Report to

**Department of Human Services
Barwon-South Western Region
Victoria**

Working Together to Meet the Complex Needs of Young People with an Intellectual Disability and Challenging Behaviour

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Mr Neil Caldecott
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Dear Mr Caldecott

Re: *Working Together* Research - Final Report

We are pleased to submit this final report, which presents the findings of the *Working Together* research project undertaken in the Barwon-South Western Region during 2000-2001. The stud was jointly funded by the Department of Human Services and the Institute of Disability Studies at Deakin University and Claire Stewart was employed as a research fellow.

While two presentations that addressed emerging findings were made at conferences during 2001 and 2002, this report completes the final analysis of the study.

You may be aware that the *Working Together* study underpins a current research project funded by the Australian Research Council with the support of industry partners - the Department of Human Services and the Department of Education, Employment and Training (Barwon-South Western Region). The current study, undertaken as doctoral research by Judy O'Sullivan within a wider research team, investigates the *Resilience and at-risk factors influencing behaviour in urban and rural adolescents with intellectual disabilities,* and is due for completion in late 2004.

We hope that this report will inform the ongoing management of support and services for young people with an intellectual disability and their families, and contribute ideas for increased collaboration among all parties.

Yours sincerely

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For the research team

Acknowledgments

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1. Executive Summary

1.1 Challenging behaviour defined

The term "challenging behaviour" describes problem behaviours sometimes presented by people with an intellectual disability and others. It includes aggressive, destructive, antisocial and self-injurious behaviour. Challenging behaviour has a significant impact on the quality of life of the individual who displays it and of those who care for and support the individual. Such behaviour also poses considerable challenges to services for people with an intellectual disability.

1.2 Nature of the project

The Department of Human Services, Barwon South-West initiated a project in 2000 in which agencies received and administered extra funding for a year to provide Intensive Behaviour Intervention Supports (IBIS) for four boys with an intellectual disability who displayed challenging behaviour and their families. In conjunction with the Department of Human Services, a research team from Deakin University undertook an evaluation of the project. The study examined the history of service provision, services and supports provided during the funded intervention period and outcomes at the conclusion of the year. Particular attention was paid to investigating parent-professional and interagency collaboration. A summary of the major findings follows.

1.3 Service responses prior to the IBIS project

Parents reported numerous attempts to get assistance to manage their sons' problem behaviours in both home and school settings prior to the IBIS project. While on occasion some help was received, the most common picture was one of not receiving timely assistance, long periods on waiting lists and uncoordinated, fragmented and unhelpful responses resulting in considerable frustration for families as their sons' problem behaviours worsened.

1.3.1 Barriers to effective family-agency collaboration included:

- having to be in a crisis to get help

- discontinuity in services – because efforts focused on urgent, crisis cases, little if anytime was allocated to follow up and to check in on how things were going; staff turnover also contributed to the discontinuity

- communication difficulties between parties – poor communication between services and families, parents experiencing difficulty communicating across different service systems (human services and education), lack of shared understanding and vision between families and service providers

1.3.2 Additional barriers to effective interagency collaboration

- Lack of resources to call on
- Difficulty in accessing support services in rural areas
- Lack of organisational support for staff
- Requests for assistance from other agencies were either not acted on or referrals were placed on long waiting lists
- Lack of trusting relationships with other professionals or agencies

1.4 Service responses during funded IBIS intervention period

A range of services and supports were purchased for the four families from the extra funding available. These included extra respite care worker time, support worker for

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school, psychologist assessments and counselling, additional case management hours, recreation and leisure activities, computer, financial assistance for transport. Other services and supports provided during this period were funded from regular programs – Behaviour Intervention Support Team (BIST), respite care workers, case management. There were varying degrees of parent, professional and interagency collaboration among participants in the planning and implementation of interventions. These ranged from instances where parents identified the areas of importance and played the major role in deciding the interventions and supports required, to parents being consulted about plans. Interagency collaboration also varied from extensive coordination to consultation. At the conclusion of the year, no agency had spent all the money that they had been allocated according to plans in their original proposals. Less specialist time and less back up support than planned was needed to implement programs or to be available in emergencies. There appeared to be benefits in being able to implement plans quickly (without having to go on waiting lists), to be flexible in responses and to work well as a team in the efficient use of resources. Towards the end of the year, remaining resources were redirected to ongoing activities considered beneficial by the families and service agencies to extend and continue the gains made.

1.5 Outcomes

At the conclusion of the year, improvements were reported for all boys in the school setting with decreased problem behaviour and increased responsiveness in the classroom. At home and other community settings, reported outcomes included dramatic improvement, some changes but not as much as desired and problem areas still to be addressed. The most successful outcomes for the young person and family came in the situation where there was the greatest parent-professional and interagency collaboration.

1.6 What worked well?

1.6.1 Parent perspectives

- Parents' views heard and needs recognised
- Flexible responses that were family-focused
- Immediacy of responses – didn't have to go on a waiting list
- Availability of extra respite and support, knowing they were not "going it alone", "there's always a follow up call", continuity of responses
- Confidence in personnel – case managers, BIST practitioners, respite caregivers, teachers

1.6.2 Service provider perspectives

- Being able to respond immediately by being able to buy in what was needed at the time and not having to go on a waiting list
- Supports individualised for the boys and their families
- Good communication between practitioners and parents and practitioners
- Commitment of all involved – parents, other professionals

1.7 What could have been done differently (both parent and provider perspectives)

- Better coordination across settings – e.g. home, school and respite
- More follow up
- Someone acting in a coordinating/case management role
- Being able to give more support to some individual personnel

1.8 Implications of findings for practice

- Importance of early intervention for children with behaviour problems
- Services that are not crisis-driven but provide timely and ongoing support
- Continuity in services and supports
- Development of a shared understanding and vision among parents and service providers
- Creation of collaborative links among all parties – individual with challenging behaviour, family, professionals, agencies
- Flexible responses that can cross agency and service system boundaries so that responses do not become fragmented and compartmentalised
- Workforce issues – training, support and retention of staff.

2. Introduction

The term "challenging behaviour" has been adopted to describe problem behaviours presented by people with an intellectual disability and encompasses a variety of problem behaviours, including aggressive, destructive, antisocial and self-injurious behaviour. Challenging behaviour typically describes behaviour or behaviours that are:

> viewed as culturally abnormal and are of such intensity, duration, frequency that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of or deny access to ordinary community facilities. (Emerson, 1995, pp. 4-5)

Challenging behaviour is defined by its impact. Whether or not behaviour is challenging is determined by complex interactions between what people do, the setting in which they do it and how the behaviour is interpreted (Emerson, 1998). The detrimental consequences of challenging behaviour can be considerable for individuals with an intellectual disability, their families and the community. These wide ranging personal and social consequences may directly impact upon the health of self and others, and on the quality of life of the person, those who care for him/her and those who live in close proximity (Emerson, 1998). This sequence of events impacts not only on family life, but also absorbs increasing levels of public resources to manage. In the absence of effective intervention, there is evidence of considerable stability in problem behaviour over time (Lowe, Felce, Perry, Baxter & Jones, 1998).

Responding to the needs of children and adolescents with disabilities who present with complex behaviour problems poses challenges to the human service systems that are called upon to become involved. This group of children and adolescents has multiple needs that cut across traditional service boundaries. Young people and their families often experience either gaps in services or multi-agency involvement that may not be well coordinated and not meet their needs. Consequently, children and adolescents can accumulate a succession of failed interventions and be placed in increasingly restrictive environments (Van Den Berg & Grealish, 1996).

Challenging behaviour is influenced by many factors, thus making the assessment and remediation of such behaviour complex (Ozanne, Bigby, Forbes, Glennen, Gordan, & Fyffe, 1999). Different behaviour patterns have been found to be associated with differing levels of functioning. Antisocial forms of behaviour such as aggression are more typical of people with less severe intellectual disability while self-injury, stereotypy and obsessive behaviour are more frequently identified in people with severe intellectual disability (Emerson, 2001). Challenging behaviour is related to difficulties in specific skill areas. Higher rates of challenging behaviour are reported among people with an intellectual disability whose social skills are poorer (Duncan, Matson, Bamburg, Cherry & Buckley, 1999) and within

populations who are non-verbal, or who have communication difficulties (Caulfield, Fischel, DeBaryshe, & Whitehurst, 1989). Children with autism, who typically experience difficulties in communication and social behaviour, have been found to experience higher than expected rates of challenging behaviour (Dunlap, Robbins & Darrow, 1994).

Bronfennbrenner's (1989) ecological systems theory provides a concentric circles framework for exploring the social contexts in which families operate. Children with disabilities and their families are viewed as part of a series of systems. Influences on families exist at all levels of the system and these can have a profound effect on family well-being. Bronfenbrenner defines the first level (inner most circle) as "a *microsystem* [that] is a pattern of activities, roles and interpersonal relations experienced by a developing person in a given face-to-face setting with particular physical and material features, and containing other persons with distinctive characteristics of temperament, personality and systems of belief "(p.41). Thus the microsystem consists of the immediate settings in which children participate for significant periods of time. The immediate family setting is paramount and includes influences such as family structure, internal resources (e.g., time, financial resources) available to the family and patterns of interaction and beliefs. Other settings in this level include school and peer group.

The *mesosystem* is defined as comprising "the linkages and processes taking place between two or more settings containing the developing person" (Bronfenbrenner, 1989, p.41). A mesosystem is a system of microsystems and encompasses the relationships that exists between the different settings in which the child participates. Processes operating are not independent but rather exert important mutual influences. Examples for families with children with disabilities are those of parent/professional relationships between home and school and between parents and disability service providers. Parental satisfaction with an intervention program is often related to whether parents have a good relationship with professionals in the program (Hanson, Beckman & Horn, 2000).

The next level, the *exosystem*, refers to the social structures and organisation in which the child and family are not direct participants but which exert a direct influence on family adaptation, hospitals, schools and social service agencies. The policies and practices of these organisations can exert a profound influence on families who may be empowered or disempowered, supported or face increased stress. The responsivity of organisations and their interagency collaboration in providing support and services to individuals with challenging behaviour and their carers may either facilitate or impede the development of effective solutions.

As Bronfenbrenner (1989, p. 42) explained, "The macrosystem may be thought of as a societal blueprint for a particular culture, subculture or other broader social context". The *macrosystem* refers to the larger social, cultural, economic and political context which provides broad influences such as political trends, economic conditions, culturally-based views of disability, different beliefs about the meaning of disability, importance of independence and role of the family. Beliefs about disability and inclusive practices, for example, influence policies concerning rights and entitlements to education at this level.

An ecological approach highlights the importance of the interactions and relationships across the different system levels. "Partnerships" and "collaboration" between families and other stakeholders have become buzzwords in the best practice descriptions of services for children with disabilities. Collaboration is described as a partnership formation (O'Looney, 1997) that denotes a durable and pervasive relationship (Harbart, Finnegan & Tyler, 1997) and that is characterised by mutual benefits, interdependencies and a formal commitment to working together for specific purposes and outcomes (Walker & Petr, 2000). Friend and Cook (2000) noted the defining elements as sharing parity, sharing responsibility for decision making, having a common goal and sharing accountability for outcomes. However, available evidence

suggests that parent/professional and interprofessional/interagency collaboration may not be well achieved. The gap between rhetoric and practice may be further compounded when a child with a disability presents with high complex support needs and/or challenging behaviour. In a study by Turnbull and Reuf (1997), parents reported wanting to work in collaboration with professionals and community members to address the challenges of creating an inclusive lifestyle for their child. They wanted assessments that helped them better understand the reasons for their child's problem behaviour, assistance in structuring family routines and strategies to enhance parent-child communication. However, parents of this group of children often report having extremely scant or tenuous supports (Turnbull & Reuf, 1997) and the least satisfaction in their dealings with services (Grant, McGrath & Ramcharan, 1994).

Another variable in developing effective responses to challenging behaviour is that of interagency collaboration in service delivery. The way that services are organised and managed has been reported as impacting on the efficacy of responses to challenging behaviour (Mansell, McGill & Emerson, 1994). Specialist intervention teams have been increasingly utilised as a major intervention strategy to decrease challenging behaviour. While research has shown that these teams can have beneficial effects, change does not automatically follow input from a specialist behaviour support team (Lowe, Felce & Blackman, 1996). In a study of the effectiveness of two specialist teams, Lowe et al. (1996) proposed a number of factors that could have accounted for the difference in success between the two teams in reducing challenging behaviour in people with an intellectual disability. The more successful team had experienced staff operating in a cohesive manner. They also made formal links with other services. Lowe et al. (1996) suggested that an urgent research priority is to identify working arrangements and methods that produce successful intervention to decrease challenging behaviour and promote the long-term transfer of competence to mainstream settings.

Compartmentalised services with different funding sources can be obstacles to a coordinated, collaborative approach among professionals and agencies. There are further difficulties in providing services to regional and rural areas that are distanced from the concentrated resources that are usually found in urban settings. People with an intellectual disability and their families are extremely vulnerable to inept, disorganised and fragmented service provision (Ozanne et al., 1999). The assessment of an individual's behaviour cannot be separated from an assessment of the adequacy of care and support provided to that person and his/her families (Naylor & Clifton, 1993). To adequately assess the needs of someone with problem behaviour requires an assessment of service competence as much as individual characteristics and life circumstances (Ozanne et al., 1999).

Positive behaviour support is an approach for resolving serious behaviour problems that has been recommended by a growing number of professionals and advocates, and is enshrined in policy and law in a number of states in the U.S.A. (Dunlap, Hieneman, Knoster, Fox, Anderson & Albin, 2000). Positive behaviour support is a collaborative, assessment-based approach aimed at developing effective, individualised interventions for people with problem behaviour, which have meaningful and durable outcomes (Carr et al., 2002; Lucyshyn, Horner, Dunlap, Albin & Ben, 2002). Positive behaviour support approaches have emerged from three main sources: applied behaviour analysis, the normalisation/inclusion movement and person/family-centred values (Carr et al., 2002). In contrast to traditional, expert driven approaches, positive behaviour support approaches emphasise stakeholder participation and are consumer driven. Consumers are not helpers but active participants and collaborators with professionals in the process of reciprocal information exchange (Carr et al., 2002; Turnbull & Turnbull, 2001). Plans are implemented that have "goodness of fit",

particularly with family life. The implementation of support involves helping families successfully implement behaviour support plans in family contexts.

In the USA, the concept of wraparound services has developed to facilitate interagency collaboration and enhance the effectiveness of intervention with young people and their families, which is directed at decreasing problem behaviour. Carr et al. (2002) have identified a convergence between the core philosophy and methods represented by positive behaviour support approaches and those of wraparound services with both emphasising the development of support plans that are needs-driven rather than service-driven. Wraparound services (Van De Berg & Grealish, 1996) have the following features: they are based in the community; they are individualised and delivered in a culturally competent manner; parents are included at every level of development; agencies have access to flexible funding; there is interagency collaboration; services are unconditional so that the child and family are not rejected but rather services must be changed; and finally outcomes are measured. Because the needs of young people with challenging behaviours cut across the territory of many agencies, system collaboration is required. The more complex the needs of the child and family, the more individualised the plans need to be and as a consequence, effective parent/professional relationships are crucial.

Contemporary behaviour intervention strategies are based on multi-dimensional assessments that include consideration of the function of the behaviour and analysis of environmental factors (Emerson, 1995; Koegel, Koegel & Dunlap, 1996). In response to such assessments, interventions have also become multi-dimensional, focusing not only on the individual and the family but also on the environment and the delivery of services. With such multi-level interventions, evaluations need to go beyond changes in the individual's challenging behaviour to those of wider quality of life and environmental changes required. It is necessary to monitor many aspects of the circumstances that confront the individual and the service (Mansell, 1994; Ozanne et al., 1999).

Successful outcomes cannot be determined by changes in challenging behaviour alone. In evaluating interventions for challenging behaviour, it is essential to monitor the effectiveness of service responses alongside that of the nature and extent of the problem behaviour (Harris, Humphreys & Thompson, 1994). Along with decreases in the challenging behaviour, factors such as increased quality of life and safeguards to the health and safety of others should also be evaluated and monitored (Harris et al., 1994). In the community one must deal with multiple interacting variables embedded in complex systems (Carr et al., 2002) and it is not possible to separate out variables in the manner demanded by traditional research designs. Using a case study approach to monitor intervention outcomes, however, can provide valuable information about what constitutes the best practices in responding to challenging behaviour. Given the complex challenges of severe behaviour problems in young people with an intellectual disability, evaluations need to include not only whether support plans respond to family identified needs, are developed in partnership and are needs-led rather than service-led, but also an investigation of human service agency responses and interagency collaboration.

3. Project Background

There has been concern in Victoria about the increasing number of young people with developmental disabilities who also have problem behaviours and require services by multiple agencies because of such behaviours. In April 2000, DHS Barwon-South Western Region asked agencies to nominate children and their families who they considered would benefit from being part of a year long initiative that would provide extra funding for Intensive Behaviour Intervention Services (IBIS) supports. The funding was a one-off

allocation that aimed to target a younger client age group (16 years and younger) as part of a strategy to prevent clients' moving into higher cost disability/justice systems. Submissions were requested from case management services to propose clients eligible for services under the Intellectually Disabled Persons' Services Act (1986), who displayed or were at risk of developing complex challenging behaviours. From these submissions Department of Human Services (DHS) Barwon South-Western Disability Client Services selected four children with an intellectual disability and their families to take part in the project. The community agencies that nominated each selected child administered the allocated extra funding to develop and implement responses to the child's complex needs during the one-year intervention period. Services were to be packaged and tailored to each individual and family and could include: specialist case management, behaviour intervention, human relations education and/or individual counseling from specialist non-government organisations, Psychiatric Services, Community Health Services, Recreational and Respite Services, Drug and Alcohol Services and Community Policing Services.

4.   Research Questions

As part of this project, a study was undertaken by the Department of Human Services Barwon-South Western Region and the Institute of Disability Studies at Deakin University. The main aim was to assess the success of the intervention. Using a case study approach, the research explored the nature of the challenging behaviours, history of service provision, family involvement in decision making, interagency collaboration, the types of services and supports purchased with the IBIS funding, and the outcomes for the young people and their families at the end of the funded intervention period as reported by parents and service providers. The study aimed to unravel some of the complexities involved, not only in young people's challenging behaviours, but also in the multiple service interventions, and to identify features of interagency collaboration that facilitate more cohesive and effective services for young people and their families. In particular the study addressed the following questions:

1.   What was the nature of the challenging behaviour that brought each child to the attention of authorities and how has this changed over time?
2.   What was the history of service provision for each child and the extent of family involvement?
3.   What were the barriers to access services and interventions to redress participants' challenging behaviour?
4.   What was the purpose and extent of service provision within and across agencies during the current funded intervention period?
5.   What changes in the young person's behaviour were perceived during the funded intervention period by the families and service providers?
6.   What changes are required in service agency responses to better address the needs of the young people and their families?

5.   Methodology

5.1   Participants

Participants in the project were four boys with an intellectual disability, aged 10 to 15 years, their parents and service providers. For the purposes of the report, the boys who were the targets of intervention are referred to by pseudonyms (Alex, Ben, Carl, David). Other participants are referred to by their relationship to the boy concerned, for example parents, mother, father, teacher, case manager. In order to protect the anonymity of participants as much as possible, detailed individual case data are not given. While such an approach limits

the reporting of some of case-rich information, it was considered prudent in view of the small number of participants.

Previous assessments (of intellectual and adaptive functioning) placed one boy (Alex) in the mild range of intellectual disability, two (Carl, David) in the moderate range and one (Ben) in the moderate to severe range. Ben was non-verbal and the assessment report noted the difficulties in obtaining an accurate assessment of his intellectual functioning. As reported in their Assessment for Eligibility for Intellectual Disability services, all four boys had significant deficits in areas of communication, daily living skills, social skills and community skills. Two boys had a diagnosis of autism or autistic features (Alex, David). Alex also had additional diagnoses of Tourette syndrome, attention deficit disorder and anxiety disorder.

5.2   Settings

All of the young people were living at home with their families, three in two parent families and one in a sole parent family with a widowed mother). All of the boys had siblings. At the beginning of the project three boys were attending special developmental schools. A fourth participant (Alex) had been attending a special school but the school had taken a recent decision to suspend him due to difficulties in managing his behaviour. Alex and David had completed the majority of their primary school years in regular schools, Ben had experienced some integration in a local primary school but was based at a special school and Carl had undertaken all his schooling at a special school. With one exception, the boys and their families had multiple agency/professional involvement at the time of the first interviews. For two families (Alex, Ben), this extended back a number of years, and for Carl's family had developed over the previous two years. David's family had just come into contact with human service systems immediately prior to the beginning of the project. Their main involvement with services previously had been with educational services and intermittently with a pediatrician.

5.3   Procedures

Four case studies of intensive behavioural intervention operating within regional and rural areas of the DHS Barwon-South Western Region service area were investigated. Such an approach provides a rich understanding of the young people and families' experiences, enables an investigation of the processes involved in intervention and allows an analysis of individual histories and outcomes to be undertaken. Detailed analysis of selected cases is an effective means of examining service system limitations, barriers to access and implementation of interventions, and factors associated with progress of interventions (Burchard, Hinden, Carro, Schaefer, Bruns, & Pandina, 1995; Burchard & Schaefer, 1992; Carr et al., 2002). The study examined the diverse array of service responses to the young people and their families taking part in the funded intervention period.

Semi-structured interviews (Appendix 1) were undertaken with families, agency staff administering the IBIS funding (three of whom also acted a case manager for a young person), and other service providers including teachers, Behaviour Intervention Support Team (B.I.S.T.) practitioners and respite care providers. Interviews with two families involved both mother and father, but in another two families only the mothers participated. Interviews with parents and agencies administering the IBIS funding were conducted on two occasions, once in the early stages of the funded intervention period and again at the end of the funded intervention period. Interviews with teachers and other service providers were conducted once during the course of the IBIS project with the exception of interviews with one teacher, which were undertaken both at the early stages of the project and at the conclusion. The first author conducted the majority of the interviews, with three completed by the second author. Three other interviews were conducted jointly. Researchers met with the four boys participating in the project in their school settings.

Case history notes and reports were also gathered from case management and school files, as permitted by ethics clearances. As well as information obtained from interviews, case file material for each young person was used to develop timelines (Burchard et al., 1995) of the history of their challenging behaviours, their treatment over time, access to services and service provider responses. Information from document analysis and texts was coded to permit analysis of themes in order to gain a better understanding of the nature and effectiveness of services. Particular attention was paid to parent-professional relationships and interagency collaboration.

6. Findings – Past Experiences

6.1 Nature and history of challenging behaviour

At the beginning of the project the young people displayed various challenging behaviours that were to be targeted for intervention as outlined in the agency proposals for IBIS funding. These behaviours included aggression towards others, destructive and oppositional behaviour and inappropriate sexual behaviour. For three of the participants, the challenging behaviour occurred across home, school and respite care settings. For the fourth participant all of the difficulties were reported as occurring at school or as being related to school (not wanting to go to school).

Parents reported their child's problem behaviours in a manner similar to those described in the agency submissions but with some differences in emphasis. For one family, their son's violent behaviour at home towards his mother and brother had led them to put his name down for an out-of-home residential placement. This young person was non-verbal and his family saw that his major difficulty and the area most in need of attention was his communication, an area that was also highlighted in the agency submission. The parents of another boy suspended from school at the beginning of the project expressed their view that "school was the biggest problem". The behaviour problems for another young person occurred mainly in the school setting, with his mother not reporting any difficulties of concern at home. His class teacher considered that his challenging behaviour (e.g. destructive behaviour, offensive verbal remarks to others and his high levels of anxiety) were more problematic than the inappropriate sexual behaviour that was the focus of the agency IBIS submission.

All of the boys had histories of challenging behaviour that extended over a number of years. While the problem behaviours had become significantly more severe in the previous two years, families' descriptions and references in case file notes indicated that the difficulties for the boys and their families had first become evident much earlier. The following examples illustrate the long history of challenging behaviour for all four boys.

> [Carl] appears to have been unable to cope and has continued to display extreme behaviour problems to the extent that his placement at preschool has broken down. (Report from preschool teacher, 1995)

> There has been a spate of toileting problems, frequent impulsive behaviour such as running away from the room, wrestling with other children, throwing things about, spitting, echolalia and other inappropriate responses in classroom activities. In short David has to be watched every minute. (Written report from classroom teacher, 1993)

> At school Alex is presenting as anxious and fidgety … A is aggressive and is a distraction in class. (School report, 1996)

Ben's aggressive and violent behaviours have been developing over a period of years. Initially it was only displayed in his home and it had got to the point where he was able to control his family and dictate his needs over everyone else. (Case manager report)

More recent case file material indicated an increasing severity of problem behaviours for participants, as well as the emergence of some problems with sexual behaviour for three of the boys.

Ben has been assaulting family members and assaulting other students. There have been reports of inappropriate sexualised behaviour. (Letter from paediatrician to case manager requesting behaviour intervention assistance for Ben and his family, May 1999).

[Mother] describes Alex as hostile and grumpy at home and as a person who stresses out easily. Alex has punched his mother and also punched his sister. Alex has lashed out at objects in the house. (Assessment of Need Report, January 1999)

In general parents and professionals could not identify any particular precursors to increases in the boys' problem behaviours. Changes in school setting for two boys (from a regular school setting to a special school for one boy and from an regular primary school setting to being integrated into regular high school for another boy) preceded marked increases in behaviour problems, although significant difficulties for both had been present before the change of school. This was described for one of the boys:

The transition from mainstream school to special school was really difficult. He certainly didn't identify himself as one of those spastic kids as he calls a lot of the kids at the special school. He displayed quite unsettled behaviour [at that time]. (case manager)

The father of the boy discussed in the quote immediately above identified the school as having had a major role in the increase in his son's challenging behaviour, describing the school as the "problem." There was speculation in a paediatrician's report that an increase in challenging behaviour for another boy may be have linked to the birth of a sister when previously the boy had been the only child in the family. There had, however, been significant behavioural difficulties apparent for this boy before that event.

6.2   History of responses to problem behaviours

Parents and service providers were asked about previous responses to the challenging behaviour presented by the boys. Case file information was also used to construct a history of service responses for each family participating in the study. All parents had made attempts to get assistance in managing their child's challenging behaviour prior to the IBIS project. One mother had even written to the State Minister for Education in 1996, asking for programs and resources to support her son at school. As is outlined further in this section, attempts to get assistance had met with limited or no success.

All families had a history of regular ongoing contact with a paediatrician although for one family this had become less frequent over the previous couple of years. Schools also had contact with the paediatricians of the boys participating in the study. Teachers made referrals to the paediatrician regarding the behavioural difficulties that were presented by three of the boys. Paediatricians also made referrals to others in an attempt to secure assistance in managing behaviour problems and wrote letters of support for extra funding. The other main involvement by paediatricians was in prescribing and monitoring medication. Three of the boys had been prescribed medication at various times in attempts to reduce problem behaviour.

The families in the study had limited support available to them in terms of extended family support. One mother was a sole parent (widow). She lived in a rural area and her family lived

some distance away. Another family reported their extended family as not supportive. As their case manager described their situation, "They are a family that is totally isolated with no network of friends or family". There was considerable negative impact on the quality of life of all families as a consequence of their sons challenging behaviour. Two families had grandparents available who could look after their children but concerns about how their child with challenging behaviour might behave led them to limit the amount of time that this option was used. For three families fears about their son's behaviour had led them to restrict going out together as a family. They found the effort involved in organising outings and visits, the consistent apprehension that their son might misbehave when they were out, combined with some previous negative experiences led to such a decision.

Three families had used respite care facilities for their child with challenging behaviour. Parents described this decision as largely to give themselves a break so they could go out as a couple or spend time with their other children. At the beginning of the study, one of these families no longer used the respite care home as they believed their son had become too anxious about going. They were also unhappy with the way the respite care home managed, or rather did not manage, their son's challenging behaviour. Two boys had respite care workers who came to the home and took them out for recreational activities.

Teaching staff reported having tried a number of strategies in response to the challenging behaviour of the four boys. For three of the participants, requests had been made by the school to the paediatrician for assistance. Reports from the schools indicated a range of strategies had been implemented such as use of rewards, withdrawing privileges and time out of the classroom. Details of these strategies and the outcomes were typically poorly documented. From the limited information, however, it appeared that these interventions had met with either no success in changing problem behaviour or some improvement in behaviour that was not sustained over time.

Parents attended regular program support group meetings that typically were used to discuss educational progress and individual educational program goals. Occasionally this forum was also used to discuss the problems presented at school. There were no personnel from outside the school present and strategies that were implemented tended to focus on the school setting rather than bridging school and home. All four boys had spent considerable amounts of time outside the classroom as a consequence of their behaviour and all parents expressed concern at the negative impact that this was having on their sons' education and learning.

Referrals and requests for referrals had been made by case managers, teachers, and paediatricians to Child and Adolescent Mental Health Services, variously for an inpatient admission (although parents considered the referral to be a couple of years too late), for respite care, and for Behaviour Intervention Support Team involvement. Although often a number of professionals and agencies were involved in working with the boys and their families, there was little evidence of collaboration in working together in a coordinated way. Teachers also worked in isolation within the school setting, typically with little support from regional educational support services outside the school.

6.3   Barriers to collaboration

Gaining timely assistance was difficult. Consideration is given in this section to family perspectives on past service responses as well as service provider perspectives. In discussing service responses, parents refer to their views about interactions with services and professionals *prior* to the funded intervention period. A number of themes emerged as barriers to effective family-agency partnerships in meeting the complex needs of the young people with challenging behaviours and their families. These are considered in detail.

6.3.1 Parent perspectives

Parents identified a number of areas in past service responses, which they viewed as limiting the effectiveness of responses to their child and themselves. These were: crisis-triggered interventions, discontinuity in services, and communication difficulties between parties. Each is briefly discussed.

a. Crisis-triggered interventions

Three families reported having to be in crisis to get help. Despite their attempts to get earlier intervention, appointments were allocated on an urgency basis and their needs were often seen as not having sufficiently high enough priority.

> *With anything the whole way through, right from when he was little right through now, you had to go into crisis to get help. If you got help when it was just a little niggle, if they had somebody there you could talk to, saying its probably going to get worse before it gets better, you could cope better. If you could get help along the way, some problems could be diverted, I wouldn't say all but like I've found every time I've wanted help I'm banging my head against a wall.* (Ben's mother)

> *I only ever went to them because once I lost control. I never had any help on that, and it got to the stage that I was actually going to [do him physical harm].… It was funny because once we went to see them, all of a sudden we had [case manager] came on the scene…. I had nothing, then all of a sudden it was everything thrown at us at once sort of thing…. I was on the waiting lists [but it] wasn't until I actually mentally and physically lost control that I got all the support.* (Carl's mother)

b. Discontinuity in services

Gaps in continuity arose in several ways. First, because most effort appeared to be focused on urgent cases, case managers tended to have little time for maintenance activities with families, such as occasionally making contact to check on progress even when things were going well. Giving families reassurance to maintain effective strategies seemed to be missing.

One mother noted that while she understood the need for services to allocate priorities, she thought that regular contact when things were going well might have been helpful. Sometimes the case manager rang her and sometimes she rang him.

> *So you could say for 12 months I was [ringing] if needed and he was in between and then after that it was when things started getting good, that was when contact sort of died down or stopped. As you are running along fine, you ring them—"help, help, help!" ... before they were ringing just to check … on you, then once it was good they all stopped. [Occasional contact from the case manager] especially when things are good because anything can happen, like even once a month, to check sort of thing instead of waiting until it all blows up again.* (Carl's mother)

A second concern was staff turnover. Continuing changes in personnel working with the child and family made it difficult to establish partnership relations. Families might start to build a good relationship with a particular worker and then that person left. From the parents' perspective, not only did new staff not have knowledge of the family history but often they also lacked service knowledge.

> *It's the system all over, they start you off and then somebody takes a package. I'm sick to death of repeating my story…. You see so many people and see so many people they don't see the files you've put in front of them so they want you to start from the beginning…. This is the whole problem with the system, the turnover of workers. I know it's a burnout job, but it's a burnout job for us.* (Ben's mother)

A third concern was that families often had to go on waiting lists to get services requested and while waiting the situation got worse. Waiting was often associated with staff leaving and delays in appointment of their replacement.

> *Yeah, that's where the BIS team should have been involved at the start,* [14 months earlier] *things were going a bit cranky.* (Alex's father)

c. Communication difficulties between parties

Several concerns arose indicating poor understanding and communication between families and service providers. One obvious starting point for effective relationships is the development and maintenance of trust. Families reported feeling sometimes that they could not trust services to respond appropriately to their child and had doubts that services knew how to manage their child's challenging behaviour. This was especially difficult when families were requested to take their child out of a setting (school or respite care) because of the difficulties experienced by service providers in managing their son's problem behaviours. This was usually at a time when they as families were also struggling to know how to manage.

> *Like there's the respite care house, they ring up and said, "Oh [Alex] has been crying. Can you come and get him?" To me the whole point of that joint is for us to have a bit of a break. He was balling his eyes out and to ring us up, they are meant to be the professionals and care for special needs kids. Every time you dropped him there, it wasn't respite -- you are sitting there thinking, "what are they doing, what's he doing?"* (Alex's father)

All families reported favourably on a number of people (teacher, teacher's assistant, respite care worker) who had worked with their child and whom they had trusted. These were personnel who families reported put in extra effort with the child and themselves, who did not give up and who families considered did not see working with their child as a chore. All families however reported gaps when such individuals left their positions or even when they were away on leave and there was no one else who was able to manage their child as successfully.

> *This woman [teacher's aide] she was so dedicated, she was like a guardian angel. David really responded to her. …She was having him doing things like writing and spelling and sums he'd never done before and he was happy to do it.* (David's mother)

A second reported concern emerged around poor communication between families and services. Some families felt there were times when they had not been informed of problems their child was experiencing in other settings, or they had not been made aware of other services that they could access in a timely way. Parents believed at times they were not listened to or believed about their child; their views were not taken as seriously as those of professional and sometimes at meetings it felt like "us [parents] lined up against them [service providers]" and there were a lot more of them.

> *Sometimes you feel you're up against an army. They're on one side and you're on the other.* (David's mother)

A third concern was communication across agencies. Parents reported difficulties in the past where there had to be communication across systems such as human services and education. Parents had often communicated separately with each and juggled appointments and meetings with a number of different agencies involved with their child. One mother reported on difficulties experienced in having a school consider and implement suggestions made by other educational specialists and health professionals (pediatrician, occupational therapist).

A number of visiting educational and health professionals have assessed David over the years, making various recommendations. These recommendations have not always been carried out as requested by visiting professionals. (David's mother)

Sometimes there had even been difficulties in communication between different divisions in the same agency.

That's the problem you've got; different departments that run different rules…, because one department told me one thing and then the other department told me another. (Ben's father)

A fourth concern was the lack of a shared understanding and vision between families and service providers. Families sometimes had different visions about how they would like to see some of their child's needs met, compared to those they believed the service providers held. This was particularly an issue with regard to how families saw the educational needs for their child and how they perceived schools were not meeting many of those needs.

But if his educational needs aren't met I don't want him in grade 6 until he's 15. They've [school] got to keep taking him up; they've got to teach him. I think they get to the stage they think It's hard enough just to manage him without having to… "what do you mean? - we've got to teach him as well!" (Alex's father)

6.3.2 Service provider perspectives

In the main service providers administering the IBIS funds had known the young person and their families for relatively short periods of time when the initial interviews were undertaken. While one agency had provided case management for the family for a year prior to the research project, the case manager at the time of the study was new to her position. For the other two agencies providing case management this had begun just prior to the commencement of the project. Assistant principals and school-teachers had known the boys and families over longer periods, although two of the boys had only been at the school for one to two years. BIST practitioners and respite care workers had known the boys for a year at most, and some had only come to know the boys during the IBIS project that was the subject of the study.

Interviewees identified the need for collaboration and communication between agencies. This was also noted in a number of reports, for example, "There is a clear need for greater communication between all members of Alex's network to ensure consistency of management". There was, however, little evidence from either interviews or case file information that this had occurred to any great extent, if at all, in past service responses. Instead responses generally were piecemeal and not integrated across different environments. Funding difficulties and lack of available resources compounded the situation. Building relationships with other professionals and trusting that professionals knew how to do their job were raised as important aspects of inter-professional and interagency collaboration in the sense that when these characteristics were not present, it was unlikely that collaboration would be achieved.

So while we had dialogue with [case management agency] during 1999 there was never any sense of we were all working on the same team. (Assistant Principal)

We ended the year with very little program. He'd been dealt with and passed on and people had come and in terms of services his family had – no. We got nothing, we got nowhere. (Assistant Principal)

There has been a history of large amounts of different medications and management techniques being used with this boy with some disparity between parents as well as systems. (Referral from one agency to another)

Teachers in particular reported having to manage on their own with little support from outside the school, even from regional educational support services.

> *We had to fight for services and when they came they were pretty ordinary, so we didn't get any support from the region.* (Assistant Principal)

In one situation an assistant principal, in desperation to get more support for the family, suspended one participant in an effort to galvanise action. It was a move that was to have negative consequences for the parent/school relationship.

> *What I hoped to do was confront the system and force it to take responsibility for this child. The parents saw it as a massive betrayal and I lost 12 months of good work [building trust] but it was successful. I got what I wanted [an inpatient admission for child].*

6.4   Regional and rural isolation

As one parent observed emphatically, "Nothing is local!" The extra time involved to travel the distances to attend appointments and meetings, and the extra costs involved in doing so sometimes added extra stresses to families who were already in stressful situations dealing with the complex needs of their child with an intellectual disability. In the present study, at least one family experienced the difficulties of long distances as the child was transferred to a specialist educational facility even further from the regular school he had attended. Not only did the child have further to travel, so did the family when he had to be delivered or collected at times different from the regular transport arrangements provided for school students.

Agencies also had difficulties in arranging timely responses to geographically isolated families in crisis as expressed in a letter from a school principal,

> *External professional help is almost impossible to obtain. We are a remote A classified school. Our support centre staff is all but non-existent and we are an hour's drive from them.*

7.   Findings - Funded Intervention Period

7.1   Proposed interventions and service approaches

Prior to the funded intervention, agencies submitted proposals for each boy, which identified the planned interventions and the extra funding required. Parents were involved to varying degrees in the development of the proposals. Two sets of parents were very involved in deciding how the funding would be used while the other two were consulted rather than directing the decisions. Table 1 shows an aggregate of the proposals made on how the extra funding would be spent across the four families.

Table 1.   Proposed Interventions using IBIS Funding

Nature of Interventions	No. of cases
Respite carer taking person out, recreation	4
Specialist counselling (human relations, sexual behaviour, anger management)	4
Specialist assessment (psychologist, communication)	3
Specialist case management (extra hours purchased)	2
Support worker for BIST interventions	1
Purchase of computer, communication equipment dependent on recommendations	1

Case managers (or where there was no case manager, staff from the agency administering the IBIS funding) were asked to describe the model they used to work with young people with challenging behaviour and their families. None of the interviewees appeared to use a specific model of case management. All of them, however, described taking a multi-component approach but they emphasised different aspects in their discussion. One case manager, for instance, focused on implementing the principles of family practice in her work and, in particular, working as a team with the family. Another emphasised the importance of a thorough assessment and understanding the underlying causes of problems before implementing any interventions. Working creatively with people to bring about change and being optimistic were identified as key features of the approach taken by another case manager.

7.2   Interventions undertaken

Actual interventions often differed from those planned because of changed circumstances, not only prior to commencement of interventions but also in recognition of emerging needs during the period of additional funding. Table 2 outlines the interventions that were ultimately implemented with each boy during the course of the year-long funded intervention period.

Table 2.   Analysis of Interventions Undertaken

	IBIS funded interventions	Other Interventions
Alex	▪ Respite care worker ▪ Computer training ▪ Financial assistance ▪ Counselling sessions for father ▪ Extra case management time ▪ Support worker in school	▪ Shared care family ▪ Art classes ▪ Paediatrician ▪ BIST ▪ Parents seeing CAMHS social worker ▪ Respite care worker ▪ Support worker in school ▪ Case management ▪ Psychiatrist
Ben	▪ Psychologist ▪ Respite care worker ▪ Support worker in school ▪ Specialist communication assessment ▪ Computer ▪ Communication aids ▪ Extra case management time ▪ Recreation and leisure activities	▪ BIST ▪ Police talked to B about the consequences of his aggressive behaviour ▪ Respite care ▪ Case management ▪ Paediatrician
Carl	▪ Psychologist assessment and report ▪ Psychologist – feedback to parents, recommendations re further supports for C	▪ Respite care worker ▪ Respite care home ▪ Paediatrician
David	▪ Psychologist assessment, development of strategies ▪ Purchase an extra massage session for D at school	▪ BIST ▪ Case management (DHS)

The interventions adopted are divided into those that were funded from the allocated IBIS money and those that were funded from regular program money or did not require funding. In some instances the extra funding was used to buy more of services that the boys already had, for example, extra case management time and extra respite care. The majority of the extra funding, however, was used to fund new services or supports such as specialist assessment. For Alex and Ben, support worker time at school was funded. In Alex's case the school took over funding the support worker after the initial IBIS funding was phased out.

Both the proposed plans and implemented interventions had multiple foci as Table 2 shows. There were, however, differences between the original plans and the implemented strategies. At the end of the IBIS funded period, no agency had spent all the money that they had been allocated. The amount of IBIS funding received by participating agencies had ranged from $14,000 - $15,000 and underspending ranged from $3,000 - $11,000. All had plans that were accepted by DHS to carry over unspent funding. The major area of difference between proposed and actual spending occurred in the area of purchasing specialist services. There was less use of specialist services than had been initially budgeted for. Specialist interventions that were undertaken did not take as long as planned for and therefore cost less. For one participant (Ben), the dramatic reduction in his aggressive behaviour resulted in less call on the use of a respite care worker to come and remove him in emergency situations (used only twice) than had been originally thought necessary. In another case, the case manager had been ill for an extensive period and plans to meet with the family were delayed.

Flexible responses to families' changed circumstances were more easily made because of the availability of funds. In the case of Alex's family, financial assistance was provided for petrol to transport their son to school. The psychologist assessment of Carl resulted in a diagnosis of autism. None of the proposals (assessment, intervention, staff training) made regarding Carl's inappropriate sexual behaviour were followed up because problems were not apparent early in the IBIS period. As a consequence of an incident of inappropriate sexual behaviour from Carl towards the end of the project period, a referral was made to a psychologist (different from the psychologist originally proposed to work with Carl on issues concerning his sexual behaviour). This assessment and intervention was funded from unspent money from the amount originally allocated.

There were also changes for families that occurred during the IBIS funded period which had not been part of the planned intervention proposals. Ben's father changed jobs so that he was no longer working an evening shift. Not only did this create extra support for Ben's mother but Ben also started spending more time with his father including time at his father's work. Ben's father also stopped one of his own friends coming to the house because he considered this person's sexualised made about women to be bad modelling for Ben. This action was his own initiative but consistent with psychologist and BIST practitioner suggestions. David's mother's new male friend began involving David in a number of outdoor activities with him. Alex's father gave up his job, following Alex's mother experiencing a depressive episode, so that he could be of more support in the home. On an individual level, Alex and Ben had changes in medication to manage their behaviour. For Ben the change appeared to have a beneficial effect but Alex became more lethargic and his medication was further adjusted towards the end of the year.

7.3   Parent/professional collaboration

As with the involvement in the original proposals for the IBIS funding, there were varying degrees of parent/professional collaboration among participants in the implementation of interventions. These ranged from instances where parents (of Alex and Ben) identified the areas of importance and played the major role in deciding the interventions and supports

required, to the parents of Carl and David being consulted and asked for their agreement to proposed plans for IBIS funding.

Two families (Alex, Ben) had the same case manager and these were also the instances where there was the greatest parent/professional collaboration. Ben's parents reported "there was never a decision made without us agreeing to it" during the intervention period. Alex's parents found the case manger to be respectful of family decisions, directed by family priorities, and flexible in responding to family need (for example, financial assistance for petrol so father could transport Alex to school, funding of counselling sessions for father, coordinating respite care for Alex and his sister who has a physical disability). A break down occurred in the relationship with the school following Alex's suspension from school. As his father noted, "I want to be informed. It's slowly starting to come around (with the school), the communication with them is better". Alex's father had taken the lead in developing a plan for his son's return to school. He thought that the school should have taken the initiative and that it should not have been his role to do so.

For David's mother, there was some coordination in terms of meetings, a sense that she was being consulted and decisions were partly guided by her preferences. Collaboration, however, was limited by a lack of a shared vision between her and the professionals involved. David's teacher and case manager both expressed beliefs that David's mother was in denial, had unrealistic expectations and false hopes for David. They also expressed concern about what they saw as high risk activities her male friend was engaging David in, such as learning to ride a motorbike and chopping wood. While David's mother was relaxed about such activities, she expressed concerns that his educational needs were not being met and that he was capable of more than he was doing at school. When some of these differences became evident during the first interviews, the researchers gained permission from mother and passed on to the case manager her concerns about the lack of shared vision regarding goals for David at school. These were not followed up with any action.

As already noted, Carl and his family had no case manager for the duration of the project and not surprisingly this family experienced the least family/professional collaboration during the project. During interviews, particularly the second interview, Carl's mother reported being unsure as to what was happening, what would happen next and who to go to when there were problems. Carl's parents had not been informed of their son's behaviour at school when problems with his sexual behaviour re-emerged. This lack of information led to feelings of guilt when there were also problems at the respite care house.

> *Well now there's a sexual behaviour showing, which I've only just found out the school was still having sexual problems. They haven't told me and I went and said I need to know what's happening and I found all of these things that he's doing at school still. I thought, "Oh thanks, you could have told me about it!" because I thought the sexual behaviour was gone. It's not, it's actually still there, because he's showing signs of it now at [respite care house]. So they've actually got to put an extra staff member on when he's there. Sort of makes me feel guilty, like I'm trying to get a rest and they need an extra staff member to watch him because his sexual behaviours are starting.*

7.4   Interprofessional/interagency collaboration

As with parent/professional collaboration, the extent of interprofessional/interagency collaboration varied across participants. In all cases, there was at least some coordination of meetings with different agency staff and professionals involved although this only occurred for personnel involved with Carl at the beginning of the intervention period. For the three boys who had case managers, generally the case manager coordinated meetings where all

involved (e.g. parents, case manager, teacher, psychologist, support worker) attended or smaller meetings such as with parents, case manager and teacher.

Ben's mother commented on the common goals and shared vision among team members. "Everyone seemed to go away with a little job. Everyone was on the same wavelength". Ben's case manager indicated that "it was about supporting everyone in being able to continue with the strategy". Information and skills were shared. For Alex and Ben, funding boundaries were also crossed with IBIS money funding a support worker in the school. To a lesser extent, this also occurred for David where some of the unspent IBIS money was used to buy resources that could be used in the school setting, such as human relations teaching material.

While individual team members worked together, there was not always support from agency administration. Individual team members took on an advocacy role as exemplified in a comment by Ben's mother:

> I guess the school were at the point where they were ready to expel him …. She [classroom teacher] wouldn't admit defeat. She didn't get a lot of support from the people above her but she told them from the start " this is how it is".

Alex's father outlined their family's situation. "You've virtually got two different perspectives on the school side. [Principal] is worried about money whereas [assistant principal], I know, she still tries to help Alex, more for Alex than the school side".

There were examples also where interagency collaboration was viewed as haphazard, as reported by David's class teacher, and it being difficult to contact the case manager who was based at a centre one hour away. There was not always a shared understanding between professionals, with David's teacher also feeling that the case manager did not understand what goes on at school. David's family lived in the most isolated, rural setting of all the participants in the study and the case manager, school and family were all in different locations. David's case manager had initially considered purchasing services interstate as the closest township to the family was in South Australia, however none of the required services was available from there. A psychologist from Melbourne made a one-off visit to see David, his case manager, teacher and mother. The psychologist's suggestions were considered useful by David's mother, teacher and case manager but David's teacher in particular would have liked more follow up. Certainly the school had benefited from a clearer understanding of required behaviour change strategies.

There were also issues about collaboration when a new member joined the team or a new service was introduced. A BIST practitioner began working with Alex six months after IBIS project began. He expressed feeling a little disjointed from the team and would have preferred more meetings with the team as a whole. In a second example, towards the end of the project David spent a weekend at a respite care home for the first time, but there was no communication with the respite care providers about the strategies successfully used to reduce some of David's inappropriate behaviour, nor advice about what to expect. As a consequence, the respite care home did experience some difficulties with David during his weekend stay. These were later reported to his case manager and school, but not his mother. The only feedback that David's mother received was a note to say that David had been "marvellous in the helping around the house" and he was "great" during his stay. Clearly, inadequate proactive advice and glossing over difficulties did little to foster open communication.

Collaboration was difficult in the absence of a case manager/coordinator for Carl and his family. Assessment became compartmentalised, with one psychologist focusing solely on assessment for autism. It had been planned that another psychologist would follow that initial assessment with one about Carl's problem sexual behaviour. As noted, this did not

eventuate as intended although at the end of the project period arrangements were being made for Carl to see a psychologist as problems with his sexual behaviour had remerged. The psychologist spoke with Carl's teachers and the respite care worker who worked with Carl in his home in the process of doing the initial assessment but there was no team collaboration in terms of strategy implementation or coordination between Carl's teachers and the respite care home.

7.5 Behavioural outcomes

This section reports changes noted in the boys' behaviours at the end of the funded intervention period. Participant perspectives were also sought on what having the extra IBIS funding enabled them to do differently, what worked well and what aspects did not work as well as planned. During the study, researchers did not direct participants to a particular method of recording behaviours. Researcher interest was in how change was typically monitored and reported. It was noteworthy, however, that very little, and in most cases no behaviour recording was carried out or reported on. This applied equally to the time before the intervention period as well as during. What recording there was consisted mainly of either incident reports at school or diary recordings such as kept by the support worker at school for Alex and Ben, or in the school home-communication diary. These tended to be in the form of general statements such as "had a good day", "was disruptive today" rather than providing detailed accounts of behaviour.

The BIST practitioner working with Alex and his family deliberately had not asked Alex's parents to do any antecedent-behaviour-consequences (A-B-C) recording. He considered that, given the crisis situation the family appeared to be in, his initial time was best spent with Alex's parents to gain an understanding of their perspectives and to be "solution focused". Where some recording was established to monitor progress, it was difficult to continue. David's teacher reported:

> Well I started making a little chart that just had two weeks on it that would just hang on the board. I'd try, when I'd put a red cross up, I'd try and remember to put red cross on it with a texter and then get David to look back on the day. But we really hardly gave out any red crosses in the end. They were all coming up blank last week. So I just stopped the charts. From laziness. Yeah.

There also appeared to be some confusion from David's teacher as to the correct application of behavioural principles in the strategy undertaken.

The behavioural outcomes that are reported therefore come largely from parents, case managers, teachers and other service provider reports with some supplementation from any records that were available. While acknowledging the overlap between home and school, outcomes are discussed first in relation to behaviour at school and then at home and community.

7.5.1 School outcomes

At the beginning of the IBIS project, significant behaviour problems were reported for all four boys at school and the situation had deteriorated to the extent for Alex, that he was not attending school at the beginning of the project. At the conclusion of the year, improvements were reported for all boys at school with decreased problem behaviour and increased responsiveness. Many of the improvements at school were attributed to interventions made as part of the project, although some were attributed to other factors.

Alex's return to school was viewed as a very positive outcome that had been significantly assisted by the strategies put in place and particularly the availability of additional support from a support worker attending school with Alex. At the conclusion of the project, Alex was

attending school full time without any additional support. Alex's assistant principal noted that "his reintroduction to school and his school placement have been more successful than I could have ever believed". Alex's parents continued to be angry about the way Alex's initial suspension from school had been handled. Alex's father considered that it should not have been his job to come up with a timetable for Alex's reintroduction to school. There also continued to be concerns from Alex's parents that his educational needs were not being met as well as they should be.

The assistant principal described Ben's behaviour as a "total turnaround". During the last six months of the IBIS period there were no reported incidents of aggressive behaviour (at home or school) or inappropriate touching from Ben. There had only been two occasions when it was necessary to call in the respite carer to remove Ben either from school or the school bus. The development of an effective communication system for Ben (communication board) was viewed as pivotal to the improvements in his behaviour. Ben's teacher's expressed surprise at what Ben was capable of doing.

> *Well in his own way he's a reader, yes he's a reader. That's the part that surprises me about Ben because he comes across as someone who doesn't present as one that would know that much and yet there is so much locked in there. He is a very switched on young man.*

David's teacher described his behaviour at the end of the intervention period in comparison to a year earlier as being "fabulous". From what was previously described as almost continuous problem behaviour, very few incidents of problem behaviour were reported. David appeared less anxious in class and there had been an increase in appropriate classroom behaviour from him.

> *For example this year he comes in and he sits at the table, whereas he never sat at the table before, he would destroy the chair. We've got rid of all the swearing at staff. He used to make derogatory comments so all of that's gone. He started sitting at the table. He started joining in. He does lots more jobs, messages around the place, there's lots more participation.* (David's teacher)

Carl's teacher and his mother reported that his behaviour at school had improved but as the school was not involved in the project team, changes in Carl's behaviour were not attributed to any specific intervention from the IBIS project. Possible reasons suggested for Carl's improved behaviour were his being in a smaller class, his class having fewer other difficult children than in his previous class and Carl's being more closely supervised in the playground thus providing fewer opportunities for him to get into trouble. Aside from those externally imposed changes, the assistant principal thought that possibly some of Carl's improved behaviour was "developmental and that he was maturing and learning". Following the final interview at the school, however, the research team was made aware of the re-emergence of inappropriate sexual behaviour displayed by Carl both at school and at his respite care home.

7.5.2   Behaviour at home and in the community

Prior to the intervention period, three of the families had reported problem behaviours at home. For one family, there had been no major problems at home and this remained the case at the conclusion of the intervention period. David's mother did, however, report it was easier on school mornings now "that he is more willing to go to school and he is more confident". She attributed some of David's increased confidence and positive change to the time her new male friend spent with David. Reported changes at home and in the community for the other three boys ranged across: experiencing dramatic improvements, some but not as much as would have been liked, and behaviour up and down with problems re-emerging after a settled period of a few months.

Alongside significant changes in behaviour at school were substantial changes at home for Ben. Prior to intervention the situation at home had become so extreme with Ben's violent behaviour that his parents had requested Ben's name go on a waiting list for an out of home placement. A year on, this was no longer the case. They had started going out again as a family Ben's mother reported,

> *He's manageable; he's grown up a lot. He's a lot better, you can have conversations with him now…. I've actually found it easier to take Ben places. We still don't take him everywhere but if somebody rings up and says we're having a barbeque, I'll say Ben is here and [they say] bring him along whereas before I would not go to that barbeque. There's no big fuss or anything or me stressed to the max anymore.*

Alex's father summed up their situation as, "Since a year ago its 100% better [school and home] but not … back to where things were 3 years ago". Alex's case manager reported, "I think the changes at home are certainly not as significant as we'd hoped when we planned but the family are in extreme crisis and I don't think it was just about the stress of disability". Alex's father indicated that now he was at home full time he found Alex's behaviour much more difficult to deal with, particularly his repetitive asking of questions. Alex's father felt exhausted and noted that "we've tried so much and nothing has worked and we do end up going through the motions I feel". The BIST practitioner reported that Ben's father found it difficult to give positive reinforcement to Alex. Ben's parents were appreciative of BIST involvement and the fact that the BIST practitioner was "showing some initiative". With the BIST practitioner involvement, Ben's parents had been targeting his after-school routine and there had been some improvement in his behaviour at that time.

Carl's mother reported that Carl's behaviour had been variable over the past year but for the three to four months prior to the final interview his behaviour had been more settled. Having an explanation from the psychologist when he made the assessment of autism for Carl helped parents understand and develop strategies for responding to him.

> *We're learning to ignore some of the behaviour. [Psychologist] suggested some strategies. It makes us understand a bit more. We don't think he's just doing it to spite us anymore. We realise now that it's not spite, it's his way of learning sort of thing…. because we've given him some more responsibilities too. He now helps do the dishes.*

They had also started to go out together as a family again.

> *We've sort of gone out more. Because we understand, we just say, oh yeah we know we've got them at home. Just ignore it sort of thing …. Yes. It's got actually easier [going out]. Last school holidays we actually went out. That's the first time in years I've felt comfortable going to town.*

Towards the end of the intervention period, however, Carl's mother reported an increase of "silly behaviour" at home and a re-emergence of the problems with inappropriate sexual behaviour at school and the respite care house.

7.6   Intervention process outcomes

This section reports the major themes that emerged from parents and service providers concerning: the aspects of the interventions that they considered worked well, what the availability of extra funding had enabled them to do differently and those aspects of the intervention with which they were not satisfied or would like to have seen done differently. Not all themes applied equally to all families or service providers.

7.6.1 What worked well?

Most parents commented positively on the family focus of interventions, the way in which their views had been heard and respected, and their needs recognised. These comments

related to the nature of case management and the support other service providers such as psychologists and BIST practitioners. Professionals working as a team with parents and being guided by family priorities were appreciated by Ben's parents.

> *They never put anything in an uncomfortable way. I feel as though I am talking to people not professionals. She [case manager] doesn't make me feel like an idiot. She's not only there for Ben, she's there for all of us…. If we were uncomfortable with something, if they felt it was right they would go into it and explain it but if we were still uncomfortable it was shelved and they'd come up with some other strategies. Instead of just telling me about what I had to do, they were asking what would be best for me in terms of different strategies.* (Ben's mother)

The ready availability of responses was another aspect that a number of parents considered worked well. In addition "knowing we won't be alone" and **"**there's back up, there's always a follow up call" were identified as valuable. "(Case manager) is just a phone call way, everyone is just a phone call away if you really need someone to do something, it's a lot better" (Alex's father). Even when some professionals pulled back in their involvement, they let parents know that they could still be contacted. Parents had confidence in the personnel working with their sons during the intervention period and appreciated that they took time to understand the young person and the family. Ben's mother commented on the increased confidence in managing their son that they as parents had gained from the support of the BIST practitioner and psychologist. She also valued the commitment of the professionals working with Ben and the family. "She [teacher] won't admit defeat and [case manager] is always there. Problems are never too hard, they're always prepared to find a solution". For Alex's parents the availability of extra respite and being able to plan ahead were among aspects of the intervention that worked well for them.

Aspects of intervention that worked well as identified by case managers and other service providers were similar to those described by parents. A critical feature was the ability to individualise responses to the needs of the young people and their families. Having the "dollars" to buy what was needed at the time (for example, extra respite worker time, support worker in school) avoided waiting lists and bureaucratic delays. It was the view of a number of service providers that the communication, collaboration and commitment of all parties involved (parents, professionals, agencies) contributed significantly to the effectiveness of the intervention.

7.6.2 What IBIS funding allowed to be done differently

Participants' discussion of what the IBIS funding enabled them to do differently reinforced those aspects that they considered worked well and that were different from past service responses. The availability of extra funding allowed more timely and flexible responses to be made (extra case management hours, respite care and support worker in school). Alex's case manager stated:

> *I think getting Alex back to school was a real positive that probably would have been a lot more difficult if we didn't have IBIS funding. We were able to go in and support the school significantly in those first 3 to 4 months.*

One parent commented on the importance of not being made to feel that the provision of extra services and supports for their son took resources away from others in need as had often previously been the case.

7.6.3 Aspects of dissatisfaction

Aspects that were identified as not working well for some participants, such as the need for better communication and coordination, were the opposite of features that had worked well for others. Some participants identified the need for more follow-up, for example, from

specialists to the school and from case manager to teachers, and for better coordination across settings, particularly the inclusion of respite care homes. Coordination was difficult when there was no one designated in a coordinating role as occurred for Carl and his family; they had no case manager during the intervention period. Parents of two of the boys still considered that there was insufficient emphasis on academic work for their sons at school.

At the completion of the year-long IBIS project, there was ongoing work with all four boys and their families, including BIST involvement, seeking counselling, continued involvement of case manager, and plans for unspent IBIS funding. Some professionals, for example, psychologists who were engaged for a particular purpose, had ceased their involvement. The extent of interagency collaboration, particularly between human service providers and schools, had reduced.

8.   Implications of findings for practice

The problem behaviours displayed by the four boys in the study were challenging not only for families but also for service providers. All of the boys had a history of problem behaviours, with increasing severity spanning several years. Parents reported numerous attempts to get assistance to manage such behaviour in both home and school settings prior to the IBIS project. While on occasion some help was received, the most common picture was one of not receiving timely assistance, long periods on waiting lists and uncoordinated, fragmented or unhelpful responses that resulted in considerable frustration for families as their sons' problem behaviours worsened and situations in the family and at school deteriorated.

Barriers to effective family/agency collaboration prior to the funded intervention period included families having to be in crisis to get help and discontinuity in services. As efforts were focused on urgent, crisis cases, little if any time was allocated to follow up. This precluded the possibility of identifying problems in early stages and responding before situations deteriorated markedly. Staff turnover also contributed to discontinuity. Service providers identified lack of resources as an additional barrier to effective interagency collaboration. In rural areas there was even greater difficulty in accessing support services because appropriate staff were not readily available in the locality. In one case, the family lived over 90 minutes travel from case management support and the child attended a school almost one hour from home. Difficulties were exacerbated by the compartmentalisation of services, having to deal with different funding systems such as human services and education and the limited communication between services.

Extra funding available through the IBIS project was used to purchase specialists services (psychologist), extra respite care worker hours, extra case management hours, communication equipment and to provide flexible financial assistance (such as purchasing petrol to enable the parent to drive his son to school rather than risk difficulties on the school bus). Interventions not provided by special IBIS funds included regular allocated case management hours, respite care (both at respite care facility and a worker coming to the boy's home to take him on recreational outings) and access to the Behaviour Intervention Support Team. The extent of parent/professional and interprofessional/interagency collaboration during the intervention period varied between participants. The most successful collaborations occurred when parents were fully involved in decision making, interventions were family-directed and family-focused, and there was effective communication and support among team members. Least collaboration occurred in the instance where there was no one in a central coordinating role. There was significant improvement reported for all four boys' behaviour at school although not all of the changes could be attributed directly to

interventions established as part of the project. The extent of improvement in the boys'
behaviour at home varied across the participants.

The generalisability of the findings is limited by the case study nature of the research. The
themes that emerged were however consistent with many of those identified in previous
research and have implications for effective responses to children presenting with problem
behaviour and their families. While the study was not designed to implement a wrap around
or positive behaviour approach (Burchard & Schaefer, 1992; Carr et al, 2002), many of the
aspects that appear to have contributed to successful outcomes shared elements with those
approaches. These aspects included being family-centred and working collaboratively in
teams and implementing multi component plans.

The study findings underline the importance of early and proactive intervention. In all four
cases, numerous requests for assistance by parents, teachers and others had been made prior
to the IBIS intervention. The absence of timely and flexible responses to these requests often
compounded the stress for caregivers. As the boys grew physically bigger and problem
behaviours became more entrenched, constructive solutions became more difficult to find
and the boys were excluded from the school and families reduced the inclusion of their sons
in family outings. Crisis-driven services were also unable to take a proactive approach and
contribute supports that might have prevented problems from escalating.

Parents' expectations in this study were similar to those found in the Turnbull and Reuf
(1997) study. Parents of children and adults with an intellectual disability and challenging
behaviour wanted to work in collaboration with professionals and community members to
address challenges of creating an inclusive lifestyle for their children. However, parents did
not want to be exclusively responsible for taking the roles of initiator, analyst and
choreographer of lifestyle changes and supports for their children. Turnbull and Reuf argued
that the challenge to the field is to create collaborative linkages among all stakeholders--
families, individuals with an intellectual disability, case managers, disability support
workers, respite care-givers, teachers, specialists, administrators, friends, neighbours and
other community citizens--that build reliable alliances. Reliable alliances entail the creation of
a shared vision and common understanding of goals, working in a relationship of trust
between all team members, shared expertise and shared responsibility for decision making.
For Ben these were among the aspects the parents and providers considered worked well in
the intervention and contributed to successful outcomes.

Building reliable alliances requires a change from traditional ways of working where the
professional is seen as the "expert" who proscribes treatment (Cunningham & Davis, 1985).
This is not to suggest that professional's skills and knowledge are not utilised but rather that
professionals are also guided by family goals, preferences and routines and work with
families to develop strategies. There is much talk about parents as the "experts" concerning
their family member with a disability but often this is not matched with practices that
demonstrate professionals heed parents' views. In the current study, for example, teachers
did not always believe parental assessment of a child's potential academic abilities and
expressed surprise at the improved academic skills shown when problem behaviour was less
evident. Professionals in the study also on occasion "protected" families by deciding not to
share information about their son's behaviour. This ultimately was unhelpful to developing
trusting relationships.

Trusting relationships take time to build and sustain and can be disrupted when there are
staff changes. Families also need to be able to trust that professionals and caregivers working
with their child are skilled. This is not to say that parents expect that professionals will have
all the answers but that they will have the requisite competencies for their job and that they
will be committed to working with parents to develop solutions to problems. In some cases,

teacher management responses were clearly inappropriate and required the input of visiting behavioural specialists to clarify goals and strategies. The notion of shared expertise needs to be revisited, with all parties accepting that they do not always possess all of the expertise in all situations. Being open to shared problem solving strengthens the relationship, affords greater opportunity for effective intervention as well as opportunities for growth in professional expertise.

Compartmentalisation of services and funding can create barriers to interprofessional and interagency collaboration. This is particularly an issue for collaboration between education and human service agencies. School programs tend to be non-collaborative, episodic and limited to the school setting (Snell, 1997). Raos and Kalyanpur (2002) contend that school-home collaboration poses several challenges. To overcome these potential obstacles requires a substantive commitment of time and effort and reconceptualisation of roles. For Ben and to a lesser extent Alex and David, there was sharing of skills and resources that crossed agency funding boundaries. In Ben's case there was also considerable support between team members. In many ways Ben's classroom teacher had greater support from the team (parents, case manager, BIST practitioner, psychologist and support worker) than she had from her own school administration who wanted to expel Ben from the school.

Working together better to respond effectively to challenging behaviour requires collaboration between the young person, families, professionals and other personnel to develop a shared understanding and strategies that are acceptable to all involved. Support and, where required, training needs to be provided to families, teachers, case managers and caregivers in order to carry out and implement positive behaviour support in a comprehensive and effective manner (Dunlap et al., 2000). Concerted efforts are needed to build the capacity of educators and community service providers to work in collaborative teams

Best practice in positive behaviour support or wraparound approaches indicate that typically interventions will be multicomponent interventions with outcomes dependent on a number of interacting factors. This was the case with Ben and his family where interventions included developing alternative communication skills and providing counselling for Ben, providing a support worker in the school to work with Ben and support his classroom teacher, developing strategies that Ben's parents could use and extending Ben's recreational activities. Given the broad aims of positive behaviour support to implement strategies that improve adaptive behaviour for individuals with problem behaviour, and increase community participation and quality of life for individuals and their families, evaluation needs to go beyond simply considering reductions in problem behaviour. As multicomponent interventions are proposed as best practice evaluation of outcomes, researchers should not look to isolate a single variable. The field is shifting away from standard technique-orientated approaches (cookbook approaches) in favour of more assessment based, individualised and contextually relevant approaches (Dunlap et al., 2000). Practitioners should also assess the efficacy of strategies implemented. The finding of this study that there was not systematic recording either for assessment or to monitor progress during intervention was probably reflective of typical practice. To justify in an accountable manner the allocation of resources, it is important that interventions are assessed. The challenge is to be pragmatic about what is achievable and to develop user-friendly ways of assessing, recording and monitoring behaviour and outcomes that will yield useful information (Carr et al., 2002)

This study shows that effective outcomes were dependent on a mix of skills and inputs that were highly influenced by contextual variables. A review of early experiences prior to the one-year intervention revealed considerable inflexibility in service provision across agencies and the exacerbation of each child's behaviour to crisis point before assistance was provided.

While the one-year intervention strategies implemented for each child had the benefit of flexible financial resources, the importance of close collaboration of all parties to achieve effective outcomes was highlighted. Problems persisted in areas where professionals and agency personnel did not share a common vision with families and where insufficient liaison occurred across all parties (e.g. respite care settings were sometimes outside the information loop). Working together effectively involves the building of trust, the sharing of expertise and openness to problem solving.

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Stewart, C., O'Connor, N., Wilson, L., Webber, L., & Bailey, S. (2001, November). *Better ways to work together: responding to the needs of young people with challenging behaviour and their families.* Paper presented at the ASSID Conference, Melbourne.

Stewart, C., O'Connor, B., Wilson, L., Webber, L., & Bailey, S. (2001, May). *Building better relationships: Families and agencies working together.* Paper presented at the CIDA Conference 2001, Inclusion: The Next Challenge, Melbourne.

Appendix: Interview Schedules for Parents, Children and Agencies

1. **Considerations checklist across all groups**
   - Have the behaviours targeted for intervention changed?
   - Level of restrictiveness of interventions
   - Evidence of behaviour change across all environments
   - Are the child and their parents satisfied with the services received and their level of involvement in service decisions?
   - How can relationships between service delivery systems and their children and their families be improved?

2. **Parent Schedule (Pre) - Semi Structured Interview Schedule** (parents)

   - Family, demographic details - ages of family members, living situation etc.
   - Services and agencies that child and family are currently involved with. (school, paediatrician, other specialists, respite care, case manger etc.)
   - History of service involvement, what has been helpful, what would family like to have seen done better or differently.
   - How does family rate the communication from disability support services about their family member?
   - How does the family rate agencies involvement of them in planning for their family member?
   - Current problems for child as described by family.
   - History of current problems, when first began, any previous attempts to intervene, what was helpful, what was not in addressing problems?
   - Current needs of child as seen by family; how would family like to see these responded to?
   - How does family rate the communication from agencies involved about the current intervention with their family member?
   - To what extent has the family been involved in the planning for the current intervention?
   - What is the nature of the current intervention, as understood by family?
   - What are the expectations of the family of the current intervention?

3. **Parent Schedule (Post) – Follow-Up Interview at Completion of Funded Intervention**

   - Situation for child re living, school.
   - Services who were involved during intervention period and services still involved with family and child.
   - Status of behaviour problems that were the focus of the intervention, from the family's perspective have they stayed the same, improved, got worse?
   - What was helpful in the intervention?
   - Were there any aspects the family would like to have seen done differently?
   - What was the level of consultation and involvement of families across the intervention period, how do families rate their satisfaction with the level of consultation and involvement?
   - How well co-ordinated did the agencies involved appear to be to the family?

- What would the family like to see from now in terms of the supports and services that they and the target individual receive?
- What follow-up is the family expecting?
- Satisfaction with the intervention

4. **Young People's Schedule (Pre)**

    General points:
    - young person to take part to extent that is possible, communication strategies to be adapted to those that are familiar to and used by young person concerned, for example our understanding is that one potential participant is non verbal but has speech therapy involvement in the development of alternative communication systems and so if this individual took part we would need to make adaptations accordingly.

    Semi-Structured Interview - (Young People)

    - Living situation
    - School, current and past, likes and dislikes about school.
    - People who work with them and what they do, case manger, teacher etc.
    - Who do they go to if they have a problem?
    - What they understand about the help they are currently receiving?
    - Who has talked with them about this help?
    - Have they been involved in the planning?
    - What are the problems as they see them, difficulties they are having?
    - What would they like to see happen over the next year for themselves?

5. **Young People's Schedule (Post) – Follow-Up at the Completion of the Funded Intervention Period**

    - Current situation
    - People who work with them now and what do they do.
    - Satisfaction with intervention
    - Level of their involvement in intervention planning as young person perceives it.

6. **Agencies Schedule (Pre) - Semi-Structured Interview Schedule - (Agencies)**

    - History of involvement with child and family.
    - Other agencies with which your agency has contact with about child and their family and how is this co-ordinated.
    - Current behaviour problems as seen by the agency.
    - What assessments have been done regarding the behaviour problems?
    - Needs of the target individual as seen by the agency.
    - How does agency plan to respond to these needs in the intervention period?
    - How will progress be monitored?
    - What outcomes are hoped to be achieved for the young person and their family as a result of intervention?
    - How will the family be involved in the planning and implementation of intervention?

- What factors might enhance the likelihood of success?
- What factors might hinder the likelihood of success?

7. Agencies Schedule (Post) – Follow-Up Interview at the Completion of Funded Intervention Period

- Involvement during funded intervention period.
- Current involvement with child and their family.
- Were there any changes to the original intervention plan and if so why, includes changes to agencies involved?
- Rating of the status of the targeted problem behaviours, improved, the same, worse.
- What were the outcomes of the intervention for the child and their family?.
- How was progress monitored throughout the intervention?
- How was the efficacy of intervention evaluated?
- What was the family involvement during the intervention?
- Who was responsible for communicating with the family?
- How were interagency responses coordinated?
- What were the most successful aspects of the intervention?
- What things were problematic during the intervention?
- Where there any aspects that could have been done differently.
- What follow up is planned?