

a. Surveys and scales administered to each family (mostly the primary caregiver) at the commencement of the IFS service.

b. Brief open-ended qualitative interviews with clients at commencement of service to explore their understanding of their referral to an IFS service.

c. Surveys and scales administered to each family (mostly the primary caregiver) at the completion of the IFS service.

d. Client(s) briefly interviewed at completion to explore their experience of the program elements and therapeutic interventions offered during the IFS service to ascertain their helpfulness.

e. IFS workers interviewed at the completion of service regarding clients’ exit plan and spectrum of support offered post IFS. These same workers were also asked to specify what strategies and program elements they thought were helpful to the family.

f. Clients and workers to complete the Working Alliance Inventory - therapist version (Horvath & Greenberg 1989) at the completion of the service and clients again at 3 months.

g. Surveys and scales administered to each family (mostly the primary caregiver) at 3 months post-completion of the IFS service.

h. Client(s) briefly interviewed 3 months post-completion to reflect on their experience of the program and to explore whether they perceive they have maintained any of the goals achieved as a result of having the IFS service.
3.7 Data Analysis

All demographic data and the scales and survey measures were subjected to statistical analysis via the statistical software package SPSS (version 17). The quantitative analysis of the data is comprehensively discussed in Section Four. The qualitative data and relevant documents were coded and thematically analysed. A selection of the qualitative data is presented in Section Five. All findings have been considered against the evaluation's aims and objectives.

3.8 Ethical Considerations

This research study has been approved by the UNSW Human Research Ethics Committee (HREC); The Spastic Centre’s Research Committee and The Spastic Centre’s Ethics Committee; and the Research Advisory Group UnitingCare NSW.ACT. The research has been carried out in a manner conforming to the principles set out by the National Health and Medical Research Council. All research participants were genuine volunteers and client participants were assured verbally and in writing that they could choose not to participate or they could withdraw from the research study at any time without any negative consequence to their ongoing treatment.

Confidentiality was ensured by aggregating all data and not distinguishing between workers or organisations. The rigour of the research process was attended to by feeding back preliminary findings to workers throughout the project for their consideration and confirmation. In this sense this project was enriched by the expertise and experience of workers from all three participating agencies – arguably akin to the action research cyclical approach to data collection, reflection and further data collection. The collaborative partnership between UNSW and the project advisory team ensured that at all times the research process was ‘practice-informed’ and appropriately focused on clients’ needs and experiences.
Section Four
What Changed? – Outcomes of the IFS Programs

The results of the original ARC study provided cause for optimism in the field of children with disabilities being kept safely with their families. In particular, the authors argued that it was the unique combination of both program elements and therapeutic interventions that was integral to the positive outcomes achieved (Baldry et al. 2005, 153). The current research project aims to replicate the previous study by examining whether similar results would be achieved in the newly funded IFS services in different geographic locations with families from a range of different backgrounds and circumstances.

Section Four will report on the outcome data collected by the chosen scales and measures used in the original project which were found to appropriately measure the effectiveness of the intensive family focussed approach.

4.1 Hypothesis One

The first hypothesis claimed that:

Parents who participate in an IFS program intervention will have less child abuse potential, psychological disorder and low family functioning and more hope and happiness.

A one way repeated measure ANOVA was employed to evaluate the level of the six measures at three points in time: pre-intervention, post-intervention and three months post intervention. The measures scores; potential child abuse F(2, 40)=14.43, p< .001, low family functioning F(2, 38)=12.232, p< .001, and psychological disorders F(2,36)=10.117, p< .001, were reduced significantly whereas the measures scores hope with Greenhouse-Geisser correction F(1.34,24.05)=13.506, p< .001 and happiness F(2,30)=4.256, p< .05, were increased significantly as predicted. Calculating pair wise comparisons using the Bonferroni correction revealed that:

- Potential child abuse, low family functioning and psychological disorders reduced significantly and hope and happiness increased significantly between pre-intervention to post-intervention.

- Potential child abuse, low family functioning and psychological disorders were reduced significantly between pre-intervention to three months post intervention. Potential child abuse, low family functioning and psychological disorders although not significant, reduced between post-intervention to 3 month post intervention.
The results are as predicted. Taken together, the results show that the IFS programs participating in this research project do have a positive effect on the well being of parents. Specifically, our results suggest that when families participate in the IFS intervention, parents reduce their child abuse potential and psychological disorders and increase their family functioning, hope and happiness. These parents do not regress back to where they were before the intervention but continue to reduce their child abuse potential and psychological disorders and increase their family functioning even at 3 months after finishing the program.

### 4.1.1 Child Abuse Potential

As shown in diagram 4.1.1, at the commencement of the IFS intervention 50% of the families in the research sample received high scores on the Child Abuse Prevention Inventory (CAP) reflecting a higher child physical abuse potential. At both completion and at the three month follow-up, child abuse potential had reduced significantly. One important finding is that child abuse potential kept decreasing after the completion of the service—see diagram 4.1.1.2.

**Diagram 4.1.1.1: Dependent Variable One - Child Abuse Potential**

The Child Abuse Prevention Inventory (CAP) is intended to assist in the screening of suspected physical child abuse cases.

**IFS Sample at Commencement**

![IFS Sample at Commencement](image)
4.1.2 Family Functioning

The McMaster Family Assessment Device (FAD) is a short, self-report measure of family functioning that describes emotional relationships and functioning within the family. In the current study the General Functioning subscale which assesses the overall health/pathology of the family, has been used. As can be seen in Diagram 4.1.2.1, 56% of families participating in the research could be described as ‘unhealthy’ or having low family functioning at commencement of the service. At completion of the IFS service, family functioning had significantly increased. At the three month follow-up there was a marginal and non significant decrease from the completion scores. However the increase in family functioning from commencement to three month follow-up remained a statistically significant increase.
Diagram 4.1.2.1: Dependent Variable Two – Family Functioning

IFS Sample - Commencement

Diagram 4.1.2.2: Family Functioning (significant: 1-2 and 1-3)
4.1.3 Psychological Disorders

The Outcome Questionnaire is a self-report questionnaire which provides comparable scores of the client level of psychological disorders. As can be seen in Diagram 4.1.3.1, at the commencement of the IFS service, 79% of client participants showed evidence of psychological disorders with symptoms of clinical significance (symptoms of distress, difficulties in interpersonal relationships and social role).

Diagram 4.1.3.1: Dependent Variable Three – Psychological Disorders

IFS Sample at Commencement

Diagram 4.1.3.2 below demonstrates that at both completion and at the three month follow-up, psychological disorders had reduced significantly. One important finding is that psychological disorders, the presence of clinical symptoms kept decreasing after the completion of the service—see diagram 4.1.3.
4.1.4 Hope

The State Hope Scale was developed to assess goal-directed thinking in a given moment. The scale assesses the individual's perceived capacity for initiating and maintaining the actions necessary to reach a goal and the ability to generate routes to his/her goals – both are seen as indicators of ‘hope’. As shown in Diagram 4.1.4.1 participants' 'hopefulness' increased significantly between pre-intervention to post-intervention. Hope decreased marginally between completion and the three month follow-up but not significantly.

Diagram 4.1.4.1: Dependent Variable Four – Hope (significance 1-2)
4.1.5 Happiness

The Happiness Measure, measures emotional well being. Respondent are asked to report their average level of happiness and the time spent in “happy”, “unhappy” and “natural” moods. As shown in Diagram 4.1.5.1 participants’ happiness increased significantly between pre-intervention to post-intervention. Happiness decreased marginally between completion and the three month follow-up but not significantly.

Diagram 4.1.5.1: Dependent Variable Five–Happiness (significance: 1-2)

4.2 Hypothesis Two

As child safety was the key area of interest in the current research, the project assessed the correlation between child abuse potential to the other four dependent variables. Accordingly, the second hypothesis claimed that:

*Correlations will be found between high child abuse potential and low family functioning, high psychological disorders and less hope and happiness.*

Two Pearson correlation matrices were constructed using commencement, completion and three month follow-up scores to explore the variables’ relationships. The results are presented in the following table:
Table 4.2.1: Inter-correlations between potential child abuse to low family functioning, psychological disorder, hope and happiness on pre, post and 3 month after intervention

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Low family functioning</th>
<th>Psychological disorders</th>
<th>Hope</th>
<th>Happiness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-potential child abuse</td>
<td>.522**</td>
<td>.745**</td>
<td>-.431**</td>
<td>-.636**</td>
</tr>
<tr>
<td>Post-potential child abuse</td>
<td>.571**</td>
<td>.607**</td>
<td>-.670**</td>
<td>-.735**</td>
</tr>
<tr>
<td>3 months after-potential child abuse</td>
<td>.513’</td>
<td>.624**</td>
<td>-.583**</td>
<td>-</td>
</tr>
</tbody>
</table>

*p < .05 **p < .01.

This table shows that as long as child abuse potential increases, family functioning decreases and psychological disorders increase. In addition, when child abuse potential increases, both hope and happiness decrease – at three different points of time. Consistent with the literature, these correlations indicate that parents with high child abuse potential have low family functioning, high psychological disorders and less hope and happiness in their life as predicted, thus supporting the null hypothesis.

As a result of the correlations above, the question arises as to which of the variables predict child abuse potential in the most efficient way. In order to answer this question stepwise regression analysis was conducted using potential child abuse as the dependent variable and low family functioning, psychological disorders, hope and happiness as the predictor variables. Stepwise regression analysis suggested that psychological disorders b = .54, t (37) = 5.22, p < .001, low family functioning b = .31, t (37) = 3.22, p < .01, and happiness b = -.24, t (37) = -2.2, p < .05, significantly predicted child abuse potential scores.

Psychological disorders, low family functioning and happiness also explained a significant proportion of variance in potential child abuse, R² = .72, F (3, 37) = .31, p < .001. Psychological disorders predict 55% of potential child abuse. Low family functioning adds 12.8% to the prediction, and happiness adds 3.7%. These results suggest that if a parent(s) has a psychological disorder, low family functioning and less happiness, the parent has a greater potential for child abuse.

4.3 The Therapeutic Relationship

The Working Alliance Scale assesses clients’ and therapists’ appraisals of the extent to which they feel they have formed an emotional bond based on trust and mutual regard, and can agree about therapeutic goals and tasks (Horvath, 1981; Horvath & Greenberg, 1986, 1989). Recent research (such as Canary 2008 and Dempsey and Keen 2008) highlights the importance of the therapeutic relationship in the provision of supportive interventions with families with a child with a disability.
In this research the Working Alliance Scale was completed by workers and clients at the completion of the service and clients again at the three month follow-up. At completion both workers and client participants scored the relationship highly (between 6 -7). The average score of the Working Alliance Scale $F (1, 21) = 103.447, p< .001$, reduced significantly across the two time periods: at completion and three months after completion.

**Working Alliance Scale: The Therapeutic Relationship**

Hence, the strength of the relationship between client and worker lessened between completion and follow-up.

Section Four of this Report has provided evidence of the effectiveness of the combination of program elements and therapeutic strategies implemented in the IFS programs participating in this research project. Section Five will now outline the qualitative experiences and perceptions of IFS clients, workers, managers and key informants to explore how and why these changes may have occurred.
Section Five

Client and Worker Perceptions and Experiences
Understanding the ‘How’ and ‘Why’ of Effectiveness

The collection of qualitative data relating to both the research aim and objectives has been on-going throughout both phases of the research process. The willing participation of staff members and IFS families from all three organisations has allowed many key program elements and issues to be identified and explored. Great care was taken in Phase One of the research process to establish that the program elements fundamental to the original IFSO services, also underpinned the newly established IFS services. The research team analysed IFS tender documents and contracts, agency websites, policy documents and program literature for each service and region to ensure that all IFS program elements were broadly shared and underpinned by the same philosophical framework. In addition, the thematic analysis of client, worker, manager and key informant interviews and focus groups in Phases One and Two highlight perceptions and experiences of the helpfulness of various therapeutic strategies common to IFS workers and agencies.

The qualitative data collected in Phase One directly addressed objectives 1 and 2, pertaining to the team formation of the new services at TSC and the new referral system as well as client exit from the services. These qualitative findings were documented in the Interim Report commissioned by TSC. Importantly, the Interim Report was distributed to all TSC workers in the IFS services which marked the commencement of a review process whereby ongoing feedback of qualitative results and issues occurred via regular staff development meetings. Feedback such as this is akin to an action research evaluation strategy with successive loops of feedback, reflection and refinement of existing practices (Grinnell 2004). Given the already extensive reporting of Phase One, Section Five will only briefly present a summary of the findings of the Interim Report in section 5.1.

5.1 Preliminary Findings Presented to TSC in the Interim Report

When The Spastic Centre of NSW commissioned the research design for this current project an interim report was requested to document the completion of Phase 1. The Interim Report was meant to be developmental and to provide a basis for The Spastic Centre to consider the following: whether it needed to review some aspects of the service; whether and how to strengthen select program elements; and how it might improve communication and interaction with other key agencies. Most importantly it provided a platform from which to reflect upon whether the foundations being laid continued to be the right ones to assist in strengthening families with a child with a disability.

Focus groups with workers from each IFS service and across TSC regions, interviews with key stakeholders and TSC managers identified the following issues in relation to objectives 1, 2 and 4.
A brief summary of the findings follows:

1. Minor Conceptual Shifts in the Key Philosophical Underpinnings of Program Elements:
   - What constitutes an intensive service
   - Early intervention re-defined
   - Move to more generic strengths-based perspectives

2. The need to fully reconcile IFS with the core business of the organisation

3. The need for transparency with the budget/funds allocated by DADHC and the guidelines for use of brokerage/FAF

4. Challenges related to the awareness/promotion of services

5. The ‘genuineness’ of the partnership between Burnside and TSC

6. Challenges of CALD and Indigenous services

7. The Referral Process was specifically examined and the following was found:
   - A lack of standardised policies and procedures across regions
   - A lack of clarity about how the IRI Panels do and should work
   - The process is cumbersome and time consuming
   - Early intervention in family crises had been compromised
   - Increased pressure to keep interventions short-term and increase numbers of families seen
   - Questions of how best to manage eligibility and priority
   - IRI Panel process had affected relationships with key stakeholders

A copy of the Interim Report is available from The Spastic Centre of NSW upon request.

### 5.1.1 Following the Interim Report

Following on from the summary of results presented in the *Interim Report*, the primary discussion in Section Five will focus on qualitative data collected after the formation of the research consortium at the commencement of Phase Two involving all three participating organisations – TSC, Northcott Disability Services and UnitingCare Burnside.

The analysis of the qualitative data will particularly address the following areas:

- Shared IFS Program Elements and Key Philosophical Underpinnings of these Elements
- Shared Therapeutic Strategies in IFS Services
- Entry to the IFS services - the Referral Panels
- Exit from the IFS Service – Where to now?
- Partnerships Between IFS Services
- Working with CALD and Indigenous Families as well as Families with a Carer with an Intellectual Disability
- Ideas for Change and Development
Data from workers (W), managers (M), clients/families (C/F) and key informants (KI) are presented in italics to indicate direct quotes from participants. Particular quotes have been chosen for inclusion in the discussion because they are representative of the themes emerging in the data analysis generally and they best encapsulate a particular theme or category of response. This chapter has chosen to use the generic term ‘worker’ to cover the different role descriptions such as therapist, caseworker or counsellor – unless a participant chooses to use one of these specific descriptors.

5.2 Shared IFS Program Elements and Key Philosophical Underpinnings of these Elements

Adapting and developing key features of the ‘Homebuilders’ model first adopted by UnitingCare Burnside, the key and innovative elements of the original IFSO program established by The Spastic Centre were:

- It was family rather than child focussed underpinned by a systems perspective in which a family is not seen in isolation but as part of a wider network of systems
- It was intensive – workers worked with a maximum of two families for a limited period of time providing out of hours support and availability by phone 24/7 ensuring maximum flexibility.
- It was underpinned by a commitment to intervening early when a family entered a crisis.
- It utilised a Solution-Focused Brief Therapy approach (Berg 1994, Cade and O’Hanlon, 1993) which seeks to build on and enhance the strengths and abilities of family members. Such an approach was seen to be consistent with the Principles of the NSW Disability Services Act (1993) and the NSW Disability Services Standards.
- A second tier of the IFSO model used a component of the grant to broker less intensive services and practical support so that the families could maintain an acceptable level of functioning.

Given the finding of the first ARC research confirming the effectiveness of the combination of program elements and therapeutic strategies, the original program elements were integral to the establishment and development of the new IFS services in TSC, UnitingCare Burnside and Northcott Disability Services. While these elements are being discussed separately in this Report for ease of reporting, the striking theme emerging from the qualitative data collected from the workers and families is once again, the importance of the unique combination of these elements with the therapeutic strategies in the provision of the new IFS services. In essence - ‘the sum is greater than the parts’. One worker succinctly encapsulates this theme in their statement:

*It is really all of what we do that is effective... Intervening early with the whole family and concentrating on them for a short but intensive period of time is just what they need before the family spirals out of control. Helping them to think differently about their situation and concentrating on their strengths is very often a different experience for these families who have previously felt like they were put in the ‘too hard basket’.*

Families were less able to specifically identify the actual combination of program elements and therapeutic strategies but did strongly acknowledge that there was something different about the overall IFS package:
It was all of it…everything that they did….the whole of it was great

It was all so different to what we have experienced previously…all of it was helpful, seeing the worker when we needed rather than having to wait for an appointment or an emergency and to have someone talk about what we do well was something new to us….

This is the first time … [child] has not been seen as the big problem and everything done for him. This service [IFS] looks at how it can help all of us and not just the disability as the biggest and only problem

Most research participants, be they families, workers or managers, commented on more than one program element indicating their appreciation of the service as a whole. The following analysis to some extent, artificially separates out the program elements but it does reflect the finding that different families often highlighted different aspects of the program as being especially helpful.

5.2.1 The Importance of a Family Focused Approach

Without exception, all families, workers and managers were convinced of the importance of intervening with the whole family and taking a family-focused approach. Families reported that frequently agencies and workers had previously provided services for, and to, the child with the disability only. A family focussed approach acknowledges that the child is located within the context of their family and that intervention is required in the family system to maintain the child safely and happily in the family home. Families provided the following experiences about the effectiveness of the whole of family approach:

- The program was really helpful to my family because the therapist didn’t take into account only one aspect of the problem. She [the therapist] looked at our family as a whole and really got to understand the children. She worked on every aspect rather than just the children.

- Rather than focussing on micro issues around my son’s behaviour it was a focus on the whole aspects of my life

- We are functioning better as a unit. The overall atmosphere in the house was improved for us

- The therapist was interested in the whole family, not like other services that focus on one person

An important theme that emerged in most of the interviews was the helpfulness of workers being able to directly assist families to understand their child’s behavioural difficulties as well as having ideas about behavioural management strategies and helping parents to see their child differently. One parent described how the IFS worker

…explained why the children behaved like they did and how they think and it helped me.
Another participant described how:

....in the past I was frustrated because I didn't understand what the kids wanted and then all of us were unhappy – the whole family

Families identified the results of the family focussed approach as being beneficial to family functioning as a whole and nominated the following benefits as achievements of the IFS intervention:

*The children better understand how their brother’s disability affects them and that he can’t help it sometimes. My partner and my son do get along better. They understand his disability better.*

*We are more supportive for each other and have better communication - we are all able to communicate now.*

*We have more understanding in the family...we now try and understand each person’s point of view and how we can work together.*

There were also specific benefits of not identifying the child with a disability as ‘the problem’ involving intervention which could even include extended family members:

*His brother and cousins accepts him as a normal boy*

*Our extended family are more relaxed now – even my sister and brother who have not known how to deal with … [child] previously.*

The benefits of a family-focussed approach were clearly articulated by both workers and families. In the completion and three month follow-up parents spoke specifically about feeling as if they were more in control of their family situation generally. For example, one participant disclosed .....*I’m calmer generally* and .....*I'm calmer with the boys.* Another participant recognised a change in the way in which they now dealt with stress and their child’s difficult behaviour .....*I’m not yelling as I used to.* Moreover parents were able to identify the effects of the program on all family members.....*we are all far more relaxed.*

### 5.2.2 An Intensive Service

The idea of what constitutes an intensive service has shifted slightly from the operational understanding of the original IFSO service. This shift has occurred in part by necessity as DADHC increased the number of families to be seen per worker from 2 to a minimum of 3 families at a time - documented in the Service Agreements with the new IFS services. Two workers aptly encapsulate the problem but represent the concerns reported by many workers:

*There is also the question of how many families each therapist can see at a time. Not understanding the need to have a very low caseload in order to be intensive is a problem.*

*[Being] … expected to work with 3 families changes the time we can spend with families and I believe this affects outcomes.*
All three organisations had looked at ways of maintaining intensity given the DADHC requirement of three families per worker. Strategies included increased use of mobile phones; balancing the intensity needed for each family seen by the same worker; and, introducing a new family before another family finally finishes their service and is in the ‘wind-down phase’ requiring less intensity from the worker.

One worker raised the following issue for consideration in light of the extra workload:

> It concerns me that IFS is promoted 24/7. None of us are super-human and the fact is that we don’t work 24 hours/day seven days a week. The fact that we can be flexible, combined with the strengths based approach and asking families what THEY [emphasis in original] would like to be different are the benefits of the program in my opinion.

Being ‘intensive’ has now been re-defined as flexible, responsive service provision with a more realistic work expectation of the therapists. While all worker participants did see themselves as available ‘24/7’ they also clearly identified the importance of boundaries and helping families to distinguish between the need for emergency contact after hours or weekends and when to use previously agreed strategies to manage stress. All workers identified flexibility of hours, the potential availability of a worker 24/7 and home visiting as the crucial components of an intensive service.

One manager of a rural service raised the issue of the perhaps unanticipated way in which geographic location can affect the intensive nature of a service:

> Due to the rural nature of the area and the amount of travel involved in visiting families means that these interventions are less intensive. Therapists spend so much time travelling to and from visits with their families that we have to be careful because often they’ll acquire hours of time in lieu from just one family.

Clearly thought needs to be given about the target number of families to be seen per worker in rural settings and consideration should be given to an extra allocation of resources for time-in-lieu and other support strategies for workers and families in rural areas.

Almost all families were convinced that the increased availability of the worker, and visits to their home were core components of the intensive service which greatly benefited their circumstances:

> The therapist came to my house, witnessed the situation and provided the service at the right time and the right place

> Having the therapist come to our house and work with us as a group was wonderful

> Just knowing that there is someone there to call upon to help you out…knowing you can rely on someone
Availability and intensive - it was good you have someone that you can contact through the day and night and get a third person’s opinion that can re-assure us that we are on the right track. We didn’t have availability like this before

The therapist was always there when we wanted. He was available. He was there for whatever I needed

The therapist helped a lot. If I needed help I would just call and ask her

In contrast, a small number of families would have liked even greater intensity in the service they received.

We saw the caseworker once or twice a week. She should be here and the program should be more intensive. It’s called intensive. Intensive means all the time… If I call and say I have had a bad day, I want support not just text messages or a phone call.

The caseworker didn’t come when the kids were here. I wanted her to be here. I want her to come so she can see. And then we will know what to do next time, how to calm our son down. I’d like to have her 24/7

The audit of case files indicated that the families who expressed a wish for greater intensity, appeared to have commenced the service later into their current crisis and were experiencing greater chaos generally. However, despite different ideas about ‘how intensive’ an intensive service should be, both worker and client participants agreed on the importance and effectiveness of providing an intensive service with home visiting and the possibility of availability, ‘24/7’.

5.2.3 The Meaning of Early Intervention

While all IFS workers supported the fundamental premise of intervening early when a family experiences a crisis, the original concept of early intervention has been somewhat compromised in the newly funded IFS programs.

One worker summarises the apparent cause of this:

[The new DADHC referral process stipulates] Families must have tried all other resources/services before they can now be referred to an IFS service. This is not early intervention. The service should be offered to the families in crisis that most need it and as early as possible - not those only at the end of the road

This operational guideline has had a major and obviously unanticipated consequence noted by workers and managers alike – that being, the tendency for referrers to over-emphasise the problems a family may currently be experiencing to enhance their eligibility.

Referral process now leads to an exaggeration of problems and then affects how these families are perceived on exit
Referrers now often exaggerate issues and difficulties with past interventions to ensure a family is taken on as soon as possible. Families can come with a referral form with a list of problems that no intervention could fix.

As has been discussed previously, the current policy relating to eligibility for referral to an IFS service explicitly prioritises families who have tried all other resources/services before they can be referred.

The majority are families referred because everything else has been tried, although there have been some families that may be considered early intervention. The team has also received referrals which state that a child will be removed if IFS doesn’t work.

Families then, are either ‘at the end of the road’ or are being presented as ‘at the end of the road’ to gain access to IFS services. Although not always possible, the first IFS program attempted to attract referrals for families in crisis before difficulties became chronic – intervening early before a crisis and the accompanying difficulties and stress becomes entrenched. This also has implications for a strengths-based approach as noted by workers in all organisations:

We need to change the referral forms because the goals and information provided by a referrer is often problem saturated and very different from what a family says the issues are.

If families were to see what was written about them to get them into the service they would have to feel totally hopeless and like there was no capacity to move forward or have a positive outcome. Also for us it is a difficulty to see this long list of problems and not feel a failure when they are referred back to their old services such as DADHC and we haven’t ticked all the referral boxes.

Whether families have a long term history of difficulties or are facing their first crisis requiring them to have tried all other services or accessed all other resources before they can be referred to an IFS service compromises the original concept of early intervention. Shifting the definition of early intervention back to ‘intervening early’ in a family’s crisis allows the IFS worker to commence work with the family at a time where there is the greatest opportunity for change. Moreover, rather than addressing a never-ending checklist of problems in the referral process the worker can better address issues raised by the family and have more scope to refer families to appropriate follow-up services at the completion of intervention. The concept of ‘intervening early’ is also more compatible with the strengths-based approach that is so fundamental to IFS interventions.
5.2.4 Strengths-Based Approaches

The original IFSO program documentation specified the use of a particular strengths-based family therapy framework - a Solution-Focused Brief Therapy approach which sought to build on and enhance the strengths and abilities of family members. In reality workers from the IFSO service reported that other therapeutic strategies (for example, behaviour programs) had always been used and that often workers had used strategies from other strengths based approaches when it was more useful for a particular family. Some workers in the current study indicated that they chose to only use a Solutions-Focused Approach because it was so useful in brief interventions, other workers chose to use a selection of solution-focussed strategies amongst other strengths-based therapeutic strategies. However the worker focus groups and managerial interviews from all three organisations mainly discussed the benefit of incorporating other therapeutic strategies and behaviour programs within a generic strengths-based framework and also strongly emphasised that a generic strengths-based approach is fundamental to effective IFS service provision.

One manager described their organisation’s philosophy of recruiting workers who choose to, and can, work from this perspective:

We expect everyone to work from a strengths perspective and explicitly advertise that in recruitment. In interviews we always ask candidates to respond to scenarios from a strengths-based perspective so we know they can do it.

A number of workers eloquently described why a strengths approach is so fundamental to the IFS intervention process

When working in disability often a parent’s own agency and efficacy is taken away through the process of seeking help for their child and not being seen as the expert when it comes to that child. Their difficulties in dealing with the child becomes the focus not their strengths and ways of coping

There’s often the expectation that the therapist is the expert with the magical cure but our perspective is that the family is the expert and the way we [the therapist] work is actually more helpful in getting families back in control and working towards their own solutions

I know the challenge for me as a worker is to resist the invitations to move in to that other expert style, to guide and direct them and tell them what they should do as if they have been doing it all wrong.

I think that’s what they like about us is that we don’t come across as the expert and see them as having problems but we are professional and we do have a knowledge base and they can draw upon that.

[Clients say] That you’re not there to tell them what to do…and that’s come out over and over again people saying “yeah you’re the first person that hasn’t told me what to do, the first person that’s really listened to what I’ve said.”
Families were universally positive about the ways in which interventions were oriented towards building on their strengths and were able to explicitly identify this approach as helpful and different from past interventions.

*The therapist helped us look at the positive points, to see the good things the child does. It showed me the light at the end of the tunnel and encouraged me to just keep going with it. This is so different to other workers in other agencies who always want to talk about my problems.*

*I try to look on the positive things now rather than the negative things.*

*The worker helped me to change the way I interacted with people to a more positive way. I changed my approach to be more positive about things.*

*I was thinking very negatively and now I have become more positive in the way I look at things and how I refer to my daughter’s behaviour problems. I take things positively and laugh at my problems instead of crying.*

In particular families appreciated the opportunity to name and develop their own goals and work towards them in a collaborative partnership with the IFS worker. A remarkably strong theme emerged in relation to the achievement felt by families:

*The program helped me to develop and understand my goals and ways to reach these goals. I haven’t achieved these goals but I’m still working on these goals. I know how to set goals for myself now. I’m in the process of achieving these goals. These goals really make me feel independent and happy.*

*I feel stronger now to handle my child’s behaviour and find solutions. The therapist helped me to work out how to find solutions and helped me find ways to get at the problems. She asked me what suited me ….she gave me options.*

*I went really well. I managed to maintain things and even improved. I set myself goals and I’m able to work on them. I know how to use help now.*

The theme of ‘knowing how to use’ help was strongly evidenced in both the client and worker interviews. The IFS intervention was seen by all as addressing current circumstances but equally as important was the way in which it helped a number of families develop an understanding of how to set goals and work towards achieving them. The effectiveness and sustainability of the IFS intervention is well encapsulated in the following quotes from family participants:

*We continued on with the strategies that we had developed even after the therapist left.*
It [IFS service] gave us a framework which helped us understand some of the advice that we get from the psychologists of DAHDC. At the time I wasn’t sure that I would maintain the progress (I thought I could lose it) but now I feel it has become part of my life.

And even in the discussion with the worker it was us who came up with our own answers. He [therapist] was able to develop our thinking skills on the spot.

Our family has managed to maintain things and has even improved. I set my self goals and now I’m able to work on them.

The implications of knowing how to use help is profound and certainly opens up opportunities for referral at the end of the service and affects the number and the intensity of follow up services needed by the family (if any). There is no suggestion that families are ‘magically’ cured; that they will not experience another crisis or that all families will be better able to use help effectively. It is more that the IFS intervention has helped a substantial number of participant families develop skills to better cope with crises and has modelled an effective way for the family to work with services in the future so they know how best to utilise resources and other opportunities.

5.2.5 The Importance of Brokerage and FAF

A second tier of the original IFSO model used a component of the grant to broker less intensive services and practical support so that the families could maintain an acceptable level of functioning. ‘Brokerage’ was one of the program elements recognised as being integral to the positive outcomes found in the previous research and was highly regarded by families.

At the time of establishment of the new IFS services at TSC there was confusion about which and how many services retained access to brokerage and how many services were to access the new form of brokerage - Family Assistance Funding (FAF) instead, where specific funding for each family was available from DADHC up to $2000. All focus groups conducted at TSC expressed concern and confusion about the administration of FAF and brokerage. For example:

Brokerage ($1500) money was always part of IFSO funding and was there every year and shouldn’t be restricted, although FAF ($2000) funding hasn’t been allocated through TSC it’s through DADHC. I know of one therapist who applied to access both types of funding and received it and another was told that was not a possibility. It seems it depends on who the manager is.

It can take up to two weeks to access brokerage for a family which is not in line with brief intensive early intervention programs. Previously we had managed it within IFSO services and this was effective rather than having managers outside of IFS deciding what is needed when they have no contact with the families themselves.

What different regions can offer families is quite grey...
Workers from all organisations found the administration of FAF problematic:

*FAF funding is more difficult to access and the guidelines are now so restrictive it is often hard to fit into the eligibility criteria*

*Part of what we do with families is work with them towards their goals. This also includes practical needs. How can we work in a respectful and creative way around practical need when so much energy is expended in fulfilling administrative guidelines that restrict rather than enable.*

One manager made the comment:

*It is now so hard to access FAF and as a result this aspect of the program is lagging behind excellent work in other areas. We are trying to creatively deal with the difficulties of the application process and will have to wait and see what ensues….*

Once received, families were extremely appreciative of financial and practical assistance:

*The money for speech therapy was wonderful. We couldn’t afford this kind of assistance before the program. He [son] has made great gains with such a concerted effort*

*The program helped me with financial issues. The program helped me work towards resolving our financial difficulties and gave me support to do this. The combination of practical and emotional support is fantastic*

*I was able to reorganise the house and bought shelves. It might seem small but it made a huge difference to our overall emotional well-being*

Not all families reported a positive experience of attempting to access FAF assistance:

*It’s a shame that the family assistance fund wasn’t achievable. DADHC has a lot of restrictions and I couldn’t get the money.*

*Funding was a problem. Really $2,000 is not a lot for the amount of effort and red tape.*

Given the demonstrated importance of financial assistance to families so that they can broker less intensive services and practical support to improve their family functioning, the administration of FAF warrants further attention. Workers and managers indicated that they had attempted to clarify guidelines but it would be helpful for DADHC (now ADHC) to evaluate the application process to access FAF and consider the accessibility of the guidelines for use of FAF.
5.3 Shared Therapeutic Strategies in IFS Services

One of the most consistent and strongly evidenced themes emerging in the analysis of the client/family interview data was the strength of the families’ relationship with their IFS worker. Almost all families who participated in the research had experienced intervention with other workers and agencies. Many of these families spoke of negative experiences, or feeling that they had been misunderstood and/or the intervention had not been successful. Occasionally families believed that a particular past intervention had actually increased their stress and the problems within the family. The particular program elements of IFS service provision facilitates therapeutic engagement and the mix of therapeutic strategies used in the IFS intervention appear, in most cases, to maximise client satisfaction with the therapeutic process.

5.3.1 The Importance of Therapeutic Engagement

Engaging families in an intensive service whilst they are in the midst of a crisis can be extremely challenging – particularly when child protection issues are one of the presenting issues in the referral. The families in this research project spoke of how their worker always appeared to understand them and what they were going through. Families expressed the view that experienced a level of empathy from the IFS worker that they had not experienced previously.

*The therapist was very understanding and very supportive of the changes we wanted to make*

*The therapist was very supportive of what we wanted and what we thought was important*

*My therapist was very understanding and helped me to come out of that bad time. She understood me and I could talk to her about everything. She was always very positive.*

*The therapist was brilliant, terrific. We covered a board range of things and it kept getting better. She really knew….*

*The caseworkers are great and were very helpful.*

Families appreciated the non-judgemental, positive approach characteristic of the strengths-based interventions adopted by all IFS workers participating in this research project.

*The therapist was very supportive, helped without criticising (parent with autism)*

*The caseworker was really helpful. He was friendly and didn't talk to us like we were idiots.*

*The caseworker helped us heaps. She was always being positive with us, with a friendly smile. The kids loved her too.*

*I called my therapist ‘angel’.*
Workers similarly identified that the particular combination of IFS program elements made for a very different therapeutic environment.

The intense nature of contact means that we can get right into the work and still work at the families pace – it makes for a strong therapeutic engagement. The respectful orientation of strengths approaches really concentrates on engaging the family.

Working with the family in their home, when they need it is a very different service opportunity. Asking them what they want, how we can be helpful to them makes it different to other services they may have received. Being able to deal with relational and practical issues is also a very big difference.

5.3.2 Increasing Confidence and Competence

The specific aim of this research project was to determine whether the families referred to an IFS program experience an increase in confidence and competence in managing their particular situations as a result of involvement in that IFS program. The focus of strength-based approaches is necessarily on building confidence and competence by recognising client and family strengths and building on these. The analysis of client/family interview data found that most family participants clearly identified feeling more confident and competent or ‘in control’ of their situation after the IFS intervention.

Families self-identified increased confidence as a direct effect of the IFS service:

The therapist gave me more confidence in my self and gave me confidence to try things

I feel more confident now - I feel more able to cope. It [IFS] makes you feel more confident that you can deal with whatever arises

I'm now more aware of and confident of controlling the situation at home and everything. I don't feel that everything is on top of me like it was before. I have been given encouragement that I can manage.

One particular theme that emerged in the analysis was the link between increased confidence and self-esteem or self-worth:

The therapist gave me more knowledge so that I can be the advocate for my child. I should act upon something I think is not right. The therapist assisted me to be more assertive. I am able to do it now…

[The IFS program gave me] self esteem - confidence in my self and in my children

The IFS program gave me a lot of confidence in managing my situation with what I can do – and that this is good enough
Worker participants discussed the importance of helping parents see their child differently by concentrating on their child’s strengths – what they could do well, focussing on achievements, however small. Increased confidence facilitated the positive ways in which parents responded to their child and managed their behaviour and particular situation:

We were unsure about our parenting skills. ... [worker] encouraged us to follow our instincts and stick with our decisions. ... [worker] gave us our confidence in ourselves - self belief and confidence...[worker] believed in us. He encouraged us. He allowed us to realise our potential. We were just rock bottom before this.

The therapist taught us techniques to better deal with [child]. Makes you feel confident that you can deal with whatever arrives.

Now I’m more relaxed and confident of handling my daughter. All the time the therapist made me feel confident and that I can do it. [worker] built my confidence in handling my daughter.

Increased confidence was also equated with other positive changes in individuals and the family as a whole:

I’m happier and able to set goals and maintain goals. Now, I feel very confident. When I wake up in the morning I feel excited about things. My attitude towards life has changed and I became a happier person.

I feel happier now I have more confidence

The therapist encouraged and empowered us as a family

The therapist gave me the confidence that I’m doing the right thing so now we can relax more

Confidence was seen as fundamental to parents feeling as if they were managing their situation - feeling more competent and in control of their lives. Workers spent a great deal of time helping clients develop goals so that families were clearer about their achievements. A theme that has been touched on before is that families were more competent in learning how to use and access help and resources:

[Worker] taught me how to set my own goals and how to seek help. Next time I have more tools to deal with things.

Before the program I couldn’t find the right people. It was difficult to get help and to know who to ask.

I learnt how to contact people on the phone. I have got help from services for my sons.

Now I have book of services and I try to find help outside like the parenting program
The therapist showed me a website that I’m using with games and toys for my child and a lot of information for parents

Next time I’ll seek help from someone - even if it’s little things, before everything gets out of control.

The value of an increased capacity to use help effectively and/or better access available resources as a result of the IFS intervention cannot be underestimated. Capacity increases opportunities for referral on program exit and increases a family’s likelihood of utilising less intensive forms of intervention.

A small number of families reported little or no change in their confidence (although not necessarily their competence) which they attributed to nothing changing about their child’s behaviour or disability or their life situation generally:

I can learn how to deal better with my daughter’s behaviour but she doesn’t know how to deal with her own behaviour. I’m dealing with her behaviour differently but the problem is still there. I’m just looking at it in a different way. There is nothing you can do to make her behaviour differently. I’m running out of options of how to deal with her.

It’s [IFS service] like taking anti-depressives. It makes you feel good but the problem is still there.

The boys haven’t been changed. They are still the same.

I didn’t implement anything from the program. I’m too busy as a single parent, too tired in the evening, too stressed, I can’t concentrate. I’m too busy to sit with my daughter. My daughter is so hard to deal with. It’s just impossible, one parent can’t do it. If I had the time...I can’t organise my life properly to use the information that the therapist gave me.

This small selection of families (two of whom rated the IFS service highly) reported that nothing had changed with their child’s behaviour or disability, changes which they saw as key to any improvement in their family circumstances. The initial ARC research found a similar group of families for whom the IFS service had limited effect. These families all reported needing longer term intensive assistance and support post the completion of the 12 week IFS program.

5.3.3 Creating a New World View - Listening, Support, Advocacy and Reassurance

Managers and workers from all three organisations reported going through rigorous employment processes and being able to meet selection criteria specifying experience in counselling/therapy and demonstrated skills in this area. Therefore it is possible to hypothesise that all IFS workers had considerable experience in this type of intervention and a general underpinning of counselling knowledge and skills within a strengths-based framework.
Families identified a number of discrete intervention strategies that they found extremely helpful throughout the IFS service. These strategies and skills are not unique to IFS interventions however the context of practice (including the program elements) and therapeutic strengths-based framework contribute to the families’ experience of a uniquely packaged service. Skills and strategies that would be routinely assumed as part of a usual counselling intervention were reported by families as being especially helpful.

5.3.3.1 Listening to Understand

‘Really listening’ was similarly identified by families participating in the first ARC research project as extremely helpful and somehow different to the way in which workers had listened in previous experiences of counselling for many participants. When the worker ‘really listened’ participants felt profoundly understood:

In contrast to what I thought would happen the therapist really listened to me and didn’t just go by the referral papers

It was good to talk to the therapist. He was there to listen. He didn’t judge or push me. I felt comfortable and understood…

Listening and someone to talk to - my therapist really understood…

I talked to my therapist about my feelings: anger, sadness…and he listened and validated a lot of my feelings. I didn’t even want his opinion but just listening. I talked to him, for example, about my husband’s illness.

‘Really listening’ was reported by participants as the forerunner to establishing trust and families feeling that they could talk to the worker. For some participants, this was the first time they had felt able to talk about themselves and their situations.

I had someone to talk to. I’m not socialised and can’t talk to my family. The therapist was the only person I can talk to. It was helping just speaking to him. I hadn’t spoken to anyone. He [therapist] always listened and he was really understanding….

The way the caseworker talked to us made us feel more comfortable. It was good to have someone to talk to.

I had someone to talk to and get outside opinion. That was the most helpful for me than anything else.

5.3.3.2 Support and Advocacy

Participants identified many of the program elements as supportive but the experience of support derived from the relationship with the worker was also identified.

Knowing there is support person to help with everyday tasks that are so difficult

Support and the lack of a judgemental attitude – knowing you can rely on someone
Families also appreciated the advocacy that workers undertook on their behalf or with them. Advocacy was equated with the worker caring for the family.

*It was nice to have someone to back you up, advocate on my behalf*

*It really felt as if the worker cared enough to fight for our family. Knowing that I had someone there that cared was really important*

A small number of families discussed the provision of minimal support after the IFS service had finished and the importance of knowing that you could make a phone call if need be.

*It’s good we know we can call him even after the program has finished. He still checks up.*

*After the program finished it helped to know that I can call my therapist*

It is unclear whether phone calls post-intervention are a common practice or a support strategy used for a select few families. Certainly many families indicated a wish for a period of less intensive intervention – a ‘wind-down’ period after the 12 week scheduled completion that could involve phone calls or monthly visits for a limited period of time

### 5.3.3.3 Reassurance, Validation and ‘Normalising’

Most families appreciated the reassurance given by workers that they had strengths and the capacity to achieve their own goals. Many participants had reported that they had felt isolated and lacking in support and information. They were often not sure whether they were ‘doing the right thing’ or could do the right thing. Reassurance and validation from the worker and ‘normalising’ participants’ experiences were seen as helpful strategies by many families.

*The therapist reassured me that I’m doing the right things. I had started to doubt myself. I thought that maybe it’s me that doesn’t see the clear picture. The therapist told me it’s not me*

*The therapist validated our situation and said it is difficult situation. It was good to hear that.*

*It made such a difference just talking to the therapist and realising that I’m not crazy. Being told that I’m ok and I’m a good person. Just the reinforcement of it all - the validation… It was just validation. Just to know that I’m OK.*

Workers similarly discussed the importance of reassuring, validating and normalising the families’ experience. Many families report a high level of isolation alongside guilt for not managing their situation as they would like. For workers to reassure them that they are not alone in their struggle and that other families experience similar stresses and management issues ‘normalises’ what previously felt like a unique burden or ‘failure’.
5.3.3.4 A Changed World View

Most families reported that the most important outcome of the IFS therapeutic intervention was a changed world view or a different way of seeing their situation. Certainly the strengths-based approach to intervention explicitly attempts to re-focus a family’s worldview to acknowledge what they can do, moving away from a deficit focussed, problem-saturated model of intervention that can typify responses to disability. One participant described this as *the program turned around my world*. Another family spoke of how working with [therapist] *changed our perspective*. Both of these quotes capture the very best outcome for the majority of IFS families participating in this project.

The qualitative data provide compelling and detailed evidence of the client’s experiences of the IFS services and their perceptions of the helpfulness of the combination of both program elements and therapeutic strategies. The remaining discussion in Section 5 examines data pertaining to other factors affecting a family’s experiences of the IFS service.

5.4 The Referral Process and IFS Services

The referral process and the operation of the DADHC Information and Referral Panels (IRI) were areas where all focus groups in Phase 1 and at the beginning of Phase Two expressed a significant degree of dissatisfaction. Documents relating to these areas were reviewed earlier in the research process however since then, much of the documentation has been changed or the actual front-line practices developed within the panels have gradually over-ridden the written guidelines. Some of the concerns raised in the following discussion have been partially resolved as the professional practice and good will of staff from the participating organisations and DADHC on the panel have ensured the optimal operation of the IRI panels. Nonetheless there remains considerable dissatisfaction about the IRI process which will now be comprehensively covered in this section.

5.4.1. The Lack of Standardised Policies and Procedures Across DADHC Regions

When the new IFS services were established, the referral policy and process was dictated centrally within DADHC however regions were left to interpret how the IRI panels were to be operationalised. Each region developed different guidelines, some of which were directly contradictory to the practice of another region. All IFS services and workers reflected confusion and uncertainty about the operation of the panels, and workers reported that this initially affected referrals.

*The way it’s been set up has excluded families in some regions but not others and we’ve lost families and for me I find that an incredible frustration*

*Two workers have been lost partly due to confusion resulting in a lack of referrals and work to be done.*
One key informant discussed the effect of shifting operational policies and procedures and the potential for confusing external agencies:

*I found the process of making the referral very confusing. I was unsure about who to ring for the referral and went on the website but there was some confusion about which area/region to contact for this family. I ended up calling the head office and they had no idea so there was bit of a ring around. Many people are not aware of how to go about making referrals, now that they’ve done it once they might go through DADHC next time.*

Workers from all three organisations reported considerable changes in how the panels are working currently (and a greater if not complete satisfaction), but the clarity gained by workers participating in the panels has not necessarily been shared by external stakeholders.

**5.4.2. A Lack of Clarity about How the IRI Panels Do and Should Work**

The grassroots operation of the IRI panels has changed considerably during this project albeit differently in each DADHC region. One manager exemplifies the fluidity of this process:

*The implementation of the policies and procedures are a ‘work in progress’. After all this time we are all still trying to negotiate how the panels will and should work which are two different things it seems.*

Within the IFS services, workers clearly expressed concern about the lack of clarity relating to how the panels should operate:

*The IRI panel might look to outsiders like it’s working smoothly, however as an insider it doesn’t feel as coordinated as appearances would suggest, it is more like a clash of personalities.*

*My understanding when the panels were first set up was that, yes DADHC are chairing the meetings and hosting it with the venue, but that it was very much meant to be that we were all in it as equal partners…but it doesn’t always feel like that.*

Many workers and some managers questioned the need for an external panel preferring instead the way in which the original IFS service managed referrals themselves.

*If we are truly a family-centred service could a self-referral system be implemented?*

*Because the referrals don’t come through the therapists at the IFS service they have no way of knowing when a family has been knocked back or have been making efforts to receive a service because it all comes through the panel. In effect we really don’t know what is happening, which affects communication with a referrer.*
These latter comments highlight the earlier discussion relating to the experience of changed patterns of communication between the referrer and IFS therapists. The panel appears to act as a ‘barrier’ between workers rather than facilitating the referral of a family. The issues of communication could also presumably affect a family’s exit from the program – this issue will be explored in the completion of service interviews.

In contrast, a DADHC key informant expressed a clearer idea of the referral process as exemplified in the following comment:

*From my perspective, I just write the referrals and these then get passed up the line to the panel and then I find out if a worker has been assigned. Every single referral I’ve written so far has been allocated a worker. I think this is due to my ability to write really good referrals that are tailored but also because all the families have been complex need and appropriate for IFS intervention.*

The original IFS service operated by TSC had the overall control to monitor and manage the referral process. This allowed them to balance the intensity required by each family in the allocation of a family to a particular IFS worker. Also, the relationship between the service and referrers was direct which allowed for a quicker entry to the service when there was capacity to take on a new family.

### 5.4.3 A Cumbersome and Time Consuming Process

The use of the panel has been described by most workers and managers as cumbersome and time consuming with workers unnecessarily tied up with administration. For example:

*I think it’s [the IRI Panel] made life a little bit harder for us as a service to keep our relationships and do all the networking that we were doing because it’s also time consuming.*

*Our time has been cut short by the amount of meetings we’re attending now.*

*I [manager] go to the meetings to save my staff time – it is really time consuming and at least I have an idea of who is being referred. It also allows me to work directly with DADHC. It is also helpful to have the same people at the meeting – allows for relationship building.*

Workers have reported concerns such as:

*I’m not sure that everyone who’s applying is actually getting through and not sure that we’re not losing them somewhere in the system along the way. The system is depersonalised…*
Difficulties have been reported by referrers as well such as the following comment from a key informant:

I always try to encourage ongoing email contact during involvement, but lately once the referral has been made there seems to be drop off in communication, one therapist didn’t even let me know that they’d finished with a family.

Workers from some regions reported appreciating the opportunity to meet with other workers from DADHC and saw this as an opportunity to network and learn from one another. The question to be raised here is whether the referral panel meeting is the best or only place for this to occur.

5.4.4 Managing Eligibility and Priority

Workers reported that eligibility criteria have been operationalised differently in the different DADHC regions, but the reported experience of a number of workers was that priority was differently awarded to referring agencies – in some cases.

There’s a tendency for DADHC referrals to be given preference, if only because they have inside information and have the ability to tailor referral forms in such a way that families will more often than not be accepted in comparison to referrals from other agencies where the referrers might not be as skilled in writing a referral.

DADHC referrals hold more weight. Still legitimate referrals and families still in need, but those coming from other agencies at the end of the day are just as needy.

In one meeting when a family’s priority was at risk of not being recognised a DADHC worker on the panel pulled out a laptop and provided more detailed information. Other referrers don’t have the luxury of providing details on the spot.

As one worker noted, the difficulty that emerges alongside this unacknowledged preference is:

I think my greatest concern is that we’re never really sure who actually makes an enquiry to IRI directly and where that person actually goes if they don’t receive adequate information.

Most of the IFS teams have struggled with the issue of how to determine eligibility and priority outside of a waiting list. The concept of ‘capacity’ has been usefully implemented in some IFS services to avoid lengthy waiting lists where:

The problem with wait lists is that families can change while they’re on the wait list and may improve or deteriorate and the information on the referral is not relevant.
[Service] and [Service] both have waiting lists but we are looking at a new system where a waiting list isn’t kept, rather updating referrers when there is capacity to pick up families and families can then be prioritised at that point.

Another therapist explains how the concept of capacity avoids difficulties in prioritising one eligible family over another stating that it becomes:

All about timing too, someone may refer an eligible family one month when there isn’t capacity so they’re turned away, but then someone else may refer a month after that and be accepted because there’s capacity.

Eligibility and the use (or not) of waiting lists are issues that are fundamental to any referral process. Uniformity of policy and procedures in these matters would greatly assist referring agencies and be helpful in transparently managing the allocation of families to an IFS service.

### 5.4.5 Awareness/Promotion of Service

Workers from the original IFSO services reported greater autonomy with regard to the referral process and more direct communication with referring agencies about the process of referral and information about the appropriateness of the IFS program for a particular family. Themes that emerged strongly in the stakeholder interviews were the lack of knowledge about the new IFS services amongst referring agencies and that communication between referring organisations/workers and IFS services was not optimal. For example the following key informants from external agencies noted:

If IFS was better known within our organisation there would be many more referrals. The only problem with word of mouth is that there can be miscommunication, had to explain many times to staff that it’s not a respite service as this is often misunderstood. It would be good to have a brochure explaining the service. [Note: pamphlets are available for all of the IFS services]

I can only really speak from a DADHC perspective, I have worked with the service for a couple of years and it has changed over that time, we initially worked much more collaboratively and visited families together and would communicate about how families needs can be met. Things have changed, communication has not been initiated as much and contact drops off. If I call they’re happy to speak but it’s less communicative.

That’s a two fold response; my most recent experiences in terms of communication have not been good. A year or so ago [prior to establishment of new services] IFS staff were better at communicating than they are now. We usually try to meet up with IFS workers and share information and I would like that to continue but it hasn’t been happening. At one stage you were able to talk on a weekly basis with IFS workers, some people are more communicative than others. I suppose I came in with expectations that hadn’t been met.
The IRI Panel process has seemingly mitigated the relationship of IFS services and workers with their key stakeholders. Two workers suggested that the referral panel has unintentionally obfuscated the nature and purpose of IFS services:

An identified problem with clients and referrers has been a lack of understanding of the nature of the work. It is really difficult to address this now as everything has to go through the panels and often the referring agencies don’t really have a handle of what we do or the type of families we see.

Often we receive a referral from DADHC where it is obvious that they have no idea what we do or the nature of our intervention and so they have a lengthy checklist of problems that need to be ‘fixed’ by the end of the 12 weeks.

Awareness/promotion of an IFS service is crucial to both the referral process and exit outcomes. Accessing information specifically about the IFS service from organisation’s websites is not as user friendly as it could be and this has contributed to both a perceived and actual lack of available information about the IFS programs among some other organisations. The fact that workers are now expected to carry three rather than two intensive clients/families at a time arguably affects the time IFS workers have available to promote the service and contribute to ensuring regular and constructive communication between IFS services and other agencies. In addition, not having any control over the referral process makes it difficult to ensure that all appropriate and eligible families are referred to IFS services.

5.4.6 Service Exit

Focus group participants raised the problem that referrers often have unrealistic expectations of the IFS service to ‘fix’ a never-ending list of family problems in a short period of time. The issue of ‘overstating’ problems to ensure that a family met the criteria of having tried all other available services and resources for the referral panel has been discussed previously. IFS workers noted the difficulty that referrers can pre-empt an exit strategy in the referral which is both unrealistic and not congruent with the ensuing intervention with the family.

We work with families towards goals that are meaningful to them and we choose not to follow the list of problems on the referral. If referrers don’t understand the way we work then they can be disappointed that they [family] exit the service differently than how they expected.

It is like they [referrer] can pre-empt what we will achieve in the intervention and they make recommendations for how a family should exit the service before they’ve [family] even commenced.

One important issue raised by workers was feeling pressured to continue a service because of the relative lack of other services available to some IFS families on exit from the service. This was similarly noted as a pressing problem in the original ARC research. Workers commented that:
Apart from Brighter Futures caseworkers, Home-Start Program and Family Support there aren't many services that can offer on-going support to IFS families.

I'd like options for referral on exit to be more connected to the other spectrums of support within our own organisation.

Some families need a slightly longer less intense 'wind-down' from the intensity of the 12 weeks - it isn't really possible to refer them for this transitional phase and where would we refer them in any case?

There is an irony in families reporting that they felt better able to use other services and resources as a result of the IFS intervention but workers often felt unable to refer on because of a lack of appropriate services both within their own organisation and externally.

While still valuing the benefits of short term intensive intervention, workers generally felt there was a need to consider that the time frame should also be judged according to an individual family's needs. As one worker suggested:

> Do we make a difference in 12 weeks? Given that the needs of some families are so different....I hope that DADHC and .... consider that this time frame should be flexible.

Workers and managers alike reported that a strict 12 week service does not suit all families with complex needs. In particular Indigenous families and those with a carer with an intellectual/developmental disability all report that a longer service would be helpful. Workers are also convinced of the benefits of a longer service for these particular families as they are also the hardest to refer on post IFS intervention. This latter issue will be more comprehensively addressed in 5.6.

Many families similarly questioned what they saw as a premature termination of the service after 12 weeks:

> I don't think the program is long enough. It's too short. By the time you get to the end of it you are only starting to understand and get involved. In the first few weeks the therapist tried to get to know everybody and all our differences and then tried to put something in place and then oh sorry... and then he left. You build up a little bit of trust then there is the end of the program.

> I loved the program but I would love it to be longer. I have been offered financial assistance but I would prefer the program to run longer. To have this person is much more important.
As well as families wanting to extend the service overall, other families suggested a less intense follow-up which they felt would help them sustain the changes they made in the initial 12 weeks of the intervention:

I’d like to have follow-up afterwards. When you do it for so many months it’s full on. It would be better to have follow-up just to keep you on track of what you are doing…and to speak to someone who knows what you have gone through. You go through the period of crisis and things have settled down, but you really don’t have somewhere to go afterwards. Everything seems to be ok and than you on your own. Just having one or couple of months follow-up afterwards would be great - one visit each month would be good.

Time frame of the program is too short and should continue and be extended on a long term basis. We would like to continue with her even once every two weeks to reinforce the work.

It’s a shame that the program is only 3 months. It was good even if we have a break and than after 6 months the therapist would come back for 4 weeks and see if we are coping, and if it’s working. If not the therapist could give us suggestions.

The idea of a ‘step-down’ service was also mentioned by workers as potentially benefiting some families and assisting them to maintain the changes made in the IFS program upon exit from the service.

5.5 Partnership with UnitingCare Burnside

UnitingCare Burnside and TSC have a long history of working collaboratively in the development of intensive family service provision. As was discussed in Section Two of the Report, the original IFSO service established at TSC was conceptually influenced by UnitingCare Burnside’s implementation of the ‘Homebuilders’ model. In the 2006 DADHC funding round, a joint tender was successfully submitted by TSC and UnitingCare Burnside to develop a partnership in South West Sydney, prioritising the intersection of Care and Protection and Disability. The IFS service offered by TSC in Prairiewood has a partnership (Memorandum of Agreement -MOA) with UnitingCare Burnside which makes it a unique service. This agreement was conceptualised as a consortium where Burnside is the lead agency and receives all the funding and is accountable to DADHC and IFS reports to Burnside (and The Spastic Centre) and directs invoices for the IFS services to UnitingCare Burnside. Burnside has an additional IFS service based at Campbelltown which is not part of the MOA with TSC.
In the focus group interviews, workers from both services were independently able to identify the potential benefits of a joint service for each organisation:

*Burnside previously had a child protection service - not disability related so TSC was able to provide information about disability specific issues and Burnside had previous knowledge of child protection issues. These differences impact the way in which the service operates in a positive way, able to consult each other on issues.*

However the teams by and large appear to run as separate services despite the idealised vision for a joint service.

*The IFS team takes referrals for certain local government areas and Burnside takes the others, not based in the same building. Basically two services but have a steering committee. Documentation between the two agencies differs, but the information being recorded is based on the same principles and both collect the same information as required by DADHC.*

The recruitment of staff to the new IFS Burnside partnership occurred separately encouraging the establishment of what operationally is two separate services:

*Interesting thinking back because the recruiting for the positions under the Burnside partnership were not done in collaboration with Burnside, looking back this probably would have been good although they didn’t invite or encourage this.*

The service at Prairiewood (The Spastic Centre – IFS), from commencement has had some difficulty recruiting and retaining staff, thought to be in part due to low referral numbers in that region. Referral rates have continued to be lower than anticipated (information current up until the completion of data collection in March 2010). The Burnside IFS service experienced a very low referral rate at commencement but referrals have increased over time.

Both TSC and Burnside maintain positive and constructive working relationships at an organisational level. However as the research project continued into Phase Two it became obvious that there were difficulties in the partnership beyond the separate operation of the services. Burnside Campbelltown service and TSC Prairiewood service which seem to be substantially influenced by a different use of language attached to divergent concepts of ‘professionalism’. After discussions with managers and from the worker focus groups, the research team believes that each of the services provides quality intensive, strengths-based interventions that are more alike in practice than dissimilar. Arguably some of the differences experienced both within and between services and agencies has been the result of definitional and professional meanings and understandings attached to different terminology. The research team deliberately chose to primarily use the generic term ‘worker’ throughout this Report to avoid privileging the use of case manager, case worker, worker, family therapist, which have different meanings and are valued differently by workers in the two organisations.
The research team has provided feedback to managers from both TSC and Burnside and have specifically discussed the working relationship as reported by the two sets of workers. Consistency in the definition, understanding and use of terminology would begin to build a better understanding and working relationship both within and between services and agencies. Further strategic discussion and planning is recommended to develop a ‘meaningful’ partnership and build on the solid relationship evident at the organisational level.

5.6 Working with CALD, Indigenous and Families with a Carer with an Intellectual Disability

This research, as specified in Objective 4, sought to investigate the effectiveness of Intensive Family Support (IFS) Programs for different client groups, particularly in relation to CALD and Indigenous families and families where the primary care-giver has an intellectual disability. The extent to which this objective has been achieved differs for each client group. The relatively low numbers of CALD and Indigenous families as well as families with a carer with an intellectual disability has meant that the research was not able to adequately address Objective 4 for each cohort individually. The qualitative data however does illuminate the particular experiences of these families and provides an opportunity to consider future directions in the provision of services in these circumstances. The qualitative data from these families will now be discussed in 5.6.1 – 5.6.3.

5.6.1 CALD Families

Ten CALD families comprising 23% of the overall sample participated in all aspects of the data collection for the project. Seven of these families had children born outside Australia (13%) and six of these families (11%) required an interpreter. Workers had successfully used interpreters throughout the intervention with these families. CALD families were thus able to be included in the quantitative data collection and contribute to the overall results reported in Section 4.

TSC workers reported a process whereby they considered how best to develop and provide a CALD service at Parramatta however workers disclosed mixed feelings about how this has, and should progress:

*What makes an organisation a CALD organisation? You have the funding and see the families but is there anything else? It’s a deeper understanding, we’ve got a long way to go and it’s really hard and there’s a real rush to see results.*

*As an organisation I think we’re not so strong on recruiting for specifically CALD communities but that’s something that’s on our radar.*

*A second language is a big benefit, bilingual. Even if they’re not from the same language group people tend to feel more comfortable if they can see difference*
Managers commented that during the initial recruitment process ‘cultural competence’ rather than a cultural background or experience were given preference for the CALD specific IFS. When interviewing for CALD positions, TSC did not target specific cultural or language groups. However workers in all focus groups acknowledged that recruiting specific ethnic/cultural workers may not be feasible but bi-lingual workers would enhance CALD participation in an IFS service:

Ideally it would be great to have more bilingual workers, Arabic and Vietnamese speaking, more CALD specific workers.

Networking is taking place to get more connections with multicultural organisations.

The research data has demonstrated that CALD families can and do, successfully access IFS services and they can effectively use this type of intervention. The way in which an organisation offers or ensures a service to CALD families is a matter for ongoing strategic planning and review. While TSC has put some effort into a review process in relation to this particular service, it is also timely to consider the future strategic development of the CALD, IFS service.

5.6.2 Indigenous Families

The project team had initially thought that a substantial number of Indigenous families would participate in the research process as two IFS programs established in the Hunter and Central Coast Region of TCS included a significant Indigenous demographic and UnitingCare Burnside had established an Indigenous IFS service (not part of the MOA with TSC). We managed however, to recruit only 2 Indigenous families both of which provided minimal data as one of the families withdrew from the research after commencement and the other withdrew from the IFS program before completion of the intervention after their therapist left the service. The Burnside Indigenous Service workers were initially willing to consider participating in the project, but a turn over in staff and subsequent employment of new staff members with little experience in the IFS way of working meant that workers felt less confident about their capacity to participate meaningfully in the project. Worker reticence was compounded by very few referrals being made to the service at that point of time and so the service chose not to participate in the research project.

There are always difficulties in recruiting Indigenous participants in mainstream research projects. In relation to one of the families we did see, the worker reported:

Mum ignored my messages and cancelled our interviews. It was a pattern in the intervention.

The other family were affected by a change in worker during the intervention period. When she withdrew from the program the new worker reported that:

The family cancelled the meeting and asked to cancel their participation in the program. The [original] therapist resigned from her position and handed over to me. Mum said the situation had improved and she did not require the service. I [therapist] only visited the family a few times before this happened.
Worker focus group discussions generally made the point that engagement of Indigenous families can be understandably problematic for non Indigenous workers. Workers felt strongly that there needs to be a different process of engaging the families which involves accepting that Indigenous families can often take longer to trust ‘professional’ intervention and may have had very negative experiences of intervention in the past. In addition, the Indigenous community (and also some CALD communities) were often less happy to have an involvement with DADHC and receive a formal disability diagnosis – which is now necessary for referral to an IFS service.

While not demonstrated by the research, workers from the Hunter and Central Coast TSC services felt that Aboriginal families had probably been some of their best success cases because of the match between Indigenous culture and the unique combination of program elements and therapeutic strategies of the IFS model. One worker described the IFS approach as:

*It really is a non-judgemental and respectful way of working with Aboriginal families.*

Alongside the above comment it was also noted that intervention would be further enhanced if there was the opportunity to work with the family for a longer period of time:

*While I think we can work well with Indigenous families and an intensive service is definitely the way to go, the short-term nature of the IFS service can be problematic. Working with Indigenous families, takes time to develop trust and to get to know all family members – including extended family members. Twelve weeks is really not enough time to deal with such complex situations.*

*Many Indigenous families have had negative experiences of ‘white’ intervention and so they are not expecting anything different from us. Strengths-based work is really the only positive way to engage with these families but it takes time for this to happen.*

As with CALD families, the worker focus groups discussed a best practice option of developing more Indigenous IFS services:

*To best meet the needs of Indigenous families I think the [agency] needs to consider employing/training Indigenous IFS workers. I don’t mean a token Indigenous worker on their own I mean a group of Indigenous workers.*

The development of other Indigenous IFS services could well benefit from reviewing the experience of the Burnside service and consulting Indigenous communities from their local area about what they would find helpful.
5.6.3 Carers with a Disability

In the original ARC research a small group of families where a carer had an intellectual disability emerged as finding the IFS intervention particularly helpful. As such the current research project aimed to see whether this remained the case for such families accessing the new IFS services. Four families (11%) participated in the research where the carer had a disability – 3 parents had an intellectual disability and one parent had autism. All three of the families where the caregiver had an intellectual disability were not included in the quantitative data collection because they found the measures difficult to answer, but they were still included in the qualitative interviews. The parent with autism participated in both the quantitative and qualitative data collection.

Workers were able to clearly outline the advantages of the IFS approach when intervening with these and other such families who had chosen not to participate in the research project.

Concentrating on what they do well is so important and very different from many other services they have received in their lifetime.

When DoCS have been involved the families are terrified that any crisis will mean that their child is taken. We come in and work with the chaos rather than blame them for what they have not been able to do.

The intensive nature of the service and the additional and equally important focus on practical assistance was particularly appreciated by the families and they provided the following examples:

[The worker] helped us clean the house and showed us what to do

She helped us move to a bigger house and helped us to organise the house

She helped us know how to look after the boys

She took us to the shops and taught me how to cook

The families also talked about emotional support and understanding as being important to them and how it helped them to develop confidence in their capacity to manage their situations:

The therapist reassured me that I’m doing the right things

I have more confidence in my own decisions now
However, like the Indigenous and some CALD families, these families also expressed a wish for a longer service or more support once the IFS intervention had finished:

Now when the kids fight I want to scream “...[worker], where are you - Help!! “. When [worker] was here we had a friendly environment. It was a little more normal when [worker] was here. Now the kids break things, fighting.

It was very helpful to have [worker]. When she left we tried to use the strategies but it doesn’t work like we wanted it to. [Worker] is not here so the situation is not as good. Everything is the same now.

It seems that the gains made in the program were difficult to sustain for these families after the completion of the IFS program. All of the participants from this group were positive about the intensive nature of the intervention and the therapeutic focus on what they did well. The length of the program and support options post completion definitely warrant further consideration if changes made during the program are to be sustained by these families.

CONCLUSION

To conclude Section 5, the research team has chosen to present the evaluations of key stakeholders and their hopes for the future of the IFS services in their area:

Good service! We endorse and support it and would also support IFS continuing if there was ever a risk of it discontinuing.

With this current family a multidisciplinary team works with them and all staff on the team received the IFS therapist well and were really impressed with the service.

Positive experience, communication is good and clear referrals are made to DADHC, able to talk to staff for updates, communication with broader community.

[I would like] Little more of what it was like at the beginning more collaboration, communication regularly, working toward common goals.

Feedback from families is still positive, mostly they like the workers involved although there have been two families who have withdrawn from the service. Not personal against worker just a matter of not being ready for the service.

Outcomes are excellent at the moment, no changes needed. I would like communication to improve between IFS and DADHC. Family’s capacities are being developed and improved and they are relying less on DADHC services and becoming more independent.
The qualitative data from workers, managers, families and key stakeholders provide clear support that the families referred to an IFS program experience an increase in confidence and competence in managing their particular situations as a result of involvement in that IFS program. Managers, workers and families have all provided thoughtful and detailed information which can potentially contribute to enhancing existing policy and practice in the provision of Intensive Family Support services.

Section Six will discuss the results and propose recommendations for best practice when intervening to assist families maintain their child with a disability safely in the family home.
Section Six

Discussion of Results

Recommendations for Future Practice

The quantitative and qualitative data collected throughout this project clearly demonstrate the effectiveness of the IFS services participating in this research. The results of the current study replicate the finding of the original ARC research that there is cause for optimism in the field of children with disabilities being kept safely with their families.

The specific aim of this research has been to determine whether the families referred to an IFS program experience an increase in confidence and competence in managing their particular situations as a result of involvement in that IFS program; and, whether the IFS program (including program elements) significantly contributed to maintaining child safety within the family. Two hypotheses were developed to assess the effectiveness of the IFS programs and address the central research aim:

- Hypothesis One - Parents who participate in an IFS program intervention will have less child abuse potential, psychological disorder and low family functioning and more hope and happiness.
- Hypothesis Two - Correlations will be found between high child abuse potential and low family functioning, high psychological disorders and less hope and happiness.

6.1 The Outcomes

The outcome data support both hypotheses. In relation to Hypothesis 1, the quantitative data demonstrate that potential child abuse, low family functioning and psychological disorders reduced significantly and hope and happiness increased significantly between commencement of the IFS service and completion (post-intervention). This indicates that the participating IFS programs are very effective and help families to increase their competence and confidence in managing different situations in their lives and maintaining children with a disability safely in their homes.

Moreover, the data demonstrate that the IFS programs have a positive impact on maintaining a child safely within their family by reducing child abuse potential and psychological disorders, improving family functioning as well as increasing hope and happiness. Support for this conclusion can also be found in the literature. Different research studies have found correlations between child abuse potential and anxiety (Aragona, 1983; Matthews, 1984; Robertson and Milner, 1985), depression (Gold, Milner, Gold, and Robertson 1985; Matthews, 1984; Robitaille, Jones, Gold, Robertson, and Milner, 1985) and family conflict (Chan and Perry, 1981; Lamphear, Stets, Whitaker, and Ross, 1985).
Other results support Hypothesis Two, that there is a correlation between child abuse potential and other factors. The results indicate that parents with high child abuse potential have low family functioning and a high level of psychological disorders, as well as less hope and happiness in their life. Furthermore, the results show that psychological disorders predict 55% of potential child abuse. The addition of low family functioning adds 12.8% to the prediction, and decreased happiness adds 3.7% to the prediction. These results suggest that if a parent(s) has a psychological disorder, low family functioning and less happiness, the parent has a greater potential for child abuse. In other words, these results suggest that the IFS programs participating in this research project do have a positive effect on the well being of parents and their children.

Importantly, the result also showed that child abuse potential, low family functioning and psychological disorders although not significant, continued to reduce between service completion (post-intervention) and 3 month follow-up (post intervention). Hope and happiness decreased marginally between completion and the three month follow-up but not significantly. This shows that the effects of treatment remained stable and were sustained. Parents did not regress back to their commencement scores prior to the IFS intervention. This result indicates that the positive effects of IFS program are not only temporary. Rather, the IFS program has a longer term effect on families, beyond the time frame of the program.

**Recommendation 1**: That the demonstrated effectiveness and sustainability of the IFS services participating in this research be recognised by ADHC\(^4\) by providing further funding for these IFS services.

### 6.2 An Overall Package

The important finding of the first ARC research was the effectiveness of the combination of program elements and therapeutic strategies and a striking theme emerging from the qualitative data collected from the workers and families in this research is once again, the confirmation of the importance of the unique combination of these elements with the therapeutic strategies in the provision of IFS services. The evidence for co-ordinated and comprehensive programs for families with a child with a disability is gradually increasing in the literature (King and Meyer 2005; Cowen, Perle and Reed 2002; and, Canary 2008). Furthermore, recent research is indicating the mode of program delivery may be associated with outcomes for families (Brown and Remine 2008). In particular, results from this study assert the importance of practice that promotes partnerships between workers and families, which also provide increased contact and individualised support.

Law, Hanna, King, Hurley, King, Kertoy and Rosenbaum (2003) argue for the allocation of a specific team and specialised workers to ensure that the integrity of a service model is maintained. The importance of this study is that it highlights the effectiveness of an intense family-centred service for a period of time thus avoiding a number of different service providers all trying to intervene in a time of family crisis.

\(^4\) The Report has referred to the acronym DADHC to this point as this was the Department’s name during the time of data collection. Maintaining the use of this acronym was intended to reduce confusion. Because the recommendations are prospective, the correct acronym – ADHC will be used in Section 6.
While recognising that all services need to evolve and change with the needs of the families and service system, results of the IFS research have supported the integrity and effectiveness of the IFS model of intervention and has replicated the results obtained in the original IFSO research project that looked at the program elements and interventions that kept families who have a child with a disability safely together.

**Recommendation 2:** That the distinctive nature of the IFS intervention is maintained as a service offering – it is not the same as a generic family support service and the effectiveness will be diluted unless the unique combination of program elements and therapeutic skills is maintained. It needs to be seen and offered as a specialist intervention.

To ensure families in crises continue to experience beneficial outcomes, any changes or modification to the IFS program elements and interventions need to be carefully assessed and evaluated so that the efficacy of the service model is not compromised. Future directions for IFS intervention will need to balance any changes to the service model with the research outcomes and in particular what families have said works for them. This is particularly the case for a selection of TSC workers who in some regions have been given, and have taken up, the opportunity to combine IFS work with other family support work. This has some benefit in terms of providing a wider scope of experience to workers, and may help with staff retention, but could make it more difficult over time to retain IFS program integrity.

### 6.3 The IFS Program Elements

The qualitative data and the literature consistently support the identified program elements of the IFS program. Section 6.3 will focus on specific program elements in order to make recommendations for development and change (where required). These recommendations are expected to enhance the IFS package as a whole.

#### 6.3.1 A Family Focus

Without exception, all families, workers and managers participating in the IFS project were convinced of the importance of intervening with the whole family and taking a family-focused approach. Families reported that frequently agencies and workers had previously provided services for, and to, the child with the disability only. Law, Hanna, King, Hurley, King, Kertoy and Rosenbaum (2003) suggest that parental satisfaction with services is strongly influenced by their experience of the service as family-centred rather than focussing on the child with the disability. Davis and Susana (2009) found similarly that as a whole, parental perceptions and experiences of family-centred professional support was one of the strongest predictors of family quality of life. Dellve, Samuelsson, Tallborn, Fasth & Hallberg’s (2006) study identified the importance of parents being decision makers for their child to avoid the pervasive lack of confidence that affects many families with a child with a disability. In the literature, the importance and effectiveness of a family focussed approach was clearly evident.
6.3.2 **Strengths-Based Approaches**

Both the IFSO and IFS programs have been fundamentally underpinned by the philosophical orientation focussing on a family’s strengths rather than problems or pathologies. In practice the strengths-based ‘lens’ is the difference between focussing on the family’s experience of stress rather than exploring how the family sustains an acceptable daily routine. The IFSO program documentation privileged the use of a particular strengths-based family therapy framework - Solution-Focused Brief Therapy - which sought to build on and enhance the strengths and abilities of family members. However, the worker focus groups and managerial interviews from all three organisations discussed the benefit of incorporating other therapeutic strategies (such as behaviour programs) within a generic strengths-based framework (supported by Singer, Ethridge and Aldana 2007). All workers and managers strongly emphasised that a generic strengths-based approach is **fundamental** to effective IFS service provision. Equally compelling is the data from families who experienced the strengths-based focus as empowering and markedly different from the usual approach of concentrating on their child’s disability and in the ways they are not managing or coping as parents.

Within the literature there is ample support for both the solution-focussed brief therapeutic intervention and strengths-based approaches more generally. Dunst, Johanson, Trivette, Hamby (1991) argue that it is crucial for intervention programs to enable and empower clients by enhancing and promoting individual and family capabilities that support and strengthen family functioning. Hastings and Taunt (2002) discuss the importance of a strengths focus and suggest that positive perceptions function to strengthen families capacities to adapt or cope with the experience of raising a child(ren) with a disability. Baldry, Bratel, Dunsire and Durrant (2005) provide evidence of the effectiveness of focusing on strengths as a core program element as well as therapeutic engagement and process.

6.3.3 **Intervening Early**

Early intervention is promoted throughout many welfare contexts as a more effective approach to service provision. When families experience a significant crisis, the timing and type of support provided can be critical in assisting families to work out what they need and what support or services are going to be most helpful to them. Early referral to IFS and the range of services and support offered by this program contributes to the prevention of crisis situations becoming entrenched. Whether families have a long term history of difficulties or are facing their first crisis, requiring them to have tried all other services or accessed all other resources before they can be referred to an IFS service compromises the original concept of early intervention.

Shifting the definition of early intervention back to ‘intervening early’ in a family’s crisis allows the IFS worker to commence work with the family at a time where there is the greatest opportunity for change. Moreover, rather than addressing a never-ending checklist of problems in the referral process the worker can better address issues raised by the family and have more scope to refer families to appropriate follow-up services at the completion of intervention (Dellve, Samuelsson, Tallborn, Fasth & Hallberg 2006; Bailey, McWilliam, Darke, Hebbeler, Simeonsson, Spiker and Wagner 1998). The concept of ‘intervening early’ is also more compatible with the strengths-based approach that is so fundamental to IFS interventions.
Recommendation 3: The key concept of early intervention needs to be re-considered in light of the referral requirement that families need to have experienced all other services before referral.

6.3.4 An Intensive Service

The idea of what constitutes an intensive service has shifted slightly from the operational understanding of the original IFSO service. This shift has occurred in part by necessity as ADHC (then DADHC) increased the number of families to be seen per worker from 2 to a minimum of 3 families at a time - documented in the Service Agreements with the new IFS services. The support for an intensive service for families in crisis where there is a child with a disability is clearly evident in the literature (Bailey, McWilliam, Darakes, Hebbeler, Simeonsson, Spiker and Wagner 1998; and, Hudson, Matthews, Gavidia-Payne, Cameron, Meldon, Radler, Nankervis 2003).

Moreover the helpfulness of an intensive approach was confirmed by the qualitative data in this research. Families at high risk or under high stress were shown to benefit due to the capacity of the program to deliver an intensive service. Although there may be times where a worker has 3 families (eg maybe starting with a third family when another is winding up), the usual pattern should be 2 families at a time. This can be worked out at a local level with supervisors/managers, but program integrity means that target numbers should lean towards less rather than more clients.

Recommendation 4: That ADHC confirm their commitment to funding an intensive service and set the number of families to be seen per worker at any one time accordingly.

Recommendation 5: Organisations and IFS services need to consider how to set the target number of families to be seen per worker in services that require travel over longer distances. Consideration should be given to an extra allocation of resources for time-in-lieu and other support strategies for workers and families in rural areas.

6.3.5 Brokerage and Practical Assistance

A second tier of the IFSO model used a component of the grant to broker less intensive services and practical support so that the families could maintain an acceptable level of functioning. ‘Brokerage’ was one of the program elements recognised as being integral to the positive outcomes found in the IFSO research and was highly regarded by families (Baldry et. al. 2005). There is ample evidence of the importance of brokerage in the literature. Owen, Frederico, Copper, Gordon & Jones (2001) detail the importance of financial assistance when dealing with the cost of equipment, home modification, transport and away-from home accommodation for assisting child with disability. Smith, Oliver & Innocenti (2001) suggest that factors such as income and financial stress, and support predict parenting stress much better than do aspects of child functioning.
Workers and managers indicated that they had attempted to clarify guidelines internally, particularly between regions and the different IFS services. Given the demonstrated importance of financial assistance to families so that they can broker less intensive services and practical support to improve their family functioning, the guidelines and administration of FAF requires further attention.

**Recommendation 6:** That ADHC evaluate the application process to access FAF and consider the appropriateness of the guidelines for use of FAF.

### 6.4 Therapeutic Strategies and Skills

One of the most consistent and strongly evidenced themes emerging in the analysis of the client/family interview data was the strength of the families’ relationship with their IFS worker. Almost all families who participated in the research had experienced intervention with other workers and agencies. Many of these families spoke of negative experiences, or feeling that they had been misunderstood and/or the intervention had not been successful. Occasionally families believed that a particular past intervention had actually increased their stress and the problems within the family.

In this research the Working Alliance Scale (Horvath, 1981; Horvath & Greenberg, 1986, 1989) was completed by workers and clients at the completion of the service and clients again at the three month follow-up. At completion both workers and client participants scored the relationship and indicated a high level of therapeutic engagement and trust. However, the strength of the relationship between client and worker lessened between completion and follow-up. One possible explanation for this is that if the intervention has been successful families move on to ‘get on with their lives’ and their prior relationship with the worker diminishes somewhat in day to day importance. Certainly the qualitative data demonstrate the strength of the therapeutic relationship in the IFS services, with families almost universally speaking in very positive terms about the relationship with their worker at completion and follow-up.

The particular program elements of IFS service provision facilitates therapeutic engagement and the mix of therapeutic strategies used in the IFS intervention appear, in most cases, to maximise client satisfaction with the therapeutic process. Dyke, Buttigieg, Blackmore and Ghose (2005) noted the importance of respectful and supportive intervention in their study and the potentially positive outcome of strengths-based partnerships. Other research (such as Canary 2008 and Dempsey and Keen 2008) highlights the importance of the therapeutic relationship as a key component underpinning the skilled provision of supportive interventions with families with a child with a disability.

**Recommendation 7:** High level specialist family therapy/intervention skills need to be maintained in terms of workforce recruitment and ongoing professional development. To maintain the high standard of professional services it is essential that the IFS workers have available to them regular and ongoing clinical supervision and mentoring by qualified and experience practitioners.
Identifying and recognizing the potential risks involved for IFS workers and the demands of an intensive service, are all part of an organisation’s duty of care to their staff. As a home based service workers potentially deal with violent situations including care and protection, domestic violence and mental health issues. Workers and managers were all cognizant of the risks involved in IFS intervention and reported the successful use of organisational strategies and supports to manage this risk. It is important for IFS services to highlight the ongoing importance of risk management in IFS service provision.

**Recommendation 8:** IFS workers need high level access to teams/supervisors to maintain quality of service and to manage OH&S issues in home visits at varied hours.

### 6.5 The Referral Panel

The referral process and the operation of the [now] ADHC Information and Referral Panels (IRI) were areas where all focus groups and managers expressed a significant degree of dissatisfaction. During the course of the research, it appears as if the actual front-line practices developed within the panels have gradually over-ridden the written guidelines. In addition, the professional practice and good will of staff from the participating organisations and DADHC attending the panels have ensured the optimal operation of the IRI process. Nonetheless there remains considerable dissatisfaction about the IRI process generally and concerns remain about the time required to attend meetings, and the effect of the process on the relationship between the referrer and the service. The referral process reported by the original IFSO service appeared to function well and allowed for IFS services to better directly promote their service to local referrers.

**Recommendation 9:** That ADHC abolish the IRI Panel process for referral and allocation of families to IFS services and allow the IFS services to manage the referral process directly.

**Recommendation 10:** That ADHC develop, in consultation with organisations providing IFS services, universal guidelines for use in each region, defining and describing ‘eligibility’, ‘priority’ and ‘capacity’ and the use of wait lists to ensure consistency in the referral process.

### 6.6 Service Exit

Workers and managers alike reported that a strict 12 week service does not suit all families with complex needs. In particular Indigenous families and those with a carer with an intellectual/developmental disability all reported that a longer service would be helpful. Workers believed that a longer service would be of benefit for these particular families as they are also the hardest to refer on post IFS intervention. The literature supports the practice wisdom that longer and/or more flexible services can better suit the way in which a worker needs to engage and work with families with complex needs (Bailey, McWilliam, Darkes, Hebbeler, Simeonsson, Spiker and Wagner 1998; and, Hudson, Matthews, Gavidia-Payne, Cameron, Mildon, Radler, Nankervis 2003).
**Recommendation 11:** That ADHC consider funding IFS services to see Indigenous and families with a carer with an intellectual disability for a slightly longer time period, acknowledging their different and complex needs.

The implications of knowing how to ‘use help better’, as emerged in the qualitative data, is profound and certainly opens up opportunities for referral at the end of the service. This acquired skill affects the number and the intensity of follow up services needed by the family (if any). It is more that the IFS intervention has helped a substantial number of participant families develop skills to better cope with crises and has modelled an effective way for the family to work with services in the future so they know how best to utilise resources and other opportunities. Some participants however, felt that the program was too short and suggested a longer phase out period rather than a definite termination at 3 months. The idea of a ‘step-down’ service was also mentioned by workers as potentially benefiting a small number of families and assisting them to maintain the changes made in the IFS program upon exit from the service.

**Recommendation 12:** That IFS services provide a less intense service - ‘a step-down’ service for 4-6 weeks post intervention for a small selection of families (as identified in the qualitative component of this research). Rather than carrying a caseload of three families, workers could provide weekly support via telephone calls or brief visits for a further period of 4-6 weeks.

### 6.7 TSC and UnitingCare Burnside Partnership

Both TSC and UnitingCare Burnside maintain positive and constructive working relationships at an organisational level. The joint IFS service offered by TSC in Prairiewood has a partnership (formalised by a Memorandum of Agreement) with UnitingCare Burnside which makes it a unique service. These services however, were established in separate locations; operate independently and there were no obvious indications of collaboration. Furthermore tensions were apparent between the Burnside and TSC workers which seem to be substantially influenced by a different use of language attached to different concepts of ‘professionalism’. After discussions with managers and the analysis of the qualitative data from the worker focus groups, the research team believes that each of the services provides quality intensive, strengths-based interventions that are more alike in practice than dissimilar. Arguably some of the tension experienced both within and between services and agencies has been the result of definitional and professional meanings and understandings attached to different terminology.

**Recommendation 13:** That UnitingCare Burnside and TSC commence a joint strategic planning process to develop operational guidelines informing how the joint service may best collaborate.

**Recommendation 14:** That the joint IFS services consider their use of language - some of the confusion and tension experienced both within and between services and agencies has been the result of the definition and understandings attached to different terminology. Consistency in the definition, understanding and use of terminology would build a better understanding and working relationship both within and between services and agencies.
6.8 Further Research

Research on the outcomes of both the IFSO and IFS services has provided evidence of the effectiveness of the ways in which the unique combination of program elements and therapeutic strategies increase the confidence and competence of families in managing their particular situations and contribute to maintaining child safety within the family. The research team proposes that ADHC and the participating organisations continue to develop a research agenda examining the effectiveness of IFS services generally. In particular the research team would suggest the following projects have merit:

**Recommendation 15:** That ADHC fund research to follow-up IFS families over a longer period of time to better establish the sustainability of the IFS intervention.

**Recommendation 16:** That ADHC fund research designed to follow-up those families who are referred and eligible, but not allocated to an IFS service. This research would provide data on the outcomes for families who do not receive an IFS intervention and provide information about coping strategies and other support received instead.


The original research protocol was developed between TSC and UNSW. This same protocol was used after Northcott Disability Service and UnitingCare Burnside joined the research consortium.

**Research Protocol**

<table>
<thead>
<tr>
<th><strong>The Spastic Centre and University of NSW Evaluation - Recruitment Protocol</strong></th>
<th><strong>Responsibility</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introduction to Research/Evaluation</strong></td>
<td>Family Therapist</td>
</tr>
<tr>
<td>1. When a new referral is accepted alert the UNSW Research Officer of this fact either by phone or email.</td>
<td>Family Therapist</td>
</tr>
<tr>
<td>2. As soon as possible (either during the first phone call or meeting with the family), introduce the research project to the family; explaining what it involves (using attached information sheet). This may be done via the referrer if more appropriate.</td>
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</tbody>
</table>

| **Obtaining Verbal Consent with the Family** | |
| --- | |
| 1. Once the research proposal has been explained to the family ask them for **verbal consent** for the following information to be passed onto the researcher from UNSW **within one working day**, either by phone or email. Please include: | Family Therapist |
| - Families name phone number(s) and address |
| - Day and time of day that is most convenient to be called |
| - Need for an interpreter and |
| - Any safety or OHS concerns noted on the referral or known to the family therapist. | Family Therapist |
| 2. If the family does not consent let the researcher know within **one working day**. | Family Therapist |
| 3. Once the researcher has this information they will contact the family **within two working days** and make the appointment | Researcher |
| 4. The Family therapist will be notified within **one working day** by email re: the time and date for the ‘Family interview by UNSW | |

| **Difficulties arranging Contact** | |
| --- | |
| 1. If the researcher is unable to make contact within two working days they will contact the therapist who is working with the family to discuss alternative contact arrangements. | Researcher |
| 2. If there are **ongoing difficulties** in making contact with the family the researcher will contact a member of the reference team and together with the Family therapist discuss the situation and possible alternatives. | Researcher/Reference team/Family therapist |
## End of IFSO Involvement

1. **Approximately two (2) weeks** before the anticipated end of IFSO involvement with a Family the researcher is to be alerted by the Family Therapist:
   - That the IFSO involvement is coming to an end and
   - To discuss an appropriate time for the researcher to contact the family to arrange the end of intervention interview.
   - The Family therapist will be notified by email re: the time and date for the ‘Family interview by UNSW’.
   - Researcher contact therapist to see if there has been any contact or current issues e.g., OH&S or change of address.
   - Researcher has clinical consultants (Joan / Don) to call her to check if she is OK during a visit if there are any “risk issues” anticipated.
   - To arrange an appropriate time for the family therapist to complete the therapist/client alliance survey either recorded over the phone or in person with either Joan or Don.

<table>
<thead>
<tr>
<th>Family Therapist</th>
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<tr>
<td>Therapist/Researcher</td>
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<td>Don or Joan</td>
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</tbody>
</table>
APPENDIX TWO

The original Participant Information Sheet was initially developed between TSC and UNSW. This same Information Sheet (differently badged) was appropriately modified for Northcott Disability Service. UnitingCare Burnside’s Participation Sheet is also included.

Participant Information Sheet

INFORMATION AND CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Evaluation of the Intensive Family Support Options Program

Participant details:

Last name: 

First name: 

Date of birth: Age: Gender: 

Address: 

Participation in this evaluation is voluntary.

If you do not wish to participate or wish to withdraw from this study at any time this will not result in any negative impact on your service provision.

Details of This Research Study

The reason for doing this study is to see how well the Intensive Family Support Options program (IFSO) works and where the program can be improved. In doing so we want to find out how helpful the IFSO program has been for your family, and your experience of the services provided to your family.

The study will be conducted by your family therapist and involves filling out the same survey three times, when you begin with IFS and then when you finish with the IFS program. Then again at 3 months after you have finished with the program. The study also involves you answering some questions asked by the family therapist you worked with, each time you complete the survey. These questions are generally about how helpful you think the IFS program has been for your family. As part of the study a Family Therapist from IFS may also look at your service file.

Signed

Date:
The results of this study may not be of direct benefit to your family however we hope that the results of this study will be used to improve IFS service delivery. The results of the study will also be given to the Department of Disability Ageing and Home Care (DADHC). Additionally, they may also be published in academic journals, in any publication, information will be provided in such a way that you cannot be identified.

There are no expected adverse effects or risks related with participation in this study.

Should you have an issue in regard to your participation in this study please contact:

Joan Bratel  
Senior Consultant Service Development and Communications  
The Spastic Centre  
Email: jbratel@tscnsw.org.au  
0417 227 043

Signed:

Date:

This research study has been approved by The Spastic Centre’s Research Committee and The Spastic Centre’s Ethics Committee and will be carried out in a manner conforming to the principles set out by the National Health and Medical Research Council.
IFS Evaluation - Family Information Sheet

You are invited to be part of a research project being conducted by the University of New South Wales with the support of UnitingCare Burnside and the Spastic Centre NSW.

The researchers from the University will look at how well the Intensive Family Support Options (IFS) program works and where the program can be improved. To answer these questions we want to find out how helpful the IFS program has been for your family, and your experience of the therapy and services provided.

If you choose to be part of the project, we will ask you to participate in two tasks:

1. When you commence the IFS program, Sarit Huppert (one of the researchers from the University) will gather some basic information about your family and help you to complete a number of questionnaires. This will take about an hour and can be organised at the Centre at a time which is convenient for you. The questionnaires are designed to find out how you are feeling and how you are coping with the many tasks and situations you confront each day. The aim of the surveys is not to judge your parenting skills but to better understand the support you need. When you complete the program, Sarit will help you fill in the same questionnaires so we can see whether being part of the IFSO program has made a difference.

2. At the completion of the program and 3 months after you have finished the program, Sarit would like to interview you about your experience of the IFS program in order to find out what bits were helpful and what we might do better. Each of the two interviews will take about 30 minutes. None of the questions you are asked are meant to pry into things that are too private and you don’t want to talk about. It is fine for you to say if you do not want to answer a question.

At the end of the project the researchers will write a report for UnitingCare Burnside which will outline the views of parents and staff members, and help us to understand how we can improve the IFS program. We will provide you with the copy of the research report.

It is completely up to you whether you do or do not want to be part of the research. If you don’t want to participate it won’t make any difference to the services your family is receiving. Burnside staff will not be told whether or not you are part of the research.

Anything you say to the researcher and every questionnaire will be kept in the strictest confidence. Your name will be taken off the forms, and they will be locked in a filing cabinet at the University of New South Wales. The researcher will not tell anybody else anything you said. If we want to write about some of your experiences, we will make up a pretend name for you so that no-one knows we are talking about your experiences.

If it is okay with you, your interview with the researcher will be tape recorded. The only reason we want to tape record what you say is so that the researcher can remember everything later on and transcribe your interview. We do not have to record the interview if you are uncomfortable with this. You can still be part of the research and the researcher will interview you without taping.
You can withdraw from the research project at any time without giving a reason. Just let Sarit know and the research team will not contact you again. Stopping your participation will not make any difference to the services you are using at Burnside. They will go on as normal.

If you have any questions about the research, please call Sarit Huppert (Researcher) on 0400 490 058 or Dr. Jan Breckenridge (Research Manager) on 9385 1863.

If you would like to participate in this research, please complete the slip below and place it in the locked box at the Centre where you are completing the IFSO program. Sarit will collect the slip and she will contact you soon.

The ethical aspects of this study have been approved by the University of New South Wales Ethics Committee and the UnitingCare NSW.ACT Research Advisory Group. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Manager Strategic Projects, UnitingCare Burnside on (02) 9407 3228. Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

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FAMILY PARTICIPTION
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Name: ________________________________

I am happy to be contacted by Sarit Huppert from the University of New South Wales to discuss participation in the research.

Phone Number: ________________________________

Best time for Sarit to call: ________________________________
IFS Evaluation - Family Consent Form

Researcher Copy

I _____________________________ (name) agree to participate in the Evaluation of the Intensive Family Support Options (IFS) Program which I am attending at UnitingCare Burnside. The research evaluation is being conducted by the researchers from the University of New South Wales.

I know that I will be asked to participate in an interview, and to complete some questionnaires. My responses in the interview and on the questionnaires will be kept confidential.

I freely choose to participate in the project and know that I can withdraw from the project at any time without giving a reason. I understand that the support I am receiving now will not change because I take part in the project or not.

I am aware that I can contact Sarit Huppert (the researcher from the University) on 0400 490 058; Dr. Jan Breckenridge (Research Manager) on 9385 1863; or Sally Cowling (UnitingCare Burnside) on 9407 3228 if I have any questions, concerns or complaints about the project.

Parent signature: ________________________________ Date: ______________

Witness signature: ______________________________ Date: ______________

* The UnitingCare NSW.ACT Research Advisory Group has reviewed this study. If you have any complaints or reservations about any aspect of your participation in the research project you can contact the Research Advisory Group through the Manager Strategic Projects, UnitingCare Burnside on (02) 9407 3228. Any complaint you make will be treated in confidence and investigated fully.
IFS Evaluation - Family Consent Form

Family Copy

I _____________________________ (name) agree to participate in the Evaluation of the Intensive Family Support Options (IFS) Program which I am attending at UnitingCare Burnside. The research evaluation is being conducted by the researchers from the University of New South Wales.

I know that I will be asked to participate in an interview, and to complete some questionnaires. My responses in the interview and on the questionnaires will be kept confidential.

I freely choose to participate in the project and know that I can withdraw from the project at any time without giving a reason. I understand that the support I am receiving now will not change because I take part in the project or not.

I am aware that I can contact Sarit Huppert (the researcher from the University) on 0400 490 058; Dr. Jan Breckenridge (Research Manager) on 9385 1863; or Sally Cowling (UnitingCare Burnside) on 9407 3228 if I have any questions, concerns or complaints about the project.

* The UnitingCare NSW.ACT Research Advisory Group has reviewed this study. If you have any complaints or reservations about any aspect of your participation in the research project you can contact the Research Advisory Group through the Manager Strategic Projects, UnitingCare Burnside on (02) 9407 3228. Any complaint you make will be treated in confidence and investigated fully.
IFS Evaluation - Staff Information Sheet

You are invited to be part of a research evaluation project being conducted by the University of New South Wales with the support of UnitingCare Burnside and The Spastic Centre NSW.

The evaluation seeks to determine whether the families referred to an Intensive Family Support Options (IFS) program experience an increase in confidence and competence in managing their particular situations as a result of involvement in that IFSO program and if the IFS program significantly contributes to maintaining child safety within the family. The evaluation will:

- Investigate the efficacy of IFS Programs for different client groups including CALD families;
- Explore, measure and analyse the effectiveness of the range of support options offered to project participants during their participation in the IFS Program; and
- Identify areas of need in relation to the improvement of service delivery to assist Burnside to maximise the quality of service delivery offered to IFS clients.

If you choose to be part of the project, we will ask you to participate in two tasks:

1. Sarit Huppert (one of the researchers from the University) will conduct a focus group with therapists working in the Burnside IFS program to explore your views on the effectiveness of the referral process and exit planning; the effectiveness of different components of the program, and the interface of child protection and disability issues when working with IFS families. The focus group will be organised at the Centre at a time convenient for staff and will take approximately one hour.

2. Sarit would also like to conduct a telephone interview with you when families participating in the evaluation complete their program to explore how you feel they have experienced different elements of the program and to ascertain their helpfulness.

At the end of the project the researchers will write a report for UnitingCare Burnside which will outline the views of parents and staff members, and help us to understand how we can improve the IFS program. We will provide you with the copy of the research report.

It is completely up to you whether you do or do not want to be part of the research. Burnside management will not be informed of your decision and it will have no impact on your professional standing or support you receive as a Burnside employee.

Anything you say to the researcher will be kept in the strictest confidence and if your views are reported or quoted in the final report we will use pseudonyms. We will seek your participation to make an audio recording of the focus group and telephone interviews. Interviews will be transcribed under a participant number and the tapes will be destroyed once the transcription is complete. We do not have to record the interview if you are uncomfortable with this. You can still be part of the research and the researcher will interview you without taping.

You can withdraw from the research project at any time without giving a reason.
If you have any questions about the research, please call Sarit Huppert (Researcher) on 0400 490 058 or Dr. Jan Breckenridge (Research Manager) on 9385 1863.

If you would like to participate in this research, please complete the slip below and place it in the locked box at your Centre. Sarit will collect the slip and she will contact you soon.

The ethical aspects of this study have been approved by the University of New South Wales Ethics Committee and the UnitingCare NSW.ACT Research Advisory Group. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Manager Strategic Projects, UnitingCare Burnside on (02) 9407 3228. Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

-------------------------------------------

STAFF PARTICIPATION

Name: ________________________________

I am happy to be contacted by Sarit Huppert from the University of New South Wales to discuss participation in the research.

Phone Number: __________________________

Best time for Sarit to call: ___________________
IFS Evaluation - Staff Consent Form

Researcher Copy

I _____________________________ (name) agree to participate in the Evaluation of the Intensive Family Support Options (IFS) Program on which I am a staff member. The research evaluation is being conducted by the researchers from the University of New South Wales.

I know that I will be asked to participate in a focus group and telephone interview. My responses in the focus group and the interview will be kept confidential.

I freely choose to participate in the project and know that I can withdraw from the project at any time without giving a reason. I understand that my professional standing and support within UnitingCare Burnside will not be influenced by my decision to, or not to, participate in the evaluation.

I am aware that I can contact Sarit Huppet (the researcher from the University) on 0400 490 058; Dr. Jan Breckenridge (Research Manager) on 9385 1863; or Sally Cowling (UnitingCare Burnside) on 9407 3228 if I have any questions, concerns or complaints about the project. *

Staff signature: ______________________________ Date: ______________

Witness signature: ______________________________ Date: ______________

* The UnitingCare NSW.ACT Research Advisory Group has reviewed this study. If you have any complaints or reservations about any aspect of your participation in the research project you can contact the Research Advisory Group through the Manager Strategic Projects, UnitingCare Burnside on (02) 9407 3228. Any complaint you make will be treated in confidence and investigated fully.
IFS Evaluation - Staff Consent Form

Staff Copy

I _____________________________ (name) agree to participate in the Evaluation of the Intensive Family Support Options (IFS) Program on which I am a staff member. The research evaluation is being conducted by the researchers from the University of New South Wales.

I know that I will be asked to participate in a focus group and telephone interview. My responses in the focus group and the interview will be kept confidential.

I freely choose to participate in the project and know that I can withdraw from the project at any time without giving a reason. I understand that my professional standing and support within UnitingCare Burnside will not be influenced by my decision to, or not to, participate in the evaluation.

I am aware that I can contact Sarit Huppert (the researcher from the University) on 0400 490 058; Dr. Jan Breckenridge (Research Manager) on 9385 1863; or Sally Cowling (UnitingCare Burnside) on 9407 3228 if I have any questions, concerns or complaints about the project.

Staff signature: ____________________________ Date: ______________

Witness signature: ____________________________ Date: ______________

* The UnitingCare NSW.ACT Research Advisory Group has reviewed this study. If you have any complaints or reservations about any aspect of your participation in the research project you can contact the Research Advisory Group through the Manager Strategic Projects, UnitingCare Burnside on (02) 9407 3228. Any complaint you make will be treated in confidence and investigated fully.
APPENDIX THREE
Scales and Measures

The Child Abuse Potential (CAP) Inventory (Form VI) (Milner, 1986) is a 160 item self-report questionnaire designed to assist in screening male and female parents or primary caregivers who are suspected of physical child abuse. In the current study the primary clinical scale has been used. The primary scale is the 77-item physical child abuse scale. Scores on the physical abuse scale are computed as a weighted sum of 77 items, with scores ranging from 0 to 486. The CAP Physical Abuse scale is comprised of seven factors scales: distress, rigidity, child with Problems, Problems from family and others, unhappiness, loneliness, and negative concept of child and self (Milner and Wimberley, 1980).

Higher scores on the CAP reflect higher child physical abuse potential. Respondents with scores above 166 and 215 are considered to at medium- and high-risk for CPA, respectively. The 77-item CAP abuse scale has the highest internal consistency reliabilities (i.e., .92-.96 for controls and .95-.98 for abusers). In this study the Cronbach Alpha shows .90. Numerous studies report constructs validity data for the CAP abuse scale (Milner, 1986, 1994, 2003). Prospective research has revealed a significant association between CAP Inventory abuse scores and subsequent physical child abuse (Milner, Gold, Ayoub, & Jacewitz, 1984).

Cronbach Alpha of the CAP Inventory

<table>
<thead>
<tr>
<th>Number of items</th>
<th>Mean</th>
<th>SD</th>
<th>Cronbach Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAP total</td>
<td>76</td>
<td>100.64</td>
<td>219.06</td>
</tr>
</tbody>
</table>

The McMaster Family Assessment Device (FAD) is a short, self-report measure of family functioning that describes emotional relationships and functioning within the family. The FAD is made up of seven scales. In the current study the general functioning subscale which assesses the overall health/pathology of the family, has been used. Each family member rates his or her agreement or disagreement with how well an item describes their families by selecting among the four alternative responses: strongly agree, agree, disagree, and strongly disagree. The general functioning scales coefficient alpha reliabilities is .92. The FAD has been validated with a number of clinical populations including a low-functioning population receiving in-home family therapy (Clark, Barrett, & Kolvin, 2000; Pfender, Sharrow, Slattery, & Bean, 1997). Kabacoff, Miller, Bishop, Epstein, and Keltner (1990) have assessed outcomes with a single administration of the FAD at termination from therapy.

Cronbach Alpha of the FAD

<table>
<thead>
<tr>
<th>Number of items</th>
<th>Mean</th>
<th>SD</th>
<th>Cronbach Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>General family</td>
<td>12</td>
<td>27.46</td>
<td>6.27</td>
</tr>
<tr>
<td>functioning</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The Outcome Questionnaire (OQ-45; Lambert, et al., 1998) is a 45-item self-report questionnaire which provides comparable scores of the client level of psychological disorders: symptomatic distress, social and interpersonal functioning and assesses the potential need for treatment and tracks the progress of clients in therapy on a session-by-session basis (Lambert, Hansen, et al., 1996). Typically, OQ-45 total scores, used to assess general psychological functioning, are based on composite scores from the three content domains. Possible total scores are based on a continuum, with non clinical (normal) at the low end and clinical (disturbed) at the high end. Previous criteria (Lambert, Hansen, et al., 1996) estimated an OQ-45 total score of 64 points as the cut off. This cut off score suggests that individuals who score 64 points or above are scoring similarly to clients treated in therapy, whereas scores of 63 and below are more indicative of untreated individuals. Previous studies have indicated that the OQ-45 is reliable, with internal consistency in the low .90s and test-retest coefficients in the low .80s (Lambert, Burlingame, et al., 1996). Prior studies have reported significant differences between scores for non clinical versus clinical populations. Test-retest reliability studies, which have compared initial with subsequent OQ-45 total scores, have shown that scores are relatively stable in untreated individuals, whereas scores of clients undergoing psychotherapy have shown significant change-sensitive effects (Vermeersch, Lambert, & Burlingame, 2000). Concurrent validity was estimated by correlating the OQ-45 total score with corresponding total scores on the symptom Checklist 90-Revised (SCL-90-R; Derogatis, 1983), Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), Zung self-Rating Depression Scale (ZSRDS; Zung, 1965), Taylor Manifest Anxiety Scale (TMA; Taylor, 1953), State-Trait Anxiety Inventory (STAI; Spielberger, 1983, Spielberger, Gorsuch, & Lushene, 1970), Inventory of Interpersonal Problems (IIP; Horowitz et al., 1988), and the Social Adjustment Scale (SAS; Weissman & Bothwell, 1976).

Cronbach Alpha of the Outcome Questionnaire

<table>
<thead>
<tr>
<th>Number of items</th>
<th>Mean</th>
<th>SD</th>
<th>Cronbach Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outcome Questionnaire (psychological disorders)</td>
<td>44</td>
<td>76.88</td>
<td>.81</td>
</tr>
</tbody>
</table>

The State Hope Scale (SHS; Snyder et al, 1996) is a six item self-report scale that was developed to assess goal-directed thinking in a given moment. Responders are asked to ranked items based on how they think about themselves right now using an eight-point Likert scale from 1 (definitely false) to 8 (definitely true). The total state hope scores can range from 6 to 48. The internal reliability of the total SHS was excellent in Synder's study (Snyder et al, 1996), with Cronbach alpha ranging from .82 to .95. For the Agency subscale the Cronbach alpha ranged from .83 to .95, and for the Pathways subscale the Cronbach Alphas ranged from .74 to .93 (Feldman and Synder, 2000). The convergent validity was for the SHS was supported by the finding that its scores correlated positively with scores on the trait Hope scale and significantly and positively with scores on the State Self Esteem Scale (Heatherton, & Polivy, 1991). In addition, as expected Synder et al. (1996) found that scores on the SHS correlated significantly and positively with state positive affect scores and significantly and negatively with negative affect scores.
Cronbach Alpha of the State Hope Scale

<table>
<thead>
<tr>
<th></th>
<th>Number of items</th>
<th>Mean</th>
<th>SD</th>
<th>Cronbach Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hope Scale</td>
<td>6</td>
<td>29.29</td>
<td>9.80</td>
<td>.84</td>
</tr>
</tbody>
</table>

The Happiness Measure (HM; Fordyce, 1988) consists of two, self-reporting items measuring emotional well-being: The first one is an 11-point happiness/unhappiness scale. Respondents are asked to report their average level of happiness on an 11-point scale (0 – Extremely unhappy (utterly depressed, completely down), to 10 – Extremely happy (feeling ecstatic, joyous, fantastic!)). The second item is a question asking for the time spent in “happy”, “unhappy” and “natural” moods. The primary criterion for happiness is the combination score that is calculated through the following formula: \([\text{scale score} \times 10 + \text{happy }\%]/2\). Kammann, Farry, and Herbison (1981) used the HM to produce a "net-time happiness score" (subtracting the unhappy % estimate from the happy % estimate). In the current study the "net-time happiness score" has been used. The HM combines both the frequency and the intensity of happiness. Fordyce (1988) reported test-retest reliability coefficients between .98 and .81 for up to 1 month and .62 for 4 months. Correlations between the HM and other related personality inventories are significant in the expected directions. The HM has demonstrated a strong and consistent convergence with a wide array of recognized happiness, well-being, and emotion instruments (Fordyce, 1988). The HM has been validated with a number of happiness, well-being, and emotion instruments (Fordyce, 1972, 1973a, b, 1977, 1983, 1986, 1987).

Cronbach Alpha of the Happiness Measure

<table>
<thead>
<tr>
<th></th>
<th>Number of items</th>
<th>Mean</th>
<th>SD</th>
<th>Cronbach Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Happiness Scale</td>
<td></td>
<td></td>
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<td></td>
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</tbody>
</table>

The Working Alliance Inventory (WAI; Horvath & Greenberg 1989) is a 36-item self-report measure (Horvath, 1981; Horvath & Greenberg, 1986, 1989). It has three subscales: Goals, Tasks, and Bond. The Goals subscale measures the extent to which a client and therapist agree on the goals (outcomes) that are the target of the intervention (Horvath & Greenberg, 1989). The Tasks subscale measures the extent to which a client and therapist agree on the counselling behaviours and cognitions that form the substance of the counselling process (Horvath & Greenberg, 1989). The Bond subscale measures the extent to which a client and therapist possess mutual trust, acceptance, and confidence (Horvath & Greenberg, 1989). Each WAI subscale is scored on a 7-point Likert type scale ranging from 1 (never) to 7 (always) and has 12 non-overlapping items. Subscale scores can range from 12 to 84 and can, if desired, be summed to obtain a total score. Thus, total scores can range from 36 to 252. Higher scores reflect more positive ratings of WA. Three versions of the WAI are available: a client version, a therapist version, and an observer version. Internal consistency estimates of alpha were .93 for the overall client score (with subscale alphas of .85 to .88) and .87 for the overall therapist score (with subscale alphas of .68 to .87) (Horvath & Greenberg, 1986, 1989). Validity has been established through significant correlations between WAI ratings and counselling outcome (Horvath & Greenberg, 1986), client characteristics (Kokotovic & Tracey, 1990), and therapist technical activity (Kivlighan, 1990).
Cronbach Alpha of the Working Alliance Inventory

<table>
<thead>
<tr>
<th>Number of items</th>
<th>Mean</th>
<th>SD</th>
<th>Cronbach Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working Alliance Scale</td>
<td>36</td>
<td>202.76</td>
<td>27.99</td>
</tr>
</tbody>
</table>