Impact, effectiveness and future application of
Positive Behaviour Teams (PBTs) in the provision of
disability support services in Western Australia

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Chapter 1 – Executive summary

The Positive Behaviour Team (PBT) is a specialist clinical service funded and operated by the Western Australia Disability Services Commission (DSC), through the Statewide Specialist Services Directorate. The service provides behaviour intervention and support to people with disabilities (6 to 25 years of age), living with their family and at risk of requiring premature out of home placement. The PBT commenced operation in 2007. More recently, it has operated in a way consistent with, and as part of the WA Positive Behaviour Framework, which was formalised in 2009.

This report documents the findings of a comprehensive evaluation of the PBT, conducted between July 2008 and December 2010. The process included 10 data collection visits to the PBT (typically for a week each time), analysis of quantitative data from all clients referred to the PBT, interviews with nearly 1/3 of families, together with interviews and surveys with all staff and a range of stakeholders both internal and external to the Disability Services Commission. The evaluation was conducted as a formally constituted research project with Human Research Ethics approval from both RMIT University and Deakin University (refer appendices 3 and 4).

The findings of the evaluation support the continuation and further development of the PBT. Both the quantitative and qualitative findings support the assertion that the PBT is achieving the aims and purposes for which it was established. While the scope and power of the statistical analyses were limited, due largely to the relatively small sample size, there was evidence of statistically significant gains being made on a number of the standardised indices (e.g., Beach Family Quality of Life Scale, Parenting Sense of Competence Scale, the Developmental Behaviour Checklist). Furthermore, even where some analyses failed to detect significant improvements across pre/post measures, where pre-intervention measures had indicated family members to be reporting ratings significantly different from those to be expected of people in the general population (i.e., clinically worse), their post intervention measures were often indistinguishable from those to be expected of people in the general population, and as such were indicative of positive gains (e.g., some subscales on the Personal Wellbeing Index, the Depression Anxiety & Stress Scale, the Coping Resources Inventory, and the Parenting Scale).

For those in receipt of PBT services, family breakdown and premature placement of the person with a disability out of the family home has been successfully avoided. Families report that they feel more knowledgeable about their son’s or daughter’s support needs, and that they have the resources needed to cope more effectively with the challenges that they encounter in the support of a family member with disability and severe challenging behaviour. There is evidence to suggest, as a consequence of the PBT’s involvement, that the safety, wellbeing, skills, and quality of life of the persons with a disability and their families have been enhanced.

However, there is also data from the current evaluation to indicate that many of the families, though benefiting substantially from the involvement of the PBT, remain fragile. Notably, many parents in particular reported symptoms indicative of poor mental health, exhibiting clinically significant levels of depression and anxiety. It is
evident that many will require access to specialist supports in the longer-term, to encourage lasting positive behaviour change and to sustain their quality of life at a standard necessary to preserve their health and wellbeing, and at a level expected by the wider community. Without such support systems, re-referral to the PBT is highly likely, and the risk of family breakdown and the need for a premature out of home placement will remain. Based on what families indicated in the current evaluation, these circumstances are highly likely at critical times such as: onset of adolescence, change of school, transition from school to post-school options, changes in employment, change of family relationships or family dynamics, or changes in family financial circumstances. The service system needs to be attuned to these critical times for families, many of which are readily predictable, and prepared to respond as might be needed.

The client group in receipt of services from the PBT were clearly those intended as the focus population. They were people with disability, living with the support of their family, and who exhibited severe challenging behaviour. These behaviours placed in jeopardy their safety and the safety of other members of their family. Furthermore, there was clear evidence that these individuals were already being excluded or in immediate danger of exclusion from community facilities essential to their development and wellbeing, such as schools and respite services. In some instances the severity of the person’s behaviour had impeded access to other community amenities, such as shopping centres and recreation facilities, and had brought families into conflict with neighbours.

The high proportion of clients with a primary diagnosis of autism (nearly 20%) or of autism in addition to their primary diagnosis of intellectual disability (approximately 40%) is worthy of particular note. These figures have implications for both the operation of the PBT (e.g., staff skills and professional development) and policy development for the DSC more broadly.

The approaches adopted with individual families, together with the intervention and support programs developed by the PBT, were clearly consistent with the established principles of Positive Behaviour Support (PBS) (Carr, Horner, Turnbull, Marquis, McLaughlin, McAtee, Smith, Ryan, Ruef, & Doolabh, 1999). They were designed to address deficient environmental conditions within families (e.g., knowledge, skills, and strained interpersonal relationships) and the service system needed by the person with disability (e.g., at schools and in respite services). Furthermore, the approaches addressed deficient behavioural repertoires of the person with disability (e.g., communication, self-care, coping, and social skills) and those involved in their support (e.g., family members and staff at school or in respite services). Functional communication, both for the person with disability and other family members, was a prominent feature of intervention and support programs. Furthermore, there was evidence to indicate that the procedures adopted by the PBT were consistent with a family systems model of intervention and a family centred approach, together with a focus on promoting quality of life for all members of the family. The features of the PBT approach were recognised and endorsed by the families in receipt of services, as indicated in interviews, and on standardised measures (e.g., The Quality of Family–Professional Partnership Measure, The Measure of Process of Care, and The Partnership Orientation Measure).

The activities and success of the PBT were recognised and endorsed not only by families but also by other stakeholders. Notably, staff from other areas of the
Disability Services Commission (e.g., Local Area Coordinators and clinicians on Community Teams) observed how effective the PBT had been in working with families they had referred for services. Furthermore, external service providers (e.g., schools and respite services) gave positive feedback concerning the impact PBT involvement had on both the individuals with disability attending their service and on their families.

Data provided by PBT staff indicated that team members were identifying gains for the families with whom they were working. Furthermore, there was evidence to suggest that the management and staff support processes developed for the PBT were effective. In particular, working in multi-disciplinary pairs and having available whole of team case conferencing to support assessment and program planning were endorsed by both team members and families. Furthermore, access to regular individual staff support and supervision sessions all appeared to contribute to a positive and healthy work environment. Staff appeared adept at and comfortable with giving and receiving feedback to each other, and happily and effectively took responsibility for looking after each other. Staff reported relatively high levels of personal/professional accomplishment and low levels of emotional exhaustion relating to their work. In addition to interview results, standardised measures of staff health affirmed the work environment to be conducive to a healthy and productive workplace (e.g., Personal Wellbeing Index, Human Services Survey, and the Occupational Stress Scale). The seniority and consequently the experience of PBT staff emerged as a potentially important contributor to both the achievements of the PBT and their positive reception (and the positive reception of program recommendations) by families.

The current study did not attempt a formal cost-benefit analysis for the PBT. However, it would be reasonable to conclude that the PBT provided a cost effective service. The average cost per client amounted to $27,966 (for an average engagement of 15 months support per client). Given the severity of the behaviours of the people referred to PBT and that the risk of premature out of home placement was one of the criteria for referral eligibility to the PBT, the cost of the PBT service compares favourably to the average cost per client per year for out of home accommodation support in Australia, and certainly represents a more cost-effective approach than relying on Individual Family Support packages (IFS) alone. Across Australia, out of home accommodation is estimated to cost between $24,611 per client per year for the model with lowest hours of support (unsuitable for clients of the PBT) to $95,308 for the model with high levels of support, inclusive of administrative costs (Fisher, Parker, Purcal, Thaler, Abelson, Pickering, Robinson, & Griffiths, 2008). The average cost for 24-hour group home accommodation in Australia is estimated at $61,000 per client per year (Productivity Commission, 2011). Of course, in addition to the cost benefits, there are the more important personal benefits of maintaining people with their family of origin especially during childhood and adolescence (e.g., maintaining social networks, continued access to familiar environments and services, participation in domestic routines and opportunities for incidental skill development), until such time as they would typically move to more independent accommodation (cf. Stancliffe & Lakin, 2005).

The report that follows provides an overview of the philosophical and operational background to the PBT, followed by a list of recommendations arising from the evaluation. The report highlights the PBT’s achievements and provides data that will be useful when planning strategies to sustain and expand the service (including the
development of similar services in collaboration with community-based organisations). The report also highlights areas for service enhancement. Implications for policy development and both intra-agency and inter-agency collaboration are identified.

There are 62 recommendations documented at section 2.2 of the report (pages 18 to 24). In support of the recommendations there is a detailed description of the research methodology (see Chapter 3), including each of the measures employed in the evaluation, and the results of both the quantitative and qualitative assessments conducted (see Chapter 4). Full references for all the assessments used and key documents referred to in the report are provided (see Chapter 5). References and resources are provided in the appendices (see Chapter 6).

In presenting this report, the author would like to acknowledge and thank the contributors; including the families who generously and honestly shared their experience, the staff of the PBT for their professionalism, and the many stakeholders who also contributed. In particular, thanks are due to Craig McIver and Jacki Hollick, without whose sustained support and substantial contribution this project would not have been possible.
Chapter 2 – Background and recommendations

2.1 Background

2.1.1 The Positive Behaviour Team (PBT)

The need for specialist services to provide assessment, intervention and support for people with disability who exhibit challenging behaviour and to support families and others providing their support is now well documented in the research literature and, internationally, in government policy and legislation (e.g., Productivity Commission, 2011). Consistent with this recognised need, the Positive Behaviour Team (PBT) is a specialist service funded and operated by the Western Australia Disability Services Commission (DSC), through the Positive Behaviour Service. Implementation of the PBT has been a staged process, having commenced in 2007. The model of service delivery, current at the time of preparing this report, is provided at appendix 1.

The PBT is managed under the auspice of the Statewide Specialist Services Directorate, within a policy context governed by the WA Positive Behaviour Framework, which was formalised in 2009. The Framework has been established in recognition of the high support needs of many people with disability who exhibit challenging behaviour. It recognises the need for highly skilled and dedicated tertiary level teams to provide specialist support in community settings. The role of the PBT within the Statewide Positive Behaviour Framework is shown in appendix 2. However, it should be noted that for the period of the current evaluation PBT involvement was restricted to the support of high needs families. The delivery of PBT services to other high needs clients of the DSC is to be the focus of future developments.

For the period covered by the current evaluation, the aim of the PBT has been, as part of the wider WA Positive Behaviour Framework, to assist people with challenging behaviour to live successfully in the community, primarily with the ongoing support of their family. To achieve this aim, the PBT was established to work in partnership with families and other primary carers to:

- Prevent family breakdown or premature placement of the person with a disability out of the home
- Strengthen the family/carer’s knowledge, skills and resources to enable them to cope more effectively
- Enhance the safety, wellbeing, skills, and quality of life of the person with a disability, along with their family/carers.

The mission of the PBT is stated to be:

“To encourage lasting, positive behaviour change and improved quality of life of the person with a disability and their family by increasing the capacity of the person, their environment, and support systems”.

The client group for the service includes people with disability, who exhibit challenging behaviour, living with the support of their family. The PBT identifies its
client group to be those persons with disability described by Emerson (2001) as exhibiting behaviours that are defined in terms of:

“…culturally abnormal behaviour(s) of such an intensity, frequency or duration 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 result in the person being denied access to, ordinary community facilities.” (p.3)

The PBT currently provides services to people with disability (and their families) living within the Perth Metropolitan area. The target group has an identified age range of 6 to 25 years of age, with a focus on support for persons living at home but at risk of premature out of home placement. These criteria were established following a review of referrals made to various teams within the Commission, and reports from community sector organisations contracted by the Commission to provide intervention and support services for people with disability and their families. It is envisaged that, if proven to be effective, the service will be expanded to serve people in other areas of Western Australia.

At the outset, the need for prolonged engagement with families was recognised. Consequently, involvement with individual clients and their families was anticipated to span a period of 6 to 12 months.

The need for a flexible model of service provision to meet the needs of a diverse range of families was also recognised. Furthermore, the need for a sound theoretical basis for formulation and delivery of services was considered paramount. Subsequently, the service was established on the basis of a number of principles and practice models with a strong evidence-base.

For example, the PBT has drawn on and adapted materials and processes developed as part of the Stepping Stones Triple P – Positive Parenting Program (Sanders, Mazzucchelli, & Studman, 2003). The Stepping Stones Triple P (SSTP) is a parenting program specifically designed for families who have a child with a disability. It is based on the original Triple P system of intervention, which has been the subject of some 30 years of development, and a series of well controlled outcome studies that have demonstrated the efficacy and effectiveness of the parent training methods used in the program (Sanders, 1999; Sanders, Mazzucchelli & Studman 2004).

In addition to the SSTP philosophy and processes, the theoretical underpinnings of the PBT and subsequent influences on its own philosophy and procedures have included Positive Behaviour Support (PBS), a family/client centred approach, family systems intervention, the importance of functional communication skills, and a focus on quality of life for the person with disability and other family members:

**Positive Behaviour Support (PBS)**

PBS is well established and recognised as the principle evidence-based approach to behaviour support in the fields of disability and education (Carr, et al., 1999). It is characterised by the application of the scientific method associated with Applied Behaviour Analysis (ABA) and the formulation of strategies to:
- Address deficient environmental conditions (e.g., physical access, activity schedules, engagement techniques and choice making opportunities)

- Address deficient behavioural repertoires (e.g., communication, self-management, ADL and social skills).

More recently, Carr 2007 identified three underlying principles that characterise the PBS approach to developing, implementing and evaluating behaviour support programs. These are that PBS programs should be designed in such a way as to:

- Redesign the counter productive and unfair environmental contexts that so many people, both with and without disabilities, have to contend with in their everyday lives

- Give people the skills, the coping strategies, and the desire/motivation to deal effectively with the frustration that is an inevitable part of life, particularly the lives of people with disabilities

- Give them and their loved ones the support they need to challenge and reconstruct systems that serve bureaucratic needs, rather than human needs.

A family/client-centred approach

The service model is predicated on a family/client centred approach, whereby the focus of assessment and intervention is on strengths, issues, and desired outcomes that are identified, and consequently have meaning for the person with the disability and their support system. This is a well-established and scientifically validated approach to the delivery of effective intervention services for children and their families generally, and for children with disability and their families in particular (King, King, Rosenbaum, & Goffin, 1999; Rosenbaum, King, Law, King & Evans, 1998). The approach ensures that the focus of intervention is meaningful, and therefore strategies introduced are more likely to be sustained. The relationship between the family and the practitioner emphasises collaboration, partnership and exchange of information designed to ensure that parents receive the support and information they need to make informed decisions about their son’s or daughter’s support. Importantly, the adoption of a philosophy of family-centred service reflects an intentional move away from an expert practitioner, top-down model of assessment and service provision. It is consistent with a contemporary service model focused on empowerment of both people with a disability and the key supports/people (typically family members), upon which they rely.

Family Systems Model of Intervention

The family systems approach (see Anderson & Sabatelli, 2010) recognises the important roles that different parts of the various systems that support people with a disability play when seeking to address challenging behaviour. Challenging behaviour always occurs within a context. Family systems approaches recognise the importance of engaging with family members, as
well as other significant support systems, to identify how these systems serve to facilitate challenging behaviour, as well as to identify what can be changed systemically to improve appropriate management of challenging behaviour.

The adoption of a positive behaviour support approach, combined with a family/client centred approach and family systems model of intervention is consistent with both the long established principles of Multi-systemic Systems Theory (MST) (Henggeler, 1998) and the current World Health Organisation’ bio-psycho-social approach to understanding disability and health promotion (cf. WHO, 2001).

**Functional communication**

Communication has long been established as a major consideration in any effort to change human behaviour (e.g., the work of Durand, 1990 & 1993). This extends to both how the behaviour is understood by those observing it as a communicative activity (i.e., a means by which the person expresses their feelings and needs, likes and dislikes) and how those responsible for implementing the intervention (i.e., family members and support staff) interact with the person with disability.

Functional communication can include the use of language with varying adaptations to meet the developmental and comprehension needs of the person with disability. It can also include the use of Augmentative and Alternative Communication (AAC) strategies. These AAC strategies can include the use of sign language, symbol systems (both pictorial and object based) and communications information technology.

At the crux of the clinical application of this approach is that challenging behaviour serves a communicative function and in understanding that function we can identify alternative ways that a person can meet their communicative need instead of resorting to challenging behaviour.

**Quality of Life (QoL)**

A major focus of the team’s activities is that of promoting for the person and their family; the so-called Five Service Accomplishments, as outlined by John O’Brien:

- Presence in the community
- Participation in meaningful activity
- Choice in everyday activities and major life events
- Competence is attained and demonstrated to the full potential of the person’s ability
- Respect for the dignity and human rights of the person.

The focus on the Five Service Accomplishments positions the work of the PBT in a contemporary service paradigm that emphasises the importance of
interventions and supports that promote quality of life (QoL). QoL has been defined by Cummins (2005) as:

“both objective and subjective, each axis being the aggregate of seven domains: material well-being, health, productivity, intimacy, safety, community, and emotional well-being. Objective domains comprise culturally-relevant measures of objective well-being. Subjective domains comprise domain satisfaction weighted by their importance to the individual”

Suffice to say, it can generally be understood as having been obtained where there is a fit between the person’s aspirations, their needs and every-day experiences across their various life domains.

To achieve its aims, the PBT (originally as a single team, and now constituted as two area-based teams) is staffed according to contemporary principles that emphasise an interdisciplinary approach to behaviour support (McVilly, 2002/2007; McVilly, 2010; Sigafoos, Arthur & O’Reilly, 2003). These professionals include experienced/senior clinical psychologists, speech pathologists, social workers, and, more recently, occupational therapists. In total there are 12.5 FTE positions, with approximately 14 staff working across the two teams at any one time. Each team is managed by a designated Team Leader (included in the aforementioned FTE and staff numbers).

Team members work in pairs with any one referral. Provision is made for approximately 35 active referrals at any one time. The assessment and intervention for each person (and family) referred is reviewed on regular occasions by both the team leader and the team as a whole, using a structured case review process.

The structured case review process was established in recognition that the complexity of the issues involved in the support of the target group that had previously not been effectively addressed by sole practitioners or staff working in relative isolation. It also recognises the importance of supporting team members to enhance team health in the face of complex clinical caseloads.

The selection of experienced staff to work on this team also takes into account the demands of working in a complex area and the need for significant expertise to do this well. Team members have the opportunity to work flexibly with families, with early morning and evening visits not uncommon. Staff are asked to be as flexible as they can be, though working outside of typical business hours is not formally required.

The work of the team is informed by, among other legislation and policy, the provisions of the Disability Services Act (WA) 1993, the Mental Health Act (WA) 1996, and the Guardianship & Administration Act (WA) 1990.

2.1.2 The evaluation research project

The PBT was established, consistent with an evidence-based approach to the provision of support services, with a research and evaluation component incorporated. This research and evaluation component is intended to be part of the PBT’s on-going operations. However, to commence this process, a formal evaluation was established. This evaluation was intended to provide some initial
reflections on the early operation of the PBT, inform its future development and provide a framework to enable on-going research and evaluation to be conducted so as to inform future developments.

The current evaluation contract was finalised on 25th June 2008. Work commenced on the project in July 2008 (16th to 18th), with initial orientation to the PBT and its work. Between August and November 2008 documentation was reviewed and literature sourced to inform the evaluation process. In December 2008 (9th to 11th), and again in February 2009 (2nd to 4th), meetings were conducted with the PBT to finalise the evaluation protocol, consistent with the proposed ‘Action Research’ methodology that was agreed for the project. Also, some review and fine-tuning of the PBT data base was undertaken, to enable the on-going collection of relevant data, as part of the PBT’s on-going operations. In March 2009 (9th to 11th), further meetings were held with the PBT and interviews with family members in receipt of PBT services commenced. During 2009 and 2010 further interviews were conducted with families and other stakeholder groups, with data collection ending in December 2010.

The objectives of the research were:

- To determine the impact and effectiveness of the services provided by the PBT

- To establish an evaluation framework and management tool that will enable the on-going evaluation of the PBT and inform future developments and submissions for funding.

To provide a research report that will cover the context of the service, inputs required, a description and analysis of factors affecting the implementation of efficient processes and the achievement of specified service outcomes.

The principle research questions were:

- Does the PBT provide a service to the target group as defined in the Service Level Agreement?

- Is the PBT strategy feasible and responsive to the needs of the target group?

- Are the PBT operations, processes, functions, and objectives met in the course of service delivery?

- Does the PBT operate in a person and family centred way?

- Does the PBT achieve significant and sustainable reductions in challenging behaviour as well as increases in the person’s quality of life?

- What is the impact on the health, wellbeing, and job satisfaction of staff providing services?

- What are the possible future directions for the PBT, including options for expansion into regional areas?
It is anticipated that de-identified data arising from the research will be available for publication in scientific journals. Any such publication will be in consultation with the DSC, which will have the right to review data prior to any such submission for publication and reserve the right to be identified as a party to the research. Some preliminary data, with the approval of the DSC, has already been presented in professional forums, including at the 2010 annual conference of the Australian Psychological Society (APS), and the 2010 annual conference of the Australasian Society for Intellectual Disability – Research to Practice (ASID).

2.2 Summary of key findings and recommendations

The current report provides evidence in support of the following recommendations:

1. That the PBTs continue to provide specialist services to people with disability who exhibit severe challenging behaviour, and to the families of these clients.

2. That the service be expanded to provide support to people with disability and their families outside of the current limited metropolitan catchment.

3. That the current focus and eligibility criteria be maintained.

4. That the capacity of families, and parents in particular, to take on and sustain the demands of a PBT intervention, continue to be taken into account at the point of determining acceptance of a referral, and that alternative options be considered as appropriate (including, where necessary, extended respite or out of home placement).

5. That the current PBT information brochure be reviewed. This review could be undertaken in consultation with a number of families which have since completed the program. The brochure would benefit from including some indication as to the timelines and activities involved. However, it would be important to also acknowledge that each family is worked with on an individual basis, and that the PBT, while following a process, remains flexible to the needs of individual families; that is, it is not a structured program in the form that families might have previously experienced specialist behaviour support and intervention services.

6. That the current PBT referral form be reviewed, in consultation with LACs.

7. That the referral process incorporate some initial standardised assessment to assist with the determination of eligibility. Suitable tools could include the Developmental Behaviour Checklist [DBC] (Einfeld, & Tonge, 2002), the Psychiatric Assessment Schedule for Adults with Developmental Disability Check List [PAS-ADD Check List] (Moss, 2002), or the Maladaptive Behaviour Sub-scale of the Scales of Independent Behavior Revised (Bruininks, Woodcock, Weatherman, & Hill, 1996). These tools provide standardised measures of the severity of behaviour and their clinical significance relative to normative populations. Such tools can be administered by non-clinicians where they are provided with appropriate training. However, the interpretation of results should remain subject to review by appropriately qualified clinicians.

8. That the periodic call for referrals be maintained as a mechanism to regulate intake, with provision for at least two such intakes per regional team, per year (as is the case presently).

9. That at the time of referral, families be provided with a written indication as to when the intake committee will make a determination of their eligibility for service.
10. That the median time between referral and determination not exceed two months, as per present timeframes.

11. That the time between allocation of referral and the introduction to service meeting, subject to family circumstances, not exceed three weeks.

12. That, based on data from the first 3 years of PBT operations, provision is made for active engagement with a family for at least 12 to 16 months, subject to individual circumstances.

13. That the service maintains its focus on positive behaviour support, functional communication, and systemic family centred practice, as the core elements of their intervention framework.

14. That, while ensuring quality through a structured assessment and intervention process, flexibility in the PBT approach is maintained and formulaic approaches are avoided.

15. That, as endorsed by families in the current evaluation, the service maintains a strong focus on the principles of family centred practice. To this end, it will be important to continue to provide PBT staff with regular reflection and in-service development on the principles of family centred practice, to maintain fidelity to these principles and avoid a drift in practice to more traditional, clinician driven processes.

16. That, to address concerns expressed by some families, greater attention is paid to explaining at the introduction to services (and throughout the intervention process) what is understood by family centred practice and, in particular, the roles and expectations for both family members and clinicians. For this purpose, the development of a plain language summary sheet could be a useful resource to use with, leave with, and later revise with families.

17. That, to address concerns expressed by some families, greater attention is paid to developing and explaining individualised timelines for the assessment and intervention process, and that these be regularly reviewed (and revised) with families (e.g., at least monthly).

18. That, to address concerns expressed by some families, continued attention is paid to ensuring that families have meaningful assessment and intervention activities to implement as early in the process as is feasible. Ideally, an initial risk assessment and safety plan should be developed following the introduction to service meeting. As early as possible in the process, parents could be left with an observation task, a record keeping activity, or goal drafting activity that will be reviewed at subsequent meetings. A basic intervention could be trailed, such as a Social Story or the differential reinforcement of other behaviour (DRO). The use of DRO would be consistent with commencing a strengths based focus to the intervention.

19. That the use of video in assessment and as part of the program implementation continue and is further expanded upon. To these ends, it would be useful for staff to undertake formal training in techniques such as Video Interaction Guidance (see Kennedy, Landor, & Todd, 2011) or Marte Meo (see Aarts, 2008).

20. That, as endorsed by families in the current evaluation, the PBT continue to prioritise (and evaluate) interventions and outcomes consistent with promoting quality of life for the person with disability and their family. To these ends, it is recommended that individualised planning explicitly make reference to and be
informed by the results from the Beach Centre Family Quality of Life Survey (Hoffman, Marguis, Poston, Summers, & Turnbull, 2006) and the Personal Wellbeing Index (Cummins, & Lau, 2006).

21. That evidence-based-practice is embedded in the on-going operation of the PBT, including the collection and evaluation of individualised and aggregated assessment data. To support and foster this approach, PBT staff could benefit from professional development and supervision in the systematic implementation of single case study design (e.g., Yin 2009). To support this, on-going links with a local university would be helpful.

22. That consideration is given to adopting, as part of the standard assessment and evaluation battery, some of the assessments used in the current evaluation. In particular, the Parenting Scale, the Depression Anxiety & Stress Scale, and the Coping Resources Inventory appear to contribute to assessment and formulation of intervention. The team is encouraged to reflect on the findings in the current report when deliberating on such decisions.

23. That the current multi-disciplinary teams, consisting of the disciplines of psychology, speech pathology, and social work, be expanded to include occupational therapy (this has since occurred in one team at the time of writing this report). Future consideration could usefully be given to the inclusion of suitably qualified and experienced nursing staff and the retention of the services of a consultant psychiatrist.

24. That priority be given to the recruitment of senior and experienced clinicians to the PBT. And that the involvement of less experienced or probationary practitioners be in a support role with respect to their involvement in interventions, with procedures established to support formal mentorship of less experienced staff.

25. That the current trans-disciplinary approach to service delivery be maintained and appropriate induction be given to new staff so as to safeguard ethical practice within the boundaries of professional competence, while at the same time maximising the effectiveness and benefits of trans-disciplinary practice (refer McVilly, 2010).

26. That resource allocation continues to provide for the maintenance of inter-disciplinary team work (including the allocation of multiple clinicians with different professional qualifications to each family), regular case conferencing, and individual professional supervision.

27. That staff supervision and professional development take into account the requirements of the Australian Health Professionals Regulation Agency [APRA] and state-based registration boards as they pertain to individual professions. Such strategies will be critical to the recruitment and retention of senior staff.

28. That PBT staff be provided with opportunities to act in supervisory positions, to mentor less experienced and probationary practitioners, as well as having opportunities to seek periodic secondment to other teams in order to gain these experiences and maintain their broader professional skill set. Such strategies will be important for the retention of experienced staff and contribute to both enhancements of the skill base of the PBT and other services. Secondments could include those internal to the Disability Services Commission, to external agencies such as the Education Department and Health Department, and to community sector organisations. Secondment to community organisations could
be particularly helpful where community sector organisations were contracted to
develop and provide services modelled on the PBT.

29. That the model of service delivery continue with an emphasis on in-home
provision of support, together with support provided in other settings where the
focus person spends their time (e.g., at respite, school, and places of further
education, day support, and places of employment).

30. That policy be pursued that would promote inter-agency collaboration in the
delivery of PBT and related services, with a particular emphasis on collaboration
with the Western Australia Department of Education and peak bodies for the
Catholic and independent school systems.

31. That, in collaboration with families, greater attention is given to setting goals that
have greater specificity and which are more readily measurable (i.e., operationally
defined, with observable progress and definitive outcomes). With respect to this
recommendation, it is evident that while it is essential to capture the initial
aspirations of families concerning their desired outcomes in many instances
families and clinicians need to work together to more effectively operationalise
these aspirations and to determine observable and measurable milestones for the
achievement of these aspirations. Aspirational statements can be useful for
capturing a family’s initial wishes, but they are problematic for the purposes of
monitoring progress and outcome evaluation.

32. That consideration be given to adopting a formal process of Goal Attainment
Scaling (GAS) for all referrals, which can be used collaboratively by families and
clinicians to regularly review progress and evaluate the outcomes of
interventions. For the purposes of standardised monitoring and comparisons,
GAS scores can be converted to T Scores (with a pre-determined mean and SD)
and Z Scores (for the purpose of evaluating how scores compare to expected /
normal distributions).

33. That, consistent with family priorities reported in the current evaluation,
interventions include strategies that explicitly support the person with disability to
make progress at home (including promoting positive relationships among family
members and skill development to promote independence and the capacity to
make a practical contribution to the household consistent with their age and
ability), progress at school or at work, to make and maintain friendships, and
which promote and support positive working relationships with other service
providers (e.g., teachers and respite providers).

34. That interventions continue to explicitly assess and address identified challenging
behaviours, acknowledging that some behaviours arise as a consequence of (and
usually a combination of) deficient skills (including communication skills, problem
solving, and coping skills), deficient environments, physical and mental health
concerns, and/or genetic conditions.

35. That the combined skills base of the PBT include the capacity to design, deliver,
and monitor interventions involving an array of strategies, including: educational,
environmental behavioural, cognitive, communication-based and sensory based,
together with medical and pharmacological interventions.

36. That the combined skills base of the PBT continue to include expertise
specifically in the developmental and support needs of people on the Autism
spectrum and, more broadly, in the area of child and adolescent mental health.
37. That change in operationally defined behaviours continue to be a focus of intervention, particularly where these behaviours place the safety of the person and others at risk, or there is risk of exclusion from facilities and services vital to the person’s health, development, and wellbeing. And that, in addition to the Developmental Behaviour Checklist (Einfeld & Tonge, 2002), standardised assessment of challenging behaviours be included among the assessments conducted by the PBT (e.g., the Maladaptive Behaviour subscale of the Scales of Independent Behavior Revised; Bruininks, Woodcock, Weatherman, & Hill, 1996).

38. That greater attention is given, where appropriate to individual circumstances, the design and implementation of programs involving differential schedules of reinforcement. For example: differential reinforcement of incompatible behaviour (DRI), differential reinforcement of other behaviour (DRO), differential reinforcement of low response rate behaviour (DRL), and differential reinforcement of high rate behaviour (DRH).

39. That program planning and monitoring incorporate standardised (or best option when standardized is not available) assessment of adaptive behaviour (e.g., Bruininks, Woodcock, Weatherman, & Hill, 1996) and communication (e.g., Bloomberg, West, Johnson, & Iacono, 2009), which includes the capacity to appraise the individual’s psycho-social and cognitive stage of development.

40. That when developing intervention programs, consideration is paid to the provision of, where appropriate, individual psychotherapy for the focus person with disability. These services could be provided directly by the PBT or on referral to a collaborating clinician. Here interventions could include cognitive behavioural therapy, mindfulness techniques, and other evidence-based strategies adapted to the person’s individual circumstances. Such therapy could focus on critical clinical issues such as anger management or anxiety management, depression, grief, or attachment issues. Here too, it needs to be acknowledged that the profile of many of the focus persons with disability are characterised by social isolation and an absence of any person outside of their family in whom they can confide. Referral for external counselling could be an important means of addressing issues in circumstances where talking with their parents or siblings was not possible or inappropriate (especially for adolescents). Importantly, such strategies would build the support network for the person beyond the family and beyond the involvement of the PBT.

41. That policy and interagency collaboration be pursued that would build capacity for the provision of on-going support through youth and adolescent services operated by community organisations. To this end, consultation with the Western Australian Association of Youth Workers could be helpful.

42. That the development of risk assessment and emergency management strategies continue to be a priority for development as soon as possible following the initial introduction to the PBT. Given the behavioural profile of persons referred to the PBT, such procedures should be a standard feature of all interventions and included in the PBT service checklist (as they are now), as well as being subject to peer review at PBT case reviews. It would be useful for the PBT to develop a minimum practice standard expected of all team members.

43. That families’ need for respite services be reviewed as soon as possible following the initial introduction to the PBT. Given the needs expressed by families during
the current evaluation, a respite review should be a standard feature of all interventions and included in the PBT service checklist.

44. That provision is made for the PBT to make priority respite referrals.

45. That particular attention is paid to improving the knowledge and skills of parents with respect to effective situational management. In particular, raising parents’ awareness of: the extent to which agreed rules are allowed to go unenforced or inadvertently provided with positive consequences for misbehaviour; their over-reactivity to situations and inappropriate displays of anger; and, over reliance on lengthy and ineffective verbal interventions or responses to their son’s or daughter’s behaviour. To these ends, the results of the Parenting Scale (Arnold, O’Leary, Wolff, & Acker, 1993) should continue to be incorporated into regular discussion with parents, together with intervention planning and review.

46. That, consistent with the needs of families reported in the current evaluation, interventions include strategies that explicitly promote: the physical health of family carers; their connection with local communities; their sense of self-worth, efficacy and achievement (with respect to both their parenting role and in other life areas); their relationships (with their son or daughter with disability, their partner, and other children); and hopes (optimism) for the future (with respect to both the future for their son or daughter with disability, and for themselves).

47. That, consistent with a holistic approach to intervention, issues that impact on and promote the standard of living of families also warrant systematic assessment and intervention planning (e.g., the family’s financial circumstances and capacity to manage debt). Such intervention could be conducted in conjunction with LACs and specialist external service providers. To these ends, it would be useful to initiate consultation, and potential collaboration, with the Financial Counsellors Association of Western Australia.

48. That, consistent with the mental health needs of families identified in the current evaluation, PBT assessments and interventions continue to include systematic consideration of the mental health needs of parents, and, in particular, symptoms associated with the clinical conditions of depression and anxiety. On-going staff development to assist PBT members with the administration and interpretation of such assessments (e.g., the DASS) will be essential.

49. That the PBT develop protocols to determine when the mental health needs of family members can be best addressed directly as part of the PBT intervention and when referral to an external clinical service might be necessary (including referral via the family GP for access to Medicare funded psychological services). However, where external referral is initiated, consistent with the holistic approach of multi-systemic family intervention, it will remain important for any such treatment to be coordinated with the ongoing PBT intervention.

50. That the PBT continue to incorporate into its skill base (i.e., through on-going formal training and review) the capacity to provide brief/solution focused psychotherapy (e.g., Guterman, 2006). Such interventions are solution-based rather than problem-oriented. They are characterised by being less concerned with how a problem arose than with the current factors sustaining it and preventing change.

51. That, as endorsed by families in the current evaluation, assessment, and interventions involve, wherever appropriate and possible, all family members (including both parents, siblings, and other significant relatives).
52. That the support needs of siblings, where appropriate, are formally acknowledged in PBT intervention processes. The development of strategies to address issues for siblings could be supported through consultation with the peak body, Siblings Australia Inc.

53. That the option for regular (non-crisis initiated) telephone contact between visits are considered throughout the course of any intervention.

54. That the value and effectiveness of internet-based/video conferencing contact with families be evaluated.

55. That the PBT staff continue to closely work with Local Area Coordinators (LACs) throughout the course of the PBT involvement, with a minimum level of involvement of: participation in the introduction to service meeting, periodic case conferencing, and closure meeting. Such strategies will be important in addressing the issues of longer-term continuity of service involvement identified in the current evaluation.

56. That consideration is given to incorporating a person/family centred planning process into the final phase of PBT involvement. This component of the process could be facilitated by a key stakeholder (with ongoing connection with the consumer and their family) identified by the family (e.g. the LAC), thus promoting re-integration with the wider service system and longer-term continuity of support.

57. That 12 months following cessation of PBT services, families have the option for a formal review of their progress and current support needs. This review could be coordinated by the LAC and ideally involve the PBT staff who were originally involved with the family.

58. That the long-term support needs of families referred to PBT be recognised in the availability of post-PBT follow-up services. These could include support from LACs, Community Teams, and other key agencies.

59. That consideration is given to the development and trial of a telephone support and triage service, available to families who have completed the PBT program. This service would require access to discharge and related summary documentation prepared by the PBT.

60. That consideration is given to the staffing mix and mode of operation of Community Teams, so that they are better able to respond to the needs of people and families with complex behaviour support needs, drawing on the experience of the implementation of the PBT. Here it should be noted that the PBT represents a specialist tertiary team model and that it would be unrealistic to attempt to replicate it across the Community Teams. However, some elements of the PBT skills base (e.g., positive behaviour support, functional communication, and multi-systemic family therapy) could usefully be incorporated into the skill set of Community Teams, together with support to develop a more collaborative and trans-disciplinary approach to service delivery.

61. That, given the profile of people referred to the PBT, it would be useful to increase the specialist skills in Community Teams with respect to the support needs of people on the Autism spectrum and in regards to the triage of issues relating to child and adolescent mental health.

62. That policy and procedures relating to referral and collaboration with both health and mental health services be reviewed in light of the development of the PBT and its future operations.
Chapter 3 – Method

3.1 Introduction to the methodology

The research was conducted as a formally constituted research project, approved by the RMIT University Human Research Ethics Committee (SET 60-08), and subsequently by the Deakin University Human Research Ethics Committee (HREC 145-2009). The research methodology included a protocol for the reporting of any instance of abuse and neglect that might come to the attention of the researchers (refer appendix 5). However, this protocol was never required to be enacted.

The research design was informed by Stufflebeam (1983/2007), which is an established framework for the evaluation of human service systems. There are two basic attributes of Stufflebeam's model of program evaluation. First, it provides for collaborative evaluation in that both service provider and external evaluator work together to provide the best possible evaluation result. Second, it is designed so that it provides information for both formative and summative evaluation of the human service program. The former is important for the purpose of program improvement; the second, for the purpose of program accountability.

In accordance with the Stufflebeam model of program evaluation, there are four components in the proposed method: (1) context evaluation, (2) input evaluation, (3) process evaluation, and (4) product evaluation.

1. **Context evaluation** involves an examination of the program’s aims and objectives. Issues of relevance here are the extent that these are: (a) consistent with relevant policy directions, (b) socially/ecologically appropriate, and (c) couched in terms that facilitate evaluation of outcome. Provision is made for consideration of both program objectives (e.g., support provision to family carers) and client outcome objectives (e.g., sustained community living).

2. **Input evaluation** involves an examination of the planned program strategies. Of special interest here is the extent to which these are consistent with what the scientific literature indicates is effective. In this case, the issue is whether the initiative utilises strategies for people with disability who exhibit challenging behaviours that are consistent with those that the research literature shows are the most effective and which are in keeping with current professional ethical considerations. Inputs can include staffing resources, equipment/technology, curriculum content, and the funding that supports all such infrastructure.

3. **Process evaluation** is an examination of the extent to which the planned program strategies are actually implemented. This component of the evaluation involves gathering information on what the service providers do during a typical week or month. It could include review of existing data, data gathered in the course of service delivery, interviews, and observations.

4. **Product evaluation** is an examination of the outcomes of the program strategies. The basic question is “has the program achieved the aims and objectives that it initially set?” Information is gathered on a number of variables as part of this evaluation utilising a number of measures such as: standardised measures of
adaptive and maladaptive behaviour, goal attainment scales, health and mental health scales, quality of life scales, and scales designed to measure the functioning and status of both staff and family members. One of the important sources of information will be an assessment of the satisfaction of those involved in the initiative, such as the clients themselves and their families/significant others.

For each of the four identified areas of the evaluation model the research questions were developed, data collection tools identified, and the source and means of collecting and analysing them was specified. The data were then synthesised and integrated to answer the questions originally posed by the DSC and those subsequently posed by the PBT during the evaluation.

Data collection was, wherever possible, embedded within the service delivery process. That is, the primary data on which the team was to be evaluated was to be clinical data gathered in the course of everyday service delivery. This was considered important for two reasons. First, it provided ecological validity for the research and the subsequent findings. Secondly, it was considered as one means of supporting the longer-term (post evaluation) objectives to establish an evaluation framework and management tool that will enable the on-going evaluation of the PBT and inform future developments and submissions for funding.

However, additional data were collected. These included interviews conducted with clients, their families and staff providing the service, as well as interviews with stakeholders such as with schools and other service providers.

An Action Research approach was designed to maximise the involvement of the key stakeholders (i.e., the PBT members) in the research and evaluation process from the outset of the project. Furthermore, the methodology was designed to foster a culture of evidence-based practice within the team. To these ends, team members were involved in developing the research questions and selecting the instruments that were used in the evaluation. This approach ensured that the data to be collected would answer both clinical and operational questions and that the findings would be both relevant and helpful to the team.

Furthermore, as the project progressed, this approach provided for feedback and discussion among the team concerning findings as they emerged and involved the team in the interpretation of data as it was collected. This process allowed the research to be both formative and summative. That is, for the research process to both contribute to the team’s on-going development over the course of the project, as well as providing a final report and recommendations to the DSC concerning its achievements and future directions.

The data collection process included interviews with various stakeholder groups. These included other DSC professionals in community teams and Local Area Coordinators, who were responsible for the majority of referrals to the PBT. Service providers, including respite agencies and schools were also consulted, as these were environments in which clients of the PBT frequented and consequently had been involved in the development and implementation of intervention strategies. Table 3.1 provides a summary of the key elements of the evaluation process.
Table 3.1 Key elements of the evaluation process and stakeholder groups

<table>
<thead>
<tr>
<th>Elements of the review process</th>
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<tbody>
<tr>
<td>Documentation review</td>
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<tr>
<td>Development of Research Protocol with PBT</td>
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<tr>
<td>Database development</td>
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<tr>
<td>Family interviews &amp; surveys</td>
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<tr>
<td>Staff interviews &amp; surveys</td>
</tr>
<tr>
<td>Local Area Coordinator focus group</td>
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<tr>
<td>Community Teams focus group</td>
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<tr>
<td>School &amp; respite service interviews</td>
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</tbody>
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3.2 Participants

3.2.1 People with disability and their families

Participants were considered in two related groups. The first group was represented by all persons referred to the PBT between June 2007 and October 2010, in the form of data gathered by the clinical team and provided to the researcher in the form of de-identified data. The second involved a sub-set of the first group, comprised of families which agreed to an interview with the researcher and a review of their intervention data in an identifiable format.

Participants all met criteria for eligibility for access to services provided by the DSC. That is, to be eligible for specialist disability services, a person must have a disability as defined by the Disability Services Act 1993 and the person seeking services must live permanently in Western Australia and be an Australian citizen; or a permanent Australian resident; or a New Zealand citizen who arrived in Australia prior to 26 February 2001.

For the purposes of eligibility assessment, disability is understood to be 'a disability – (a) which is attributable to an intellectual, psychiatric, cognitive, neurological, sensory, or physical impairment or a combination of those impairments; (b) which is permanent or likely to be permanent; (c) which may or may not be of a chronic or episodic nature; and (d) which results in – (i) a substantially reduced capacity of the person for communication, social interaction, learning or mobility; and (ii) a need for continuing support services’ Disability Act WA, 1993; Section 3). Here, it should be noted that while the DSC provides services to persons with a disability as defined by the Act, those persons whose primary disability is psychiatric are supported by the mental health arm of the Health Department.

All persons referred for PBT services were already registered with the DSC for specialist disability services. All had previously been involved in specialist services designed for people with disability who show challenging behaviours (e.g., Cool Kids Program) and/or their families had been involved in specialist family programs modelled on, for example, the Positive Parenting Program (Triple P) or Stepping Stones.

There was a total of 114 referrals to the PBT between June 2007 and December 2010. Table 3.2 show progress with these referrals and numbers of persons within this group from CALD and Indigenous families.
Table 3.2 Summary of referrals and their subsequent status August 2007 to October 2010

<table>
<thead>
<tr>
<th>Referral Status</th>
<th>Total Persons/Families</th>
<th>CALD</th>
<th>Indigenous</th>
</tr>
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<tbody>
<tr>
<td>Received</td>
<td>114*</td>
<td>17*</td>
<td>2</td>
</tr>
<tr>
<td>Accepted</td>
<td>102</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Rejected</td>
<td>12</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Declined by families</td>
<td>14</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Completed</td>
<td>37</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Continuing</td>
<td>32</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Pending (for March 2011)</td>
<td>13</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Never allocated</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

* Includes 3 referrals (1 CALD family) received by the Home Based Autism Service (HBAS), which preceded the PBT, but which received a PBT service. There were an additional 7 persons (3 CALD), not included in the table, with whom team members worked in the transition from the HBAS model to the PBT Model – however, these persons received the traditional HBAS intervention.

Overall, there was an acceptance rate of approximately 90% of those referred. Reasons for declining a referral included: referral received from ‘out of area’ (2) at a time when access to PBT was restricted to specific metro service regions; a determination that the family was not ready for the intervention (1); the family was considered a low priority based on the criteria that took into account the severity of the behaviour and the associated likelihood of out of home placement (6); and a determination by the LAC involved with the family that intervention was not required (3).

There were 14 referrals that, following acceptance, were subsequently declined by families, one of which was a CALD family. One family relocated interstate. One person was later re-referred and accepted for services. There were 4 persons accepted, but not allocated within the holding list period (approx. 6-months), and who were not re-submitted in the next referral round when the holding list was closed.

There were 32 persons continuing to receive service as at December 2010. Of these, 9 were in assessment, 19 were in active intervention, and 4 were in the maintenance phase of support.

The profile of those persons receiving support is given in Table 3.3. However, it needs to be noted that complete database files were only intact for 90 of the 102 referrals accepted. Subsequent calculations are based on those data available via the PBT database.

There were 18 families on the database that volunteered to participate in the family interviews and review of their programs in an identifiable format, of which 5 had completed the PBT process. At the time the interviews were conducted (August 2009 to June 2010), these families represented approximately 27% of families receiving services from the PBT.
Table 3.3 Demographic profile of persons referred to PBT

<table>
<thead>
<tr>
<th>Demographic Description</th>
<th>Gender</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age Range: 5 to 27 years*</td>
<td></td>
<td>73(81%)</td>
<td>17 (19%)</td>
</tr>
<tr>
<td>Mean 14 yrs, 9 months (SD 3 yrs, 11 months)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median 15 years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mode 11 years (12.5%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disability</td>
<td></td>
<td>Intellectual</td>
<td>35 (39%) – 23 Males &amp; 12 Females</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Autism</td>
<td>16 (18%) – All Males</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Intellectual + Autism</td>
<td>39 (43%) – 34 Males &amp; 5 Females</td>
</tr>
</tbody>
</table>

* One person was within the allocated age limit of up to 25 years at the time of referral, but was 27 when they exited from the service.

The primary presenting issues for the participants at the time of referral, as reported by their families were:

- Aggression = 31%
- Aggression and self-injury = 25%
- Non-compliance = 20%
- Risk-taking = 11%
- Socially unacceptable behaviour and toileting issues = 13%.

Concerns raised by families during initial assessments included references to:

- Child’s safety
- School exclusion
- Safety of family members
- Impact on parent’s relationship
- Impact on siblings
- Communication difficulties with child
- Social Skills deficits
- Lack of ability to exercise control by parents
- Limited independence of child/dependence on parents.
2.2.2 Positive Behaviour Team staff

The PBT was constructed as a multi-disciplinary team consisting of psychologists, speech pathologists, and social workers. In total there were 12.5 FTE positions, with approximately 14 staff working across the two teams (North and South) at any one time. Each team was managed by a designated Team Leader who is included in the aforementioned FTE and staff numbers.

Table 3.4 PBT staff allocation as at June 2011

<table>
<thead>
<tr>
<th>North Team</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical psychologist</td>
<td>0.7 FTE (1 staff)</td>
</tr>
<tr>
<td>Speech pathologist</td>
<td>0.5 FTE (1 staff)</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>0.8 FTE (1 staff)</td>
</tr>
<tr>
<td>Social worker</td>
<td>1.4 FTE (2 staff)</td>
</tr>
<tr>
<td>Team Leader (Speech pathologist)</td>
<td>1.0 FTE (1 staff)</td>
</tr>
<tr>
<td>Vacant FTE:</td>
<td>1.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>South Team</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical psychologist</td>
<td>1.6 (2 staff)</td>
</tr>
<tr>
<td>Speech pathologist</td>
<td>2.3 (3 staff)</td>
</tr>
<tr>
<td>Social worker</td>
<td>1.4 FTE (2 staff)</td>
</tr>
<tr>
<td>Team Leader (Social worker)</td>
<td>1.0 FTE (1 staff member)</td>
</tr>
<tr>
<td>Vacant FTE:</td>
<td>0.2</td>
</tr>
</tbody>
</table>

The PBT comprised of an all female workforce except the one male who was also the original Team Leader of the combined team. The age range was 26 to 62 years of age (mean = 40 years, 11 months; SD = 11 years, 10 months).

Twenty one (21) staff volunteered to participate in interviews (i.e., 100% of staff on the team at the time of interview and one staff member who returned from leave to participate in the interview). These were 9 psychologists, 7 speech pathologists, and 5 social workers.

Nineteen (19) reported themselves to be permanent staff with the DSC. Twelve (12) of the team were employed full-time in their positions. They had worked in a professional capacity for between 3 and 30+ years (mean = 11 years, 2 months; SD = 6 years, 9 months). At the time of their respective interviews, they had worked with the PBT for an average of 14 months, 21 days (SD = 8 months, 6 days), ranging from 4 months to 2 + years (median = 18 months, with 38% of the staff reporting having been with the team for nearly 2 years or more).

All had a minimum of a 4 year undergraduate degree relevant to their discipline. Three (3) had a Diploma of Education, 7 had a Masters degree (6 psychologists + 1 social worker), 1 had a Doctorate of Psychology, and 2 had a PhD (both psychologists).

Staff reported an average working week of 30 ½ hours (SD = 8.54 hours). They reported an average travel time to work of 29 minutes (SD = 14.3 minutes); as close as 5 minutes away and as long as 60 minute’s drive.
2.2.3 Other stakeholders

**Local Area Coordinators**
Four representatives of Local Area Coordinators were interviewed. Combined, they had experience of 16 people referred to the PBT.

**Community Teams**
Five representatives of Community Teams were involved in a focus group. All participants in the focus group were psychologists. Combined, they had experience of 26 people referred to the PBT.

**Schools & Respite Services**
During the period of the evaluation, the PBT worked with 24 schools in relation to clients referred to their service. The schools are listed in Table 3.5.

Table 3.5 Schools with which the PBT worked

<table>
<thead>
<tr>
<th>Armadale Education Support Centre</th>
<th>Gilmore College (Kwinana Senior HS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Armadale TAFE</td>
<td>Gladys Newton</td>
</tr>
<tr>
<td>Atwell College</td>
<td>Kenwick School</td>
</tr>
<tr>
<td>Bayswater Primary School</td>
<td>Leda Primary</td>
</tr>
<tr>
<td>Carson St School</td>
<td>Leeming Senior High School</td>
</tr>
<tr>
<td>Castleragh</td>
<td>Malibu School</td>
</tr>
<tr>
<td>Cloverdale Primary</td>
<td>Riverton Education Support Centre</td>
</tr>
<tr>
<td>Coolbellup Learning Centre</td>
<td></td>
</tr>
<tr>
<td>Creaney Special Education Unit</td>
<td>Rockingham Beach Primary</td>
</tr>
<tr>
<td>Cyril Jackson</td>
<td>Rossmoyne HS</td>
</tr>
<tr>
<td>Durham road School</td>
<td>Settlers Primary</td>
</tr>
<tr>
<td>East Hamersley Primary school</td>
<td>Success Primary</td>
</tr>
<tr>
<td></td>
<td>Yanchep DHS</td>
</tr>
</tbody>
</table>

During the period of the evaluation, the PBT worked with 8 respite agencies in relation to clients referred to their service. The respite services are listed in Table 3.6.
Table 3.6 Respite services with which the PBT worked

<table>
<thead>
<tr>
<th>Activ Foundation</th>
<th>Lady Lawley In Home Respite</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism Association of WA</td>
<td>Lady Lawley Out of Home Respite</td>
</tr>
<tr>
<td>Baptist Care</td>
<td>Life Without Barriers</td>
</tr>
<tr>
<td>I.D. Entity</td>
<td>Perth Home Care Services</td>
</tr>
</tbody>
</table>

Involvement with schools and respite services included:

- seeking information that might assist with understanding the client’s support needs
- providing information concerning the client’s support needs and their home-based program
- conducting negotiations in relation to maintaining the client in school or gaining access to respite while the intervention was established
- working directly with the school or respite to develop programs applicable to that setting.

For the purposes of the current evaluation, priority was given to meeting with key personnel in six schools where the PBT had prolonged engagement, such as working directly with teachers and teachers’ aides in the development of support strategies.
3.3 Instruments

Data were collected from the stakeholder groups using both standardised questionnaires and interviews (conducted individually and in focus groups). Here follows a description of each of the standardised questionnaires.

First, there are descriptions of those questionnaires that were conducted with families directly by PBT staff in the usual course of their clinical assessments. Secondly, there are descriptions of those questionnaires conducted by the researcher in separate interviews with families. Thirdly, there are descriptions of the standardised questionnaires conducted by the researcher with PBT staff. Fourthly, questions used with stakeholders in focus groups and interviews are outlined.

3.3.1 Administered to families by staff of the Positive Behaviour Team

For families, the following standardised questionnaires were administered by the PBT in the usual course of their clinical activities:


The Beach Center Family Quality of Life Scale (FQOL Scale) is a self-report assessment of a family’s perceptions of their satisfaction with different aspects of life, which are said to affect the overall quality of life experienced by the family. The focus of the original scale was on families of children with disabilities aged from birth through 21 years. Its application to families of adults with disabilities is currently under investigation.

The FQOL Scale is broken down into five subscales: family interaction; parenting; emotional well-being; physical/material well-being; and disability-related support. These subscales are derived from a total of 25 items. For each item, respondents report their degree of satisfaction on a 5-point scale: 1 = very dissatisfied, 3 = neither satisfied nor dissatisfied, and 5 = very satisfied. Higher scores indicate greater quality of life.

The validity of the FQOL scale is well established. Both item-level FQOL structure and subscale-level FQOL structure are reported to have an acceptable fit. Convergent validity has been established with other tools developed to measure facets of family quality of life. Similarly, reliability has been established with alpha scores >.85. Test-retest reliability has been examined, with all correlations reported as significant at the .01 level or beyond.


The Personal Wellbeing Index 4th Edition (PWI) is an individual measure of subjective wellbeing (SWB) or “satisfaction with life as a whole”. Respondents are asked how satisfied they are in eight life domains: standard of living; personal health; achievement in life; personal relationships; personal safety; community-connectedness; future security; and their personal philosophy of...
life/religious beliefs. In addition, they are asked to rate their satisfaction with life as a whole.

For each item, respondents indicate their level of satisfaction on a scale of 0 to 10, with higher scores indicating higher satisfaction (i.e., 0 = completely dissatisfied, 10 = completely satisfied, and 5 indicating a neutral midpoint). Scores on the eight primary domains (i.e., excluding satisfaction with life as a whole) are combined, averaged, and then converted into a single composite, percentage of scale maximum score which has a range of 0-100%. This procedure is undertaken to standardise the data so that comparisons between data gathered using different response formats can be made. Scores between 70-80% indicate that SWB homeostasis is maintained. Scores lower than 70% indicate that SWB homeostasis has failed. This latter phenomenon is theorised to be an indicator of mental ill-health (e.g., depression).

The PWI-ID has been shown to possess validity, with all life domains intercorrelating with at least one other variable at >.48 and all domains explaining 57.97% of the superordinate domain “satisfaction with life as a whole”. The PWI-ID also possesses adequate internal reliability ($\alpha = 0.76$) and good test-retest reliability as indicated by an intraclass correlation coefficient of $r = 0.57$ and test-retest coefficient of $r = 0.58$. In addition to norms for the general Australian population, there are studies providing comparative data for Australian family carers.


The Depression Anxiety & Stress Scale (DASS) is a 42-item self-report measure of the negative emotional states of depression, anxiety, and stress. The DASS has been designed to address the requirements of both researchers and clinicians. Each of the three DASS subscales contains 14 items divided into groupings of 2-5 questions with similar content.

The **Depression scale** assesses dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest/involvement, anhedonia, and inertia. The **Anxiety scale** assesses autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect. The **Stress scale** is sensitive to levels of chronic non-specific arousal, such as difficulty relaxing, nervous arousal, and being easily upset/agitated, irritable/over-reactive, and impatient.

Respondent’s use a 4-point severity/frequency scales to rate the extent to which they have experienced each state over the past week. Scores for depression, anxiety and stress are calculated by summing the scores for the relevant items. Higher scores indicate higher levels of depression, anxiety, or stress.

Studies suggest that the DASS has excellent internal consistency (alpha > .8) and temporal stability, and provides a better separation of the features of anxiety and depression, relative to other existing measures. Factor analysis revealed a three factor solution, which corresponded well with the three subscales of the DASS. Construct validity has been supported by moderately high correlations of the DASS with indices of convergent validity (0.65 and
0.75) and lower correlations of the DASS with indices of divergent validity (range -0.22 to 0.07). Support for criterion validity has been provided by a statistically significant difference in DASS scores between diagnostic groups.


The Coping Resources Inventory (CRI) is a 60-item instrument that measures personal coping resources in five domains: cognitive, social, emotional, spiritual/philosophical, and physical. For each of the 60 items, respondents use a 4-point scale to indicate how often they have engaged in the behaviour described in the item over the past 6 months. Scores for each scale are the sum of item responses, with negatively worded items recoded prior to scoring. In addition to the five individual scale scores, a total resources score is computed by summing the five scale scores. The higher the scale score the higher the resources available to the respondent and, by implication, the more able they are anticipated to cope with life events.

The five scales are described as measuring the following facets of an individual’s coping resources: (1) cognitive: measures the extent to which individuals manifest a positive sense of self-worth, a positive outlook toward others, and a general sense of optimism (e.g., “I feel as worthwhile as anyone else”); (2) social: the degree to which individuals are imbedded in social networks that are able to provide support in times of stress (e.g. “I am part of a group, other than my family, that cares about me”); (3) emotional: the degree to which individuals are able to identify and express a range of affect, based on the premise that a range of emotional response aids in ameliorating the negative consequences of stress (e.g. “I can cry when sad”); (4) spiritual/philosophical: the extent to which actions of individuals are guided by stable and consistent values derived from religious, familial, or cultural tradition, or from a personal philosophy. Such values might serve to define the meaning of potentially stressful events and to prescribe strategies for responding effectively (e.g. “I know what is important in life”); and (5) physical: degree to which individuals engage in health-promoting behaviours believed to contribute to increased physical well-being (e.g., “I exercise vigorously 3-4 times a week”).

The reliability of the total resources score has been reported with alpha coefficients > .8. When compared with self-rating of coping resources, the correlations of the same trait across methods provide evidence for convergent validity, with correlations among method ranging from 0.61 to 0.80. Additional evidence is provided in the manual for the discriminate validity of the scale through comparing a series of target groups and controls (e.g., healthy vs. ill college students, cardiac rehabilitation patients vs. a control group, and high school and peer counsellors vs. a control).


The Parenting Scale (PS) is a 30-item self-report questionnaire designed to measure disciplining practices of parents of young children. The scale has three subscales: laxness, over-reactivity, and verbosity. The laxness
factor relates to permissive discipline. These items describe ways in which parents give in, allow rules to go unenforced, or provide positive consequences for misbehaviour. The over-reactivity factor consists of items reflecting mistakes such as displays of anger, meanness, and irritability. The verbosity factor consists of items reflecting lengthy verbal responses and a reliance on talking even when talking is ineffective. Subscale scores are calculated by summing the item ratings and dividing by the number of items in the scale. Higher scores represent elevated levels of (inappropriate) disciplining.

The scale has been constructed using paired descriptions of parenting behaviour, with each item consisting of two anchors describing at one end an inappropriate parenting technique and on the other end its adaptive opposite. Between the two anchors, parents rate themselves along a 7-point scale. For example, the inappropriate anchor of one item is when my child misbehaves, I raise my voice or yell, and its effective counterpart is speak to my child calmly. Such a format allows parents to characterise their behaviours in a manner that is less dependent on the rates of children's misbehaviours than would be the case if parents were asked, for example, how often they yell. This allows for the identification of inappropriate parenting techniques regardless of how frequently they occur.

Internal consistency for the PS has been reported as high, with alpha coefficients of .83, .82, and .63 for the laxness, over-reactivity, and verbosity subscales respectively. Test – retest statistics for laxness, over-reactivity, and verbosity have been reported as .83, .82, and .79 respectively. The developers of the scale present evidence that scores on the three factors are positively correlated with objective measures of dysfunctional discipline techniques and poor child behaviour.


The Parenting Sense of Competence Scale (PSOC) is a 17-item scale developed to assess parenting satisfaction, sense of efficacy, and self-esteem. Each item is answered on a 6-point scale, ranging from strongly disagree to strongly agree. The items measuring satisfaction are forward scored and the items measuring efficacy are reverse scored, so that for all items a higher score indicates greater self-esteem with respect to parenting activities.

The satisfaction sub-scale reflects parenting frustration, anxiety, and motivation, while the efficacy subscale assesses capability, problem-solving ability, and competence. There are parallel versions for mothers and fathers, which differ only in the use of the word ‘mother’ or ‘father’ in respect to the phrasing of items. Respondents are asked to think about a ‘focus child’, where there are multiple children in the family.

Satisfactory reliability has been reported, with alpha coefficients of > .70 for both the satisfaction and the efficacy subscales. Internal reliability has been
Impact, effectiveness, & future applications of PBT in WA

reported at .72 and test-retest reliability over a 6-week period has ranged from .46 to .82.


The Developmental Behaviour Checklist (DBC) is a suite of instruments for the assessment of behavioural and emotional problems of children, adolescents, and adults with developmental and intellectual disabilities. In its various forms (DBC-Parent Form & DBC-Teacher Form for children and adolescents; and DBC-A Form for adults with disability), it is presented as a questionnaire which is completed by parents or other primary carers. The child/parent version consists of 96 items. It asks the respondent to report on problem behaviours over the preceding six month period. Each behavioural description is scored on a 3-point rating scale, where 0 = ‘not true as far as you know’, 1 = ‘somewhat or sometimes true’, and 2 = ‘very true or often true’.

Five subscales are generated, each describing behaviours indicative of mental ill-health or poor social adjustment: disruptive/antisocial, self-absorbed, communicative disturbance, anxiety, and social relating. The DBC can be scored at three levels: the first is the Total Behaviour Problem Score, which gives an overall measure of behavioural/emotional disturbance; the second level is that of the subscale scores which measure disturbance in five (DBC-P & DBC-T) or six (DBC-A) dimensions; and the third level is for scoring of individual items.

The DBC has a high inter-rater reliability between parents and between teachers (.6 to .8). Alpha is reported to be .941. Test retest reliability and internal consistency are high. The DBC-P has also been demonstrated to be sensitive to change over time. The instrument has high criterion group validity in distinguishing psychiatric cases from non cases (t = 7.8, p < .001). The area under the ROC curve is reported at > 0.9. This means that it is both specific and sensitive with regard to expert clinician judgement of the focus person as a psychiatric case or non-case. There is also a high correlation between a total score on the DBC checklist and the maladaptive behaviour scales of both the AAMD Adaptive Behaviour Scales (Lambert & Windmiller, 1981), and the Scales of Independent Behaviour (Bruininks et al., 1984).

3.3.2 Administered to families by the researcher

For families who volunteered to participate in identifiable data collection in addition to a semi-structured interview (see Appendix 8), the following standardised questionnaires were administered by the researcher as independent interviews:


The Measure of Parents’ and Service Providers’ Beliefs about Participation in Family-Centered Services is a 28-item measure designed to assess the extent to which parents and service providers subscribe to beliefs proposed to
represent best practice in family centred services. Respondents indicate their beliefs using a 7-point scale anchored along a continuum from 1 = strongly disagree to 7 = strongly agree. Items are phrased in both a positive and negative context, with some scores reversed so as to provide for the calculation of higher ratings consistently indicating stronger beliefs with respect to working in a family centered way.

There are 5 subscales reflecting different sets of beliefs: the benefits of family centred practice; the practical feasibility of family centred approaches; the intention to work in a family centred way; adherence to the principles of family centred practice; and the absence of negative outcomes associated with the approach. The scale has established construct validity and strong internal consistency.


The Partnership Orientation Measure (POM) is a 7-item measure designed to provide an indication of a family member’s perception of the degree to which a professional with whom they are working uses a partnership orientation in their approach to service provision. There are seven themes of partnership orientation reflected in the subscale structure in so far as the family member believes the professional to work in a way that: focuses on strengths of the child and the family; promotes team work and collaboration among those working with the child; provides encouragement; is sensitive and responsive; uses effective communication; promotes skill development; and is resourceful and shares information.

Respondents provide ratings for each theme on a 6-point scale, with 1 indicating that a consultant’s use of a specific partnership orientation theme was totally ineffective (i.e., it could not have not been worse) and a rating of 6 indicating that the consultant’s use of the theme was totally effective (i.e., it could not have been better). Scores are added, with higher scores indicating higher levels of perceived partnership.

The content validity of the POM has been established with reference to the literature and review by an expert panel, which rated relevance of items, item representativeness of effective service provision, and clarity of item definition. The POM scores are reported to be highly reliable ($\alpha = .896$) and possess high internal consistency ($\alpha > .896$).


The Measure of Processes of Care – Short Form (MPOC–20) is a measure of parents’ perceptions of the family-centred behaviour of service providers. The short version is reported to be as effective as the original 56-item form and easier for parents to complete. The measure includes five subscales: enabling and partnership; providing general information; providing specific
information about the child, coordinated and comprehensive care for the child and family; and respectful and supportive care.

Respondents use a 7-point scale (1 = not at all to 7 = to a very great extent) to rate the extent to which they have experienced a variety of behaviours of service providers that are proposed to reflect the essential features of family centred services. Higher scores reflect the perception that services have been delivered in a more family-centred style.

The scales are reported to have good test–retest reliability (intraclass correlation coefficients ranging from .78 to .88) and good internal consistency (Cronbach’s alphas over .80). They are reported to have good construct and discriminative validity in that high scores are reported to be strongly associated with higher satisfaction with services and lower parental stress in dealing with service providers.


The Quality of Family – Professional Partnerships Scale (QFPPS) is an 18-item scale developed to measure parents’ perceptions of the extent to which professionals work in partnership with them when developing and delivering support programs for their son or daughter. For each item, parents first provide a rating on a 5-point scale of importance of that item to them (1 = of little importance, 3 = important, and 5 = critically important). They then provide a rating on a 5-point scale indicating their degree of satisfaction with the way in which the service provider delivered support with respect to that item (1 = very dissatisfied, 3 = neutral, and 5 = very satisfied). On both scales, higher scores are interpreted as more positive.

The items on the QFPPS group to provide two subscales, measuring the extent to which the practitioner is perceived to be child focused and family focused. The two subscales are combined to provide an average partnership rating with respect to both importance and satisfaction.

The QFPPS is reported to be valid with reference to the literature and expert ratings. Its reliability is reported to be high for both ratings of importance and satisfaction (alpha scores > .9).

3.3.3 Administered to staff of the Positive Behaviour Team by the researcher

For staff, in addition to a semi-structured interview (see Appendix 11), the following standardised questionnaires were administered by the researchers as independent interviews:


The Personal Wellbeing Index 4th Edition (PWI) is an individual measure of subjective wellbeing (SWB) or “satisfaction with life as a whole”. Respondents are asked how satisfied they are in eight life domains: standard of living; personal health; achievement in life; personal relationships; personal safety;
community-connectedness; future security; and their personal philosophy of life/religious beliefs. In addition, they are asked to rate their satisfaction with life as a whole.

For each item, respondents indicate their level of satisfaction on a scale of 0 to 10, with higher scores indicating higher satisfaction (i.e., 0 = completely dissatisfied, 10 = completely satisfied, and 5 indicating a neutral midpoint). Scores on the eight primary domains (i.e., excluding satisfaction with life as a whole) are combined, averaged, and then converted into a single composite, percentage of scale maximum score which has a range of 0-100%. This procedure is undertaken to standardise the data so that comparisons between data gathered using different response formats can be made. Scores between 70-80% indicate that SWB homeostasis is maintained. Scores lower than 70% indicate that SWB homeostasis has failed. This latter phenomenon is theorised to be an indicator of mental ill-health (e.g., depression).

The PWI-ID has been shown to possess validity, with all life domains intercorrelating with at least one other variable at >.48 and all domains explaining 57.97% of the superordinate domain satisfaction with life as a whole. The PWI-ID also possesses adequate internal reliability (α = 0.76) and good test-retest reliability as indicated by an intraclass correlation coefficient of r = 0.57 and test-retest coefficient of r = 0.58. There are established norms for the general Australian population.


The Maslach Burnout Inventory (MBI) is a 22-item self-report questionnaire designed to measure three psychological constructs proposed to interact and subsequently affect occupational health and performance. The three subscales are: emotional exhaustion, which refers to feelings of being overextended and drained from one’s emotional resources; depersonalization, which refers to negative, cynical, detached, and impersonal attitudes and feelings towards other people; and personal accomplishment, which refers to feelings of competence and to achievement in the workplace.

All items are scored on a 7-point frequency rating scale, ranging from 0 (never) to 6 (every day). High scores on emotional exhaustion and depersonalisation, and low scores on personal accomplishment are said to be indicative of ‘occupational burnout syndrome’. The three factor model has been repeatedly validated in the literature and the assessment is reported to have good test-re-test reliability.


The Occupational Stress Inventory- Revised (OSI-R) is a 140-item assessment of issues theorised to affect occupational health and performance. It is divided into three domains, each of which are in turn divided into subscales: occupational roles domain referring to role overload, role insufficiency, role ambiguity, role boundary, responsibility, and physical environment; personal strain domain including vocational strain, psychological
strain, interpersonal strain, and physical strain; and personal resources domain including: recreation, self-care, social supports, and rational/cognitive.

Respondents answer questions according to a 5-point scale in relation to how true each is about their personal circumstances at the present time: 1 = rarely or never true, 2 = occasionally true, 3 = often true, 4 = usually true, and 5 = most of the time. Good internal consistency scores are reported for OSI-R with Cronbach’s alpha of .88, .93, and .89 for ORQ, PSQ, and PRQ, respectively.

For the occupational strain and personal strain domains, higher scores indicate higher levels of stress. T-scores above 70 are expected to occur in only approximately 2% of people and, as such, are to be interpreted as statistically significant and indicate a strong probability of maladaptive stress. Scores in the range of 60-69 can be interpreted as indicative of mild levels of maladaptive stress. Scores in the range of 40-59 are within a standard deviation of the mean and are interpreted as being within the normal range. Scores below 40 indicate a relative absence of occupational stress and psychological strain.

For the personal resources domain, high scores indicate highly developed coping resources. For these scales, scores at or below a T-score of 30 are interpreted as being indicative of a significant lack of coping resources. Scores in the range of 30-39 suggest mild deficits in coping skills. Scores in the range of 40-59 indicate average resources, while higher scores indicate increasingly strong coping resources.

The OSI has well established validity and reliability. The factor structure of the three domains and their respective subscales have been replicated in the literature.


The Measure of Parents’ and Service Providers’ Beliefs about Participation in Family-Centered Services is a 28-item measure designed to assess the extent to which parents and service providers subscribe to beliefs proposed to represent best practice in family centred services. Respondents indicate their beliefs using a 7-point scale anchored along a continuum from 1 = strongly disagree to 7 = strongly agree. Items are phrased in both a positive and negative context, with some scores reversed so as to provide for the calculation of higher ratings consistently indicating stronger beliefs with respect to working in a family centred way.

There are 5 subscales reflecting different sets of beliefs: the benefits of family centred practice, the practical feasibility of family centred approaches, the intention to work in a family centred way, adherence to the principles of family centred practice, and the absence of negative outcomes associated with the approach. The scale has established construct validity and strong internal consistency.
3.3.4 Administered to stakeholders by the researcher

Stakeholders (Local Area Co-ordinators, Community Teams, schools, and respite services) participated in either focus group discussions or individual interviews. The focus group discussion and interviews were facilitated by four key questions, as outlined in Table 3.7.

Table 3.7 Key questions for stakeholder focus groups

<p>| | |</p>
<table>
<thead>
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<tbody>
<tr>
<td>A.</td>
<td>What do you experience as the needs of families supporting a person with disability at home?</td>
</tr>
<tr>
<td>B.</td>
<td>What are your expectations of the PBT as part of the service response/solution?</td>
</tr>
<tr>
<td>C.</td>
<td>What has been your experience of the PBT: referral, assessment, implementation, and closure?</td>
</tr>
<tr>
<td>D.</td>
<td>What are your suggestions for the future development of the PBT?</td>
</tr>
</tbody>
</table>

3.4 Procedure

Ethics approval for the project was provided initially by RMIT University Human Research Ethics Committee (SET HREC-60-08) and later by the Deakin University Human Research Ethics Committee (HREC 145-2009) (appendices 3 and 4 refer). The research methodology included a protocol for reporting any instances of abuse and neglect that might come to the attention of the researcher team (refer appendix 5). However, this protocol was never required to be enacted.

Assessment data for all families referred to the team were collected by clinical staff and stored in an Access database maintained by the Disability Services Commission (refer to 2.3.1 above). De-identified data were then provided to the researcher in Excel spreadsheets and uploaded to the Statistical Package for the Social Sciences (SPSS – version 17) for analysis. In addition, families were invited to volunteer to participate in interviews with the researcher and to consent to having their individual programs reviewed (refer to 2.3.2 above) (refer appendices 6, 7, and 8).

Staff volunteered to provide anonymous responses to a questionnaire pack (refer to 2.3.3 above). In addition, they volunteered to participation in individual interviews (refer appendices 9, 10 and 11).

Other stakeholders were invited to participate in focus groups or individual interviews (refer to 2.3.4 above). There was one focus group for Local Area Co-ordinators and one for Community Teams. School and respite providers were interviewed individually.

The quantitative analysis included descriptive statistics and the use of t-tests (independent, paired-samples, and single sample). Results for each assessment tool are reported independently. Multivariate analyses have not been reported due to relatively small sample sizes. For the interpretation of statistical significance $\alpha = .05$. Consideration of effect sizes were with reference to Cohen (1988), whereby .01 represents a small effect, .06 a moderate effect, and .14 a large effect.
The qualitative analysis was conducted using inductive thematic analysis and the constant comparative method. The sample size was deemed insufficient to attempt the development of a grounded theory.
Chapter 4 - Results

4.1 Positive Behaviour Team milestones

The PBT referral processes included a number of key milestones. These were the time between referral to allocation of team members, the time between the allocation of team members to an initial ‘introduction to service meeting’, and the time which elapsed between the initial introduction to services and the cessation of services. These times are summarised in Table 4.1. In addition to the average number of days for each milestone, the median is also reported given the relatively large range of days for each milestone. These large ranges in time can be accounted for by a number of outliers in the data set, arising from individual family circumstances that affected the administrative processes. Here issues included families that once accepted were not in a position to take up the service immediately and some families that though having completed the majority of the program were not yet ready to cease contact with the service due to reoccurring difficulties which impacted on the consolidation of the gains they had made.

Table 4.1 Time elapsed between critical phases in the PBT process

<table>
<thead>
<tr>
<th>Phase</th>
<th>Time elapsed (days)</th>
<th>Mean</th>
<th>Median</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral to allocation of team members</td>
<td>90.5</td>
<td>90.5</td>
<td>32.5</td>
<td>200</td>
<td>0 to 385</td>
</tr>
<tr>
<td>Allocation to ‘introduction to service’</td>
<td>20.06</td>
<td>24.0</td>
<td>54.69</td>
<td>3 to 132</td>
<td></td>
</tr>
<tr>
<td>Introduction to services to cessation of services</td>
<td>383.0</td>
<td>453.5</td>
<td>203.57</td>
<td>13 to 763</td>
<td></td>
</tr>
</tbody>
</table>

4.2 Client and family goals

The PBT established goals with families at the outset of each intervention. These goals were typically set at the end of the initial assessment phase. On closure of involvement, goals were evaluated by clinicians in consultation with families according to the following categories: met, partially met, unmet, or discontinued. The success rate, as a percentage of all goals set, is reported in Table 4.2.

Table 4.2 Goal status at closure of involvement for N = 47 clients

<table>
<thead>
<tr>
<th>Goal classification</th>
<th>Percentage of all goals set</th>
</tr>
</thead>
<tbody>
<tr>
<td>Met</td>
<td>32%</td>
</tr>
<tr>
<td>Partially met</td>
<td>45%</td>
</tr>
<tr>
<td>Unmet</td>
<td>10%</td>
</tr>
<tr>
<td>Discontinued</td>
<td>13%</td>
</tr>
</tbody>
</table>
There was no formal process of Goal Attainment Scaling (GAS) that would have otherwise allowed for a more systematic evaluation of outcomes. GAS has been long established as a systematic means of evaluating outcomes in health and community services (for details of original concepts see Kiresuk & Sherman, 1968). GAS has the advantage of not only being useful for individuals to monitor their own progress but for the purposes of standardised monitoring and comparisons GAS scores can be converted to T Scores (with a pre-determined mean and SD) and Z Scores (for the purpose of evaluating how scores compare to expected/normal distributions).

A summary of typical goals is provided in Table 4.3. A comprehensive list of (de-identified) goals is provided at appendix 12. Some goals were formulated in a way that allowed for objective evaluation of progress towards their attainment. However, other goals were more aspirational in their formulation, reflecting a family’s idealised description of a successful intervention. These aspirational goals can be effective in capturing a family’s desired outcome, but are problematic for the purposes of monitoring progress and outcome evaluation.

Table 4.3 Examples of typical goals set at the end of the assessment phase

<table>
<thead>
<tr>
<th>Objective (measurable ) goals</th>
<th>Aspirational goals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduce intensity of self-harm behaviour by 50% in 6 months</td>
<td>Things to be more fair at home between X and X (brothers)</td>
</tr>
<tr>
<td>Reduce prompts by 50% for toileting using Mum’s baseline</td>
<td>Not to have “ground-hog day”</td>
</tr>
<tr>
<td>Increase sitting time for evening meal to 5 minutes</td>
<td>To learn to compromise a little</td>
</tr>
<tr>
<td>X to be able to recognise pain and tell people she is in pain</td>
<td>For X to learn to his full capability/potential at school</td>
</tr>
</tbody>
</table>

4.3 Family assessments conducted by Positive Behaviour Team

For each of the assessments conducted by the PBT practitioners in the course of their work with families, the initial results for all families assessed are reported below. These results provide a profile of the status of each of the families in terms of the standardised measures. Comparisons with normative samples are provided where suitable samples were available. In addition, where post intervention assessments were conducted, a pre-post comparison is also reported. These results provide some indication as to the change over time for families. However, it needs to be noted that given the applied nature of the project, pre-post measures were only available where family circumstances were conducive to repeating the measures.

4.3.1 Beach Center Family Quality of Life Survey

Data for initial assessments using the Beach Center Family Quality of Life Survey were available for 79 parents, representing 48 referrals to the PBT. At follow-up, there were data for 33 parents, representing 24 referrals. These data are presented in tables Table 4.4 to Table 4.6 below.
Analyses indicate that at the point of initial assessment parents were, on average, reporting family quality of life at a level significantly below that to be expected of typical families. Overall they rated their level of satisfaction with life at 64% scale maximum, compared to the average satisfaction rating on this scale of 84% scale maximum. There were no significant differences between total satisfaction scores for mothers and fathers in the study.

The results suggest that parents were reporting a lack of satisfaction with interactions among family members and in their role as a parent, poor emotional and physical wellbeing, and dissatisfaction with the support available for their family member with disability.

When post intervention measures were compared to pre intervention measures (a median time period of approximately 12 months), there were statistically significant improvements in ratings of satisfaction on all five of the Beach Survey subscales. The greatest improvements were with respect to emotional wellbeing: from 54% scale maximum to 67% scale maximum. Satisfaction with physical wellbeing improved from 70% scale maximum to 79% scale maximum. Satisfaction with parenting improved from 67% scale maximum to 76% scale maximum. Satisfaction with family interaction improved from 66% scale maximum to 74% scale maximum. And satisfaction with the supports available for their family member with disability improved from 64% scale maximum to 72% scale maximum. The total score, indicating average satisfaction with quality of life overall, also showed a strong clinical (though not statistically significant) trend towards improvement: 64% scale maximum to 82% scale maximum.

When the post intervention measures were compared with normative data, there was no statistically significant difference between the total satisfaction score and that to be expected of families in the normative sample: PBT families reporting overall satisfaction at 82% scale maximum, compared to the normative sample at 84% scale maximum. These findings can be interpreted as indicative of a successful intervention, in so far as family member’s self-reports of their family quality of life improved to the extent that they were statistically indistinguishable from the reports of typical families. However, it should be noted that at a subscale level, though showing improvements overall, PBT families continued to report their quality of life below that of the normative sample.

With respect to the indicators of importance, issues related to the support of the family member with disability were consistently rated as the most important issue for families. These included issues such: as having support to make progress at home, support to make progress at school or at work, support to make friends, and support to have good relationships with service providers.

Table 4.4 Difference between Beach Family Quality of Life scores for parents pre intervention (n = 79) and normative data (n = 280)

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre intervention</th>
<th>Norms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Family Importance</td>
<td>4.08</td>
<td>.801</td>
</tr>
<tr>
<td>Item</td>
<td>Pre</td>
<td>Post</td>
</tr>
<tr>
<td>-------------------------</td>
<td>----------------</td>
<td>----------------</td>
</tr>
<tr>
<td>Family interaction</td>
<td>Importance</td>
<td>4.11</td>
</tr>
<tr>
<td></td>
<td>Satisfaction</td>
<td>3.31</td>
</tr>
<tr>
<td>Parenting</td>
<td>Importance</td>
<td>3.91</td>
</tr>
<tr>
<td></td>
<td>Satisfaction</td>
<td>3.37</td>
</tr>
<tr>
<td>Emotional support</td>
<td>Importance</td>
<td>4.07</td>
</tr>
<tr>
<td></td>
<td>Satisfaction</td>
<td>3.52</td>
</tr>
<tr>
<td>Physical wellbeing</td>
<td>Importance</td>
<td>4.06</td>
</tr>
<tr>
<td></td>
<td>Satisfaction</td>
<td>3.52</td>
</tr>
<tr>
<td>Disability support</td>
<td>Importance</td>
<td>4.27</td>
</tr>
<tr>
<td></td>
<td>Satisfaction</td>
<td>3.14</td>
</tr>
<tr>
<td>Total</td>
<td>Importance</td>
<td>4.08</td>
</tr>
<tr>
<td></td>
<td>Satisfaction</td>
<td>3.22</td>
</tr>
</tbody>
</table>

Table 4.5 Difference between Beach Family Quality of Life scores for n = 33 parents pre/post intervention
<table>
<thead>
<tr>
<th>wellbeing</th>
<th>Satisfaction</th>
<th>2.70</th>
<th>.86</th>
<th>3.34</th>
<th>0.86</th>
<th>-3.75</th>
<th>.001</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical wellbeing</td>
<td>Importance</td>
<td>4.15</td>
<td>.78</td>
<td>4.19</td>
<td>0.69</td>
<td>-0.30</td>
<td>.767</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>3.49</td>
<td>.70</td>
<td>3.97</td>
<td>0.62</td>
<td>-3.70</td>
<td>.001</td>
<td></td>
</tr>
<tr>
<td>Disability support</td>
<td>Importance</td>
<td>4.41</td>
<td>.89</td>
<td>4.30</td>
<td>1.00</td>
<td>0.47</td>
<td>.640</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>3.22</td>
<td>.88</td>
<td>3.61</td>
<td>0.93</td>
<td>-2.69</td>
<td>.011</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>Importance</td>
<td>4.13</td>
<td>.71</td>
<td>4.58</td>
<td>3.14</td>
<td>-0.79</td>
<td>.433</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>3.22</td>
<td>.59</td>
<td>4.12</td>
<td>3.11</td>
<td>-1.89</td>
<td>.067</td>
<td></td>
</tr>
</tbody>
</table>

Table 4.6 Difference between Beach Family Quality of Life scores for parents post intervention (n = 38) and normative data

<table>
<thead>
<tr>
<th>Item</th>
<th>Post intervention</th>
<th>Norms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Family interaction</td>
<td>Importance</td>
<td>3.99</td>
</tr>
<tr>
<td></td>
<td>Satisfaction</td>
<td>3.70</td>
</tr>
<tr>
<td>Parenting</td>
<td>Importance</td>
<td>3.98</td>
</tr>
<tr>
<td></td>
<td>Satisfaction</td>
<td>3.81</td>
</tr>
<tr>
<td>Emotional wellbeing</td>
<td>Importance</td>
<td>4.08</td>
</tr>
<tr>
<td></td>
<td>Satisfaction</td>
<td>3.34</td>
</tr>
<tr>
<td>Physical wellbeing</td>
<td>Importance</td>
<td>4.19</td>
</tr>
<tr>
<td></td>
<td>Satisfaction</td>
<td>3.97</td>
</tr>
<tr>
<td>Disability</td>
<td>Importance</td>
<td>4.30</td>
</tr>
</tbody>
</table>
support  |  Satisfaction  |  3.61  |  0.93  |  4.40  |  .14  |  -5.25  |  .000  
Total   |  Importance    |  4.58  |  3.14  |  4.48  |  .13  |  -0.70  |  .945  
Satisfaction |  4.12  |  3.11  |  4.18  |  .25  |  -0.12  |  .906  

4.3.2 Personal Wellbeing Index, 4\textsuperscript{th} Edition

Data for initial assessments using the Personal Wellbeing Index were available for 49 parents, representing 27 referrals to the PBT. At follow-up there were data for 17 parents, representing 9 referrals. These data are presented in tables Table 4.7 to Table 4.9 below.

Analyses indicate that at the point of initial assessment parents were, on average, reporting family quality of life at a level significantly below that to be expected of typical families (with an effect size that would be considered large, $d = .89$, $r = .41$). Overall they rated their level of satisfaction with ‘life as a whole’ at 54% scale maximum, compared to the expected rating for a typical population of 75% scale maximum. The average rating across all subscales was 62% scale maximum, which would still be considered significantly below that to be expected of adults in the general population.

These PWI results are indicative of a collapse of homeostasis and a potential indicator of serious mental ill-health (e.g., clinical depression) among family carers. This interpretation is consistent with the findings from the Depression Anxiety and Stress Scale (reported below), which indicate clinically significant levels of both Depression and Anxiety. There were no significant differences between total satisfaction scores for mothers (5.88) and those for fathers (6.51).

The results suggest that parents were reporting a significant lack of satisfaction with (in order of priority from the level of least satisfaction) their health, connection to community, standard of living, sense of achievement, future prospects, and relationships. Overall, reported satisfaction with their personal safety and sense of philosophical/religious fulfilment was comparable with that expected of the general population.

When post intervention measures were compared to pre intervention measures (a median time period of approximately 11.5 months), there were no statistically significant improvements. However, these results need to be considered in light of the comparatively small sample size and consequently the limited statistical power to detect change over a relatively short period of time. The time period here is particularly relevant, given the PWI is a measure of the “trait of wellbeing”, which is known to be relatively stable over time unless there is a substantial impact on a person’s life experience. It is therefore best used as a longer-term measure of life satisfaction.

However, it is notable that when post intervention ratings are compared to normative data for Australia, though overall ratings remain below the levels expected of a typical Australian population, reported levels of satisfaction with personal safety,
connection to community, future prospects, and personal achievement are not statistically different from those to be expected of typical Australian adults. These findings suggest a trend towards improved personal wellbeing. These improvements should be considered noteworthy, considering the relatively stable nature of the trait of personal wellbeing (as noted above), with changes (increases or decreases) usually indicative of a substantial change to life circumstances such that these changes are sufficient to vary internally regulated status of homeostasis. In the context of the PBT intervention, these results suggest that the PBT intervention strategies could have contributed to improvements in personal wellbeing and a positive realignment of family members’ homeostasis (and mental health).

Table 4.7 Difference between Personal Wellbeing Index (PWI) scores for parents pre intervention (n = 49) and normative data for the Australian population (n = 2200+) (Cummins, 2005)

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre intervention</th>
<th>Australian norms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Standard of living</td>
<td>6.22</td>
<td>2.30</td>
</tr>
<tr>
<td>Health</td>
<td>5.16</td>
<td>2.63</td>
</tr>
<tr>
<td>Achievement</td>
<td>5.61</td>
<td>2.56</td>
</tr>
<tr>
<td>Relationships</td>
<td>6.88</td>
<td>2.31</td>
</tr>
<tr>
<td>Safety</td>
<td>7.37</td>
<td>2.61</td>
</tr>
<tr>
<td>Community</td>
<td>5.61</td>
<td>2.24</td>
</tr>
<tr>
<td>Future</td>
<td>5.37</td>
<td>2.76</td>
</tr>
<tr>
<td>Philosophy/religion</td>
<td>7.08</td>
<td>2.29</td>
</tr>
<tr>
<td>Average PWI</td>
<td>6.16</td>
<td>1.76</td>
</tr>
<tr>
<td>Life as a whole</td>
<td>5.37</td>
<td>2.62</td>
</tr>
</tbody>
</table>

Table 4.8 Difference between Personal Wellbeing Index (PWI) scores for n = 18 parents pre/post intervention

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre</th>
<th>Post</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Standard of living</td>
<td>6.39</td>
<td>1.58</td>
</tr>
<tr>
<td>Item</td>
<td>Post intervention</td>
<td>Australian Norms</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-------------------</td>
<td>------------------</td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Standard of living</td>
<td>6.61</td>
<td>1.82</td>
</tr>
<tr>
<td>Health</td>
<td>6.00</td>
<td>2.38</td>
</tr>
<tr>
<td>Achievement</td>
<td>6.22</td>
<td>2.51</td>
</tr>
<tr>
<td>Relationships</td>
<td>6.33</td>
<td>2.97</td>
</tr>
<tr>
<td>Safety</td>
<td>7.11</td>
<td>2.81</td>
</tr>
<tr>
<td>Community</td>
<td>6.56</td>
<td>1.76</td>
</tr>
<tr>
<td>Future</td>
<td>6.39</td>
<td>1.94</td>
</tr>
<tr>
<td>Philosophy/religion</td>
<td>6.00</td>
<td>3.21</td>
</tr>
<tr>
<td>Average PWI</td>
<td>6.42</td>
<td>1.69</td>
</tr>
<tr>
<td>Life as a whole</td>
<td>5.50</td>
<td>2.96</td>
</tr>
</tbody>
</table>

Table 4.9 Difference between Personal Wellbeing Index (PWI) scores for parents post intervention (n = 49) and normative data for the Australian population (n = 2200+) (Cummins, 2005)
4.3.3 Depression Anxiety & Stress Scales (2nd ed.)

Data for initial assessments using the Depression Anxiety & Stress Scale were available for 84 parents, representing 42 referrals to the PBT. At follow-up, there were data for 38 parents, representing 19 referrals. These data are presented in tables Table 4.10 to Table 4.12 below.

Analyses indicate that at the point of initial assessment parents were, on average, reporting mental health symptoms at levels significantly above those to be expected of the typical Australian population and indicative of psychopathology (total scores indicative of ratings worse than those to be expected of at least 84% of the population). Parents reported significantly elevated levels of depression (worse than those to be expected of at least 82% of the population), anxiety (worse than those to expected of at least 76% of the population) and stress (worse than those to be expected of at least 78% of the population). These results could be considered consistent with the findings from the Personal Wellbeing Index (as reported above), which were consistent with a collapse of homeostasis and indicative of serious mental ill-health. There were no significant differences between total DASS scores for mothers (30.39) and those for fathers (31.95).

When post intervention measures were compared to pre intervention measures (a median time period of approximately 11.7 months), there were statistically significant improvements on the total DASS score, though this did remain above the 70th percentile. Notably, parents reported significant improvements in their ratings of depression (down from 82nd percentile to the 75th percentile) and stress (down from the 76th percentile to the 70th percentile).

When post intervention DASS ratings were compared with scores expected of the general population, while post intervention ratings of stress were statistically greater than those to be expected of the general population, there was no statistically significant difference between ratings for depression or anxiety, nor was there a statistically significant difference between parents’ total DASS score and that expected for the typical Australian population. These results, in light of the pre intervention ratings, can be interpreted as indicating the positive impact of the intervention, though caution is still warranted given the fact that the scores remain elevated relative to the general population, at approximately the 70th percentile.

Table 4.10 Difference between Depression Anxiety & Stress Scale (DASS) scores for parents pre intervention (n = 84) and normative data (n = 1700+) (Crawford & Henry, 2003)

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre intervention</th>
<th>Norms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Depression</td>
<td>10.74</td>
<td>9.99</td>
</tr>
<tr>
<td>Anxiety</td>
<td>5.82</td>
<td>6.66</td>
</tr>
<tr>
<td>Stress</td>
<td>14.63</td>
<td>9.09</td>
</tr>
<tr>
<td>Total DASS score</td>
<td>31.19</td>
<td>22.85</td>
</tr>
</tbody>
</table>
Table 4.11 Difference between Depression Anxiety & Stress Scale (DASS) scores for n = 38 parents pre/post intervention

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre M</th>
<th>SD</th>
<th>Post M</th>
<th>SD</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>9.61</td>
<td>8.77</td>
<td>7.13</td>
<td>8.69</td>
<td>2.17</td>
<td>.037</td>
</tr>
<tr>
<td>Anxiety</td>
<td>5.29</td>
<td>6.22</td>
<td>4.45</td>
<td>5.14</td>
<td>1.09</td>
<td>.282</td>
</tr>
<tr>
<td>Stress</td>
<td>15.68</td>
<td>7.32</td>
<td>12.39</td>
<td>6.78</td>
<td>2.80</td>
<td>.008</td>
</tr>
<tr>
<td>Total DASS</td>
<td>30.58</td>
<td>20.53</td>
<td>23.97</td>
<td>18.38</td>
<td>2.47</td>
<td>.018</td>
</tr>
</tbody>
</table>

Table 4.12 Difference between Depression Anxiety & Stress Scale (DASS) scores for parents pre intervention (n = 38) and normative data (n = 1700+) (Crawford & Henry, 2003)

<table>
<thead>
<tr>
<th>Item</th>
<th>Post intervention M</th>
<th>SD</th>
<th>Norms M</th>
<th>SD</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>7.13</td>
<td>8.69</td>
<td>5.55</td>
<td>7.48</td>
<td>1.12</td>
<td>.269</td>
</tr>
<tr>
<td>Anxiety</td>
<td>4.45</td>
<td>5.14</td>
<td>3.56</td>
<td>5.39</td>
<td>1.06</td>
<td>.294</td>
</tr>
<tr>
<td>Stress</td>
<td>12.39</td>
<td>6.78</td>
<td>9.27</td>
<td>8.04</td>
<td>2.83</td>
<td>.007</td>
</tr>
<tr>
<td>Total DASS</td>
<td>23.97</td>
<td>18.38</td>
<td>18.38</td>
<td>18.82</td>
<td>1.88</td>
<td>.070</td>
</tr>
</tbody>
</table>

4.3.4 Coping Resources Inventory

Data for initial assessments using the Coping Resources Inventory were available for 52 parents, representing 26 referrals to the PBT. At follow-up, there were data for 18 parents, representing 9 referrals. These data are presented in tables Table 4.13 to Table 4.15 below.

Analyses indicate that at the point of initial assessment, parents were, on average, reporting coping resources significantly below those to be expected of adults; that is, at a level to be expected of approximately the lower 43 percent of adults. There were no significant differences between total scores for mothers and fathers. Fathers were on average reporting coping resources at the 42<sup>nd</sup> percentile and mothers at the 41<sup>st</sup> percentile.

These results suggest that parents were reporting: low levels of self-worth and a lack of optimism; that they were experiencing poor, or an absence of supportive social networks; they had a limited capacity to express emotion; that they were
experiencing poor or a lack of spiritual, philosophical or cultural supports; and that they were not effectively engaged in health-promoting activities.

When post intervention measures were compared to pre intervention measures (a median time period of approximately 12 months), there was evidence of a trend towards improvement across most subscales and the total score. Though, the improvements were not statistically significant. Here however, when interpreting these results statistically, the relatively small sample size and resulting lack of power to detect statistically significant changes needs to be taken into account.

When the post intervention measures were compared with the normative data there was some evidence of improvement. That is, while at the pre intervention assessment all subscale scores were statistically significantly below the scores to be expected of typical adults, at post intervention only the subscale score of physical coping (i.e., engagement in health-promoting behaviours believed to contribute to increased physical well-being) remained significantly below the average. Given the comparatively small sample size and, subsequently, the limited statistical power to identify change over time, these trends in the data should be viewed positively.

Table 4.13 Difference between Coping Resources Inventory (CRI) scores for parents pre intervention (n = 52) and normative data (n = 843) (Marting & Hammer, 2004)

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre intervention</th>
<th>Norms</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive</td>
<td></td>
<td></td>
<td>24.06</td>
<td>5.14</td>
<td>27.49</td>
<td>4.54</td>
<td>-4.82</td>
<td>.000</td>
</tr>
<tr>
<td>Social</td>
<td></td>
<td></td>
<td>36.77</td>
<td>5.70</td>
<td>39.35</td>
<td>6.03</td>
<td>-3.26</td>
<td>.002</td>
</tr>
<tr>
<td>Emotional</td>
<td></td>
<td></td>
<td>41.98</td>
<td>7.28</td>
<td>46.12</td>
<td>7.49</td>
<td>-4.10</td>
<td>.000</td>
</tr>
<tr>
<td>Philosophical</td>
<td></td>
<td></td>
<td>27.37</td>
<td>5.58</td>
<td>32.02</td>
<td>6.10</td>
<td>-6.02</td>
<td>.000</td>
</tr>
<tr>
<td>Physical</td>
<td></td>
<td></td>
<td>24.31</td>
<td>5.47</td>
<td>28.95</td>
<td>5.37</td>
<td>-6.13</td>
<td>.000</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td>154.48</td>
<td>21.67</td>
<td>174.17</td>
<td>21.88</td>
<td>-6.55</td>
<td>.000</td>
</tr>
</tbody>
</table>

Table 4.14 Difference between Coping Resources Inventory (CRI) scores for n = 18 parents pre/post intervention

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre</th>
<th>Post</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive</td>
<td>24.06</td>
<td>5.54</td>
<td>25.00</td>
<td>5.09</td>
<td>-1.13</td>
<td>.273</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social</td>
<td>36.77</td>
<td>5.42</td>
<td>36.28</td>
<td>6.78</td>
<td>0.91</td>
<td>.376</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional</td>
<td>41.98</td>
<td>6.44</td>
<td>42.17</td>
<td>8.60</td>
<td>-0.89</td>
<td>.388</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Philosophical  27.37  6.84  30.17  7.19  -1.71  .106  
Physical  24.31  6.10  25.78  6.04  -1.66  .114  
Total  154.48  21.81  159.39  27.50  -1.15  .265  

Table 4.15 Difference between Coping Resources Inventory (CRI) scores for parents post intervention (n = 18) and normative data (n = 843) (Marting & Hammer, 2004)

<table>
<thead>
<tr>
<th>Item</th>
<th>Post intervention</th>
<th>Norms</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Cognitive</td>
<td>25.00</td>
<td>5.09</td>
<td>27.49</td>
<td>4.54</td>
</tr>
<tr>
<td>Social</td>
<td>36.28</td>
<td>6.78</td>
<td>39.35</td>
<td>6.03</td>
</tr>
<tr>
<td>Emotional</td>
<td>42.17</td>
<td>8.60</td>
<td>46.12</td>
<td>7.49</td>
</tr>
<tr>
<td>Philosophical</td>
<td>30.17</td>
<td>7.19</td>
<td>32.02</td>
<td>6.10</td>
</tr>
<tr>
<td>Physical</td>
<td>25.78</td>
<td>6.04</td>
<td>28.95</td>
<td>5.37</td>
</tr>
<tr>
<td>Total</td>
<td>159.39</td>
<td>27.50</td>
<td>174.17</td>
<td>21.88</td>
</tr>
</tbody>
</table>

4.3.5 Parenting Scale

Data for initial assessments using the Parenting Scale were available for 105 parents, representing 60 referrals to the PBT. At follow-up, there were data for 49 parents, representing 31 referrals. These data are presented in tables Table 4.16 to Table 4.18 below.

Analyses indicate that, at the point of initial assessment, parents were on average, reporting the use of parenting techniques, identified in the literature as ineffective or potentially perpetuating inappropriate behaviour in children, at levels above those to be expected of parents in the general population. There were no significant differences between total score ratings for mothers (3.32) and fathers (3.30). The ratings included consideration of levels of laxness or permissiveness that allowed rules to go unenforced or inadvertently provided positive consequences for misbehaviour (44% scale maximum, compared to 34% for typical parents), over-reactivity to situations and inappropriate displays of anger towards the child (43% scale maximum, compared to 34% for typical parents), and verbosity in the form of lengthy verbal responses and a reliance on talking even when talking is ineffective (52% scale maximum, compared to 44% for typical parents). Their total score was at 47% scale maximum, compared to 37% for typical parents.

When post intervention measures were compared to pre intervention measures (a median time period of approximately 12 months having elapsed), there were no
statistically significant changes in any of the Parenting Scale ratings. However, all average ratings did show some evidence of improvement across mean scores. Here it should be noted that the sample size was relatively small and consequently the statistical power to detect change was limited.

However, it should also be noted that when the post intervention ratings were compared with the normative sample, the ratings of verbosity had decreased to the extent that there was no statistically significant difference discernable between self-reported ratings for parents referred to the PBT and parents in the normative sample. Self-reported ratings of verbosity had decreased to 47% scale maximum, compared to 44% in the normative sample. This result could be interpreted to indicate that the intervention had resulted in a decrease in parents’ use of excessively lengthy verbal responses to children and a reliance on talking, even when talking was observed to be ineffective at moderating the child’s behaviour.

Table 4.16 Difference between the Parenting Scale scores for parents pre intervention (n = 105) and normative data (n = 51) (Arnold, et al., 1993)

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre intervention</th>
<th>Norms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Laxness</td>
<td>3.09</td>
<td>0.85</td>
</tr>
<tr>
<td>Over reactivity</td>
<td>3.04</td>
<td>0.92</td>
</tr>
<tr>
<td>Verbosity</td>
<td>3.62</td>
<td>0.85</td>
</tr>
<tr>
<td>Total score</td>
<td>3.31</td>
<td>0.65</td>
</tr>
</tbody>
</table>

Table 4.17 Difference between Parenting Scale scores for parents pre/post intervention (n = 49)

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre</th>
<th>Post</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Laxness</td>
<td>3.00</td>
<td>0.76</td>
</tr>
<tr>
<td>Over reactivity</td>
<td>2.96</td>
<td>0.88</td>
</tr>
<tr>
<td>Verbosity</td>
<td>3.51</td>
<td>0.73</td>
</tr>
<tr>
<td>Total score</td>
<td>3.15</td>
<td>0.62</td>
</tr>
</tbody>
</table>
Table 4.18 Difference between Parenting Scale scores for parents post intervention (n = 49) and normative data (n = 51) (Arnold, et al., 1993)

<table>
<thead>
<tr>
<th>Item</th>
<th>Post intervention</th>
<th>Norms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Laxness</td>
<td>2.82</td>
<td>0.82</td>
</tr>
<tr>
<td>Over reactivity</td>
<td>2.79</td>
<td>0.88</td>
</tr>
<tr>
<td>Verbosity</td>
<td>3.30</td>
<td>1.00</td>
</tr>
<tr>
<td>Total score</td>
<td>3.04</td>
<td>0.77</td>
</tr>
</tbody>
</table>

4.3.6 Parenting Sense of Competence Scale

Data for initial assessments using the Parenting Sense of Competence Scale were available for 27 parents, representing 17 referrals to the PBT. At follow-up, there were data for only 8 parents, representing 5 referrals. These data are presented in tables Table 4.19 to Table 4.21 below.

Analyses indicate that at the point of initial assessment parents were, on average, self-reporting overall competence at a level statistically significantly below that to be expected of parents in the general population. So too, their levels of both self-reported satisfaction and levels of efficacy were below those to be expected of parents in the general population. There were no significant differences between total scores for mothers (53.29) and fathers (55.55).

When post intervention scores are compared with pre intervention scores (with a median time period of approximately 15 months having elapsed), there is evidence to indicate a statistically significant improvement in self-reported ratings of overall competence. This improvement appears to be best accounted for by the statistically significant improvement in self-reported ratings of satisfaction with their parenting role.

Though caution is warranted given the relatively small numbers of responses available on this measure, it is noteworthy that when post intervention measures are compared with normative data there is no discernable statistical difference between self-reported ratings of parents referred to the PBT and normative data. In light of the statistically significant differences that were evident at pre intervention, these findings could be interpreted as an indication of intervention effectiveness.

Table 4.19 Difference between the Parenting Sense of Competence Scale scores for parents pre intervention (n = 27) and normative data (n = 111) (Ohan, et al, 2000)

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre intervention</th>
<th>Norms*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>30.07</td>
<td>7.25</td>
</tr>
</tbody>
</table>
Efficacy & future applications of PBT in WA

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre M</th>
<th>Pre SD</th>
<th>Post M</th>
<th>Post SD</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction</td>
<td>34.00</td>
<td>7.19</td>
<td>40.13</td>
<td>4.99</td>
<td>-2.39</td>
<td>.048</td>
</tr>
<tr>
<td>Efficacy</td>
<td>25.00</td>
<td>5.21</td>
<td>26.63</td>
<td>4.75</td>
<td>-0.93</td>
<td>.385</td>
</tr>
<tr>
<td>Total</td>
<td>59.00</td>
<td>6.48</td>
<td>66.75</td>
<td>5.20</td>
<td>-3.00</td>
<td>.020</td>
</tr>
</tbody>
</table>

Table 4.20 Difference between Parenting Sense of Competence Scale scores for parents pre/post intervention (n = 8)

Table 4.21 Difference between Parenting Sense of Competence Scale scores for parents post intervention (n = 8) and normative data (n = 111) (Ohan, et al, 2000)

<table>
<thead>
<tr>
<th>Item</th>
<th>Post M</th>
<th>Post SD</th>
<th>Norms M</th>
<th>Norms SD</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction</td>
<td>40.13</td>
<td>4.99</td>
<td>39.45</td>
<td>6.74</td>
<td>0.38</td>
<td>.714</td>
</tr>
<tr>
<td>Efficacy</td>
<td>26.63</td>
<td>4.75</td>
<td>27.36</td>
<td>5.44</td>
<td>-0.44</td>
<td>.675</td>
</tr>
<tr>
<td>Total</td>
<td>66.75</td>
<td>5.20</td>
<td>66.81</td>
<td>8.54</td>
<td>-0.03</td>
<td>.975</td>
</tr>
</tbody>
</table>

4.3.7 Developmental Behaviour Checklist, Revised

Data for initial assessments using the Developmental Behaviour Checklist - Parent were available for 74 parents, representing 37 referrals to the PBT. At follow-up (median time elapsed was 12 months), there were data for 25 parents, representing 13 referrals. These data are presented in tables Table 4.22 to Table 4.24 below.

Analyses indicate that at the point of initial assessment parents were reporting their son or daughter’s maladaptive behaviour profile at levels significantly above those to be expected of both typically developing children and children with disability. There were no significant differences between the average Total Problem Behaviour Scores reported by mothers (79.35) compared to those reported by fathers (79.14). The reported behaviours included externalised disruptive and antisocial behaviour, internalised self-absorbed behaviours, disturbed communication, heightened levels of anxiety, and poor social relatedness. All subscale scores indicated behaviour to be as maladaptive or worse than that to be expected of at least 80% of children (with
or without disability), with Total Problem Behaviour Scores at approximately the 90th percentile. All average scores exceeded the clinical cut-offs, indicating the potential for clinically significant psychopathology.

Following intervention, scores on the Developmental Behaviour Checklist indicated statistically significant improvements on the Total Problem Behaviour Score. Though remaining above the level accepted as indicative of psychopathology, total scores were decreasing towards the 70th percentile. Notably, statistically significant improvements were evident in the ratings of disruptive and antisocial behaviour, and in respect to social relatedness.

Table 4.22 Difference between Developmental Behaviour Checklist (DBC) scores for parents pre intervention (n = 74) and Australian normative data (n = 454) (Einfeld & Tonge, 2002)

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre intervention</th>
<th>Australian norms¹</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Disruptive/antisocial</td>
<td>26.05</td>
<td>9.51</td>
</tr>
<tr>
<td>Self-absorbed</td>
<td>27.35</td>
<td>11.08</td>
</tr>
<tr>
<td>Communication disturbance</td>
<td>10.14</td>
<td>4.10</td>
</tr>
<tr>
<td>Anxiety</td>
<td>7.45</td>
<td>8.60</td>
</tr>
<tr>
<td>Social relatedness</td>
<td>8.26</td>
<td>3.34</td>
</tr>
<tr>
<td>Total problem behaviour</td>
<td>79.24</td>
<td>21.39</td>
</tr>
</tbody>
</table>

DBC raw scores at 50th percentile.
Clinical cut-off approximations: Disruptive/Antisocial - 14; Self-absorbed - 14; Communication Disturbance - 6; Anxiety – 4.5; Social Relatedness - 5; Total Problem Behaviour - 46.

Table 4.23 Difference between Developmental Behaviour Checklist (DBC) scores for n = 25 parents pre/post intervention

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre</th>
<th>Post</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Disruptive/antisocial</td>
<td>25.52</td>
<td>8.69</td>
</tr>
<tr>
<td>Self-absorbed</td>
<td>20.44</td>
<td>9.87</td>
</tr>
<tr>
<td>Communication disturbance</td>
<td>9.44</td>
<td>4.03</td>
</tr>
<tr>
<td>Anxiety</td>
<td>7.08</td>
<td>9.98</td>
</tr>
<tr>
<td>Social relatedness</td>
<td>7.80</td>
<td>3.00</td>
</tr>
</tbody>
</table>
Table 4.24 Difference between Developmental Behaviour Checklist (DBC) scores for parents post intervention (n = 25) and Australian normative data (n = 937) (Einfeld & Tonge, 2002)

<table>
<thead>
<tr>
<th>Item</th>
<th>Post intervention</th>
<th>Australian Norms¹</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Disruptive/antisocial</td>
<td>18.80</td>
<td>8.78</td>
</tr>
<tr>
<td>Self-absorbed</td>
<td>17.92</td>
<td>10.33</td>
</tr>
<tr>
<td>Communication disturbance</td>
<td>8.08</td>
<td>4.32</td>
</tr>
<tr>
<td>Anxiety</td>
<td>5.68</td>
<td>2.84</td>
</tr>
<tr>
<td>Social relatedness</td>
<td>6.40</td>
<td>2.97</td>
</tr>
<tr>
<td>Total problem behaviour</td>
<td>56.88</td>
<td>21.96</td>
</tr>
</tbody>
</table>

DBC raw scores at 50th percentile.

Clinical cut-off approximations: Disruptive/Antisocial - 14; Self-absorbed - 14; Communication Disturbance - 6; Anxiety – 4.5; Social Relatedness - 5; Total Problem Behaviour - 46.

4.4 Family assessments conducted by the researcher

For families who volunteered to participate in identifiable data collection, each undertook an interview and completed a number of standardised questionnaires administered directly by the researcher. However, it should be noted that given the applied nature of the research, the families participating at this phase were self-selected. The majority of interviews and questionnaires were completed by mothers. Where fathers participated in interviews, questionnaires were completed jointly by both parents.

4.4.1 Measure of Beliefs about Participation in Family-Centred Services

Families reported an overall belief in adopting a family-centred intervention approach to support for their son or daughter. They gave an average level of endorsement of the approach at 78% scale maximum, indicative of strong agreement with the proposed features of a family centred approach. The total score and subscale scores were all comparable to the views expressed by families in the comparative group, with the exception of their views concerning the absence of negative outcomes. Parents involved with the PBT expressed a statistically significant higher level of endorsement in the absence of negative outcomes associated with adopting a family centred approach (i.e., a higher positive appraisal of the approach)
compared to the views expressed by the comparative sample of US families. A comparison of family and staff responses on this scale is presented at section 3.7.5.

Families reported that they believed there would be few if any negative outcomes to the implementation of a family-centred approach to service provision. On average, they reported 86% endorsement of the perceived absence of negative outcomes. Questionnaire subscale scores did not indicate any issues of particular importance to families with respect to potential negative outcomes. Overall, families did not endorse any concerns regarding the inability of this approach to meet the needs of parents, that service providers might need to sacrifice professional integrity, that the approach would lead to less time being spent in direct services to the child, that service providers might have difficulty sharing roles with families during the intervention process, or that service providers might have difficulties working directly with families and other service providers.

Families surveyed reported a relatively high level of endorsement (on average, 88% scale maximum) of the principles identified as central to family-centred services. The strongest level of endorsement was given to the principle of encouraging the involvement of all family members is a good thing and it is important to consider the needs of all family members in service delivery (e.g., parents, siblings, grandparents). Both were rated on average above 90% scale maximum.

Similarly, families provided a relatively high level of endorsement (on average, 86% scale maximum) with respect to their belief in their own capacity (self-efficacy) to work within and implement a family-centred approach. They indicated that they intended to participate in services in a family-centred way, that they were confident they would be able to do the things expected of them according to a family-centred approach, that they would be able to work with others in a family-centred way, and that they had the skills and abilities needed to participate in a family-centred approach. All of these were endorsed at 81% scale maximum or higher.

Families endorsed the potential benefits of the family-centred approach on average at 86% scale maximum. Families reported a relatively strong belief that a family-centred approach would make service delivery effective because everyone on the team would be working toward the same goals, and that in a family-centred approach, families will “follow through” better with treatment plans because they are partners with service providers. Similarly, high levels of endorsement were given to the propositions that participating in services in a family-centred way is essential, that family-centred service will reduce service providers’ stress because the responsibility for decision-making will be shared between parents and service providers, that as compared to traditional practice, service providers using a family-centred approach will be more satisfied with the care they provide, and that a family-centred approach will be more beneficial than a traditional approach to service delivery. The only item on this subscale to fall below an average endorsement of 80% scale maximum was with respect to family-centred services increasing the efficiency of service delivery by improving communication among service providers and families. However, this item was still endorsed on average at 76% scale maximum.

It was with respect to their beliefs in the practical feasibility of implementing a family-centred approach to service provision that families expressed relative concern. On average, they endorsed items concerning the practicalities of implementation at only 56% scale maximum. This rating was comparable with the views expressed by the
US sample, which expressed endorsement on average at only 54% scale maximum. Families were most concerned that parents' lack of awareness of expectations of them (according to principles of family-centred service) will affect the ideal practice of family-centred service. Similarly, there were concerns that service providers' lack of familiarity, experience, or training in matters related to family-centred service will affect the ideal practice of family-centred service and that compared to traditional practice, family-centred service will increase the work of service providers. Of comparatively lesser concern were views regarding the possibility that family-centred service will take more time to implement than traditional service delivery, that in a family-centred approach, families will be required to take on responsibilities they would rather have service providers perform, that parents' lack of understanding of what family-centred service really means will affect the ideal practice of family-centred service, and service providers' preferences, desires, or opinions regarding their role in the delivery of services will create obstacles affecting the ideal practice of family-centred service.

Table 4.25 Difference between Measure of Beliefs About Participation in Family-Centered Services subscale scores reported by parents in receipt of services from the Positive Behaviour Team (n = 18) and comparative data (King et al., 2003; n = 494)

<table>
<thead>
<tr>
<th>Item</th>
<th>PBT parents</th>
<th>Comparison sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>1. Benefits</td>
<td>5.92</td>
<td>.63</td>
</tr>
<tr>
<td>2. Practical feasibility</td>
<td>3.89</td>
<td>1.06</td>
</tr>
<tr>
<td>3. Self-efficacy to implement</td>
<td>6.00</td>
<td>0.77</td>
</tr>
<tr>
<td>4. Principles</td>
<td>6.16</td>
<td>0.68</td>
</tr>
<tr>
<td>5. Absence of negative outcomes</td>
<td>6.00</td>
<td>0.88</td>
</tr>
<tr>
<td>6. Overall belief</td>
<td>5.48</td>
<td>0.47</td>
</tr>
</tbody>
</table>

Table 4.26 Difference between Measure of Beliefs about Participation in Family-Centered Services item scores reported by parents in receipt of services from the Positive Behaviour Team (n = 18)

| Item                                                                 | PBT Parents |
|                                                                      | M    | SD  |
| 1. Service providers will have difficulty working with families or other service providers in implementing a family-centred philosophy. | 5.67 | 1.81 |
2. Family-centred service means that service providers will sacrifice their professional integrity.  

3. As compared to traditional practice, service providers using a family-centred approach will be more satisfied with the services they provide.  

4. Parents should always have the ultimate responsibility for making decisions about their son’s/daughter’s support services.  

5. A family-centred approach will reduce the quality of services for people with disability (because less time will be spent providing direct services to the person with disability).  

6. In a family-centred approach, service providers will be unsure how to share roles with families.  

7. Participating in services in a family-centred way is essential.  

8. Parents’ lack of understanding of what family-centred service really means will affect the ideal practice of family-centred service.  

9. A family-centred approach will be more beneficial to people with disability than a traditional approach to service delivery.  

10. It is important to attend to family priorities for goals and services (even when these priorities differ a lot from the priorities of the service providers).  

11. In a family-centred approach, families will “follow through” better with intervention & support plans because they are partners with service providers.  

12. Family-centred service will reduce service providers’ stress because the responsibility for decision-making will be shared between parents and service providers.  

13. I have the skills and abilities needed to participate in a family-centred approach to service.  

14. Compared to traditional practice, family-centred service will increase the work of service providers.  

15. Family-centred service will take more time to implement than traditional service delivery.  

16. It is important to consider the needs of all family members in service delivery (e.g., parents, siblings, grandparents).  

17. A family-centred approach will make service delivery effective because everyone on the team is working toward the same goals.
18. Encouraging the involvement of all family members is a good thing. 6.56 0.86
19. A family-centred approach will not meet the needs of parents. 6.44 0.71
20. I am confident that I am able to work with others in a family-centred way. 6.00 0.91
21. Service providers’ preferences, desires, or opinions regarding their role in the delivery of services will create obstacles affecting the ideal practice of family-centred service. 4.94 1.47
22. In a family-centred approach, families will be required to take on responsibilities they would rather have service providers perform. 4.11 1.91
23. Family-centred service will increase the efficiency of service delivery by improving communication among service providers and families. 6.22 0.65
24. Service providers’ lack of familiarity, experience, or training in matters related to family-centred service will affect the ideal practice of family-centred service. 3.06 1.16
25. It is essential to encourage and have family members choose how much they want to be involved in making decisions about their son’s/daughter’s services. 6.11 1.02
26. I intend to participate in services in a family-centred way. 6.33 0.91
27. I am able to do the things expected of me according to a family-centred approach. 6.00 0.84
28. Parents’ lack of awareness of expectations of them (according to principles of family-centred service) will affect the ideal practice of family-centred service. 2.83 1.38

4.4.2 Quality of Family–Professional Partnerships (QFPPS)

Families rated the importance of service providers working in partnership with them at 86% scale maximum (i.e., in the range indicative of being important to critically important). These results were indistinguishable from those of families reported in the comparative sample. Overall, families provided relatively high ratings of the importance of service providers being both person/child focused (87% scale maximum) and family focused (86% scale maximum) in their approach to service provision.

The most important elements of a person/child-focused partnership were that service providers: treat your family member with disability with dignity; help you to gain skills or get information, to get what your family member with disability needs; have the
skills to help your family member with disability succeed; and values your opinion about your family member with disability’s needs. All of these were rated at or above 90% scale maximum.

For the families in the current study, the most important element of a family focused partnership was that service providers are people that you can depend on and trust. This element was rated on average at 90% scale maximum. Other important elements were that service providers would: protect your family’s privacy, are friendly, pay attention to what you have to say, listen without judging, and shows respect for your family’s values and beliefs. All of these were rated on average at 85% scale maximum or greater.

With respect to their experience of working in partnership with the PBT, families reported an average satisfaction rating of 83% scale maximum (i.e., in the range indicative of being satisfied to very satisfied). Families reported a partnership satisfaction rating with respect to the PBTs family focus at 88% scale maximum, and satisfaction rating with respect to the PBTs person/child focus at 77% scale maximum. These results were indistinguishable from those of families reported in the comparative sample.

With respect to being person/child focused, families were most satisfied that PBT staff treated their family member with dignity and respect. This was rated at 94% scale maximum. Families also reported relatively high levels of satisfaction with the experience that PBT staff values your opinion about your family member with disability’s needs. This was rated at 81% scale maximum.

With respect to being family focused, families were most satisfied that PBT staff were friendly, showed respect for the family’s values and beliefs, were available when you needed them, and that they listened without judging. All of these features of the PBT were rated above 90% scale maximum.

Table 4.27 Difference between Professional Partnership Scale subscale & total scores reported by parents in receipt of services from the Positive Behaviour Team (n = 18) and comparative data (n = 205) (Summers, et al, 2005)

<table>
<thead>
<tr>
<th>Item</th>
<th>PBT parents</th>
<th>Comparison sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td><strong>Person/child focused</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Importance</td>
<td>4.36</td>
<td>.63</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>3.86</td>
<td>.47</td>
</tr>
<tr>
<td><strong>Family focused</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Importance</td>
<td>4.28</td>
<td>.63</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>4.40</td>
<td>.51</td>
</tr>
<tr>
<td><strong>Average partnership</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Importance</td>
<td>4.32</td>
<td>.58</td>
</tr>
</tbody>
</table>
Table 4.28 Difference between Professional Partnership Scale mean item scores reported by parents in receipt of services from the Positive Behaviour Team (n = 18) and comparative data (n = 205) (Summers, et al, 2005)

<table>
<thead>
<tr>
<th>Item</th>
<th>PBT Parents</th>
<th>Comparison Sample</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Helps you to gain skills or get information, to get what your family member with disability needs</td>
<td>Importance: 4.56, SD: .78</td>
<td>Satisfaction: 3.83, SD: .92</td>
<td>0.84</td>
<td>.411</td>
</tr>
<tr>
<td>2. Has the skills to help your family member with disability succeed</td>
<td>Importance: 4.56, SD: .78</td>
<td>Satisfaction: 3.61, SD: 1.04</td>
<td>-0.84</td>
<td>.415</td>
</tr>
<tr>
<td>3. Provides services that meet the individual needs of your family member with disability</td>
<td>Importance: 4.17, SD: .99</td>
<td>Satisfaction: 3.44, SD: .98</td>
<td>-2.43</td>
<td>.027</td>
</tr>
<tr>
<td>4. Speaks up for your family member with disability’s best interests when working with other service providers</td>
<td>Importance: 4.33, SD: .77</td>
<td>Satisfaction: 3.83, SD: .86</td>
<td>-0.54</td>
<td>.600</td>
</tr>
<tr>
<td>5. Lets you know about the good things your family member with disability does</td>
<td>Importance: 4.00, SD: .91</td>
<td>Satisfaction: 3.94, SD: .87</td>
<td>-1.87</td>
<td>.079</td>
</tr>
<tr>
<td>6. Treats your family member with disability with dignity</td>
<td>Importance: 4.61, SD: .70</td>
<td>Satisfaction: 4.72, SD: .58</td>
<td>-0.78</td>
<td>.444</td>
</tr>
<tr>
<td>7. Builds on your family member with disability’s strengths</td>
<td>Importance: 4.28, SD: .83</td>
<td>Satisfaction: 3.61, SD: .70</td>
<td>-1.45</td>
<td>.166</td>
</tr>
<tr>
<td>8. Values your opinion about your family member with disability’s needs</td>
<td>Importance: 4.50, SD: .71</td>
<td>Satisfaction: 4.06, SD: 1.11</td>
<td>-0.66</td>
<td>.518</td>
</tr>
<tr>
<td></td>
<td>Positive Behaviours of PBT Staff</td>
<td>Importance</td>
<td>Satisfaction</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---------------------------------</td>
<td>------------</td>
<td>--------------</td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>Keeps your family member with disability safe when working with them</td>
<td>4.22</td>
<td>3.72</td>
<td>.88</td>
</tr>
<tr>
<td>10.</td>
<td>Are available when you need them</td>
<td>4.00</td>
<td>4.56</td>
<td>.91</td>
</tr>
<tr>
<td>11.</td>
<td>Are honest, even when they have bad news</td>
<td>4.22</td>
<td>3.89</td>
<td>.81</td>
</tr>
<tr>
<td>12.</td>
<td>Use words that you understand</td>
<td>4.11</td>
<td>4.39</td>
<td>.83</td>
</tr>
<tr>
<td>13.</td>
<td>Protect your family’s privacy</td>
<td>4.39</td>
<td>4.39</td>
<td>1.09</td>
</tr>
<tr>
<td>14.</td>
<td>Show respect for your family’s values and beliefs</td>
<td>4.28</td>
<td>4.61</td>
<td>.83</td>
</tr>
<tr>
<td>15.</td>
<td>Listen without judging your family member with a disability or your family</td>
<td>4.33</td>
<td>4.50</td>
<td>.84</td>
</tr>
<tr>
<td>16.</td>
<td>Are people that you can depend on and trust</td>
<td>4.50</td>
<td>4.33</td>
<td>.71</td>
</tr>
<tr>
<td>17.</td>
<td>Pay attention to what you have to say</td>
<td>4.33</td>
<td>4.33</td>
<td>.84</td>
</tr>
<tr>
<td>18.</td>
<td>Are friendly</td>
<td>4.39</td>
<td>4.61</td>
<td>.78</td>
</tr>
</tbody>
</table>

4.4.3 Measure of Processes of Care (MPOC-20)

Families overall rating of the behaviours of PBT staff in relation to the provision of family-centred and effective services was at 75% scale maximum. This rating was comparable with the rating for the comparative sample, which was at 70% scale maximum. This rating indicated that families observed the positive behaviours of PBT staff to a fairly great extent.
The behaviours most evident to families were those that indicated staff to be respectful and supportive (84% scale maximum). The average rating for this subscale was statistically significantly greater than the average rating achieved in the comparative sample (76% scale maximum). Staff behaviours most evident to families were: providing enough time to talk so you don’t feel rushed (at a level statistically significantly greater than the rating attained in the comparative sample), treating you as an equal rather than just as the parent of a client with disability (at a level statistically significantly greater than the rating attained in the comparative sample), treating you as an individual rather than as a “typical” parent of a person with a disability (at a level statistically significantly greater than the rating attained in the comparative sample), helping you to feel competent as a parent, and providing a caring atmosphere rather than just give you information. All were rated above the 81% scale maximum.

Families also reported PBT staff to deliver services in a coordinated and comprehensive way (81% scale maximum). The average rating for this subscale was statistically significantly greater than the average rating achieved in the comparative sample (74% scale maximum). The behaviours most valued by staff were: planning together so they are all working in the same direction (at a level statistically significantly greater than the rating attained in the comparative sample), making sure that at least one team member is someone who works with you and your family over a long period of time (at a level statistically significantly greater than the rating attained in the comparative sample), look at the needs of your “whole” son/daughter (e.g., at mental, emotional, and social needs) instead of just at physical needs, and giving you information about your son/daughter that is consistent from person to person. All these facets of PBT staff behaviour were rated greater than 81% scale maximum.

Families reported that the way in which PBT staff delivered services was typified by behaviours which were enabling and consistent with a partnership approach (73% scale maximum). However, overall, ratings were comparable (no statistically significant difference) to those obtained in the comparative sample (71% scale maximum). These behaviours included: fully explaining support and intervention choices and providing opportunities for you to make decisions about the support and intervention services you want. Both of these were rated at approximately 76% scale maximum. The aspect of letting you choose when to receive information and the type of information you want was rated at 67% scale maximum.

Families reported the provision of specific information relating to their son or daughter’s support and intervention needs at 68% scale maximum. This facet of PBT services was rated at a level below that attained for the comparative sample (73% scale maximum). The activity rated highest was telling you about the results from assessments. This was rated at 73% scale maximum. Providing you written information about your son’s/daughter’s progress and provide you with written information about what your son/daughter is doing in the intervention program; the goals and strategies, were rated at or above 62% scale maximum.

The provision of general information relating to supports and services generally was rated at 60% scale maximum. This was comparable with the rating attained by the comparative sample (57% scale maximum). The activity most valued in terms of providing general information was providing opportunities for the entire family to obtain information. This was rated at 70% scale maximum and at a level statistically
significantly greater than the rating attained in the comparative sample. Other activities of PBT staff which were valued included: giving you information about the types of services offered at the organization or in your community; having information available to you in various forms, such as a booklet, kit, video, etc. (at a level statistically significantly greater than the rating attained in the comparative sample); and having information available about your son’s/daughter’s disability (e.g., its causes, how it progresses, future outlook). The aspect of providing general information which was rated lowest by families was providing advice on how to get information or to contact other parents (e.g., organization’s parent resource library). This was rated at 56% scale maximum.

Table 4.29 Difference between Measure of Process of Care subscale scores reported by parents in receipt of services from the Positive Behaviour Team (n = 18) and comparative data (n = 369) (King, et al., 2004)

<table>
<thead>
<tr>
<th>Item</th>
<th>PBT parents</th>
<th>Comparison sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Enabling &amp; partnership</td>
<td>5.11</td>
<td>1.07</td>
</tr>
<tr>
<td>Providing general information</td>
<td>4.21</td>
<td>1.07</td>
</tr>
<tr>
<td>Providing specific information</td>
<td>4.76</td>
<td>1.15</td>
</tr>
<tr>
<td>Coordinated &amp; comprehensive</td>
<td>5.64</td>
<td>0.86</td>
</tr>
<tr>
<td>Respectful &amp; supportive</td>
<td>5.86</td>
<td>0.83</td>
</tr>
<tr>
<td>Average MPOC score</td>
<td>5.22</td>
<td>0.83</td>
</tr>
</tbody>
</table>

Table 4.30 Difference between Measure of Process of Care item scores reported by parents in receipt of services from the Positive Behaviour Team (n = 18) and comparative data (n = 369) (King, et al., 2004)

<table>
<thead>
<tr>
<th>Item</th>
<th>PBT parents</th>
<th>Comparison sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>1. Help you to feel competent as a parent?</td>
<td>5.67</td>
<td>1.03</td>
</tr>
<tr>
<td>2. Provide you with written information about what your son/daughter is doing in the intervention program; the goals and strategies?</td>
<td>4.39</td>
<td>1.58</td>
</tr>
</tbody>
</table>
3. Provide a caring atmosphere rather than just give you information?  
5.67 1.14 5.37 1.43 1.11 .284

4. Let you choose when to receive information and the type of information you want?  
4.67 1.72 4.82 1.70 -0.38 .709

5. Look at the needs of your “whole” son/daughter (e.g., at mental, emotional, and social needs) instead of just at physical needs?  
5.72 1.13 5.16 1.59 2.12 .049

6. Make sure that at least one team member is someone who works with you and your family over a long period of time?  
5.83 1.25 5.02 1.83 2.76 .013

7. Fully explains support and intervention choices to you?  
5.39 1.24 5.05 1.71 1.16 .263

8. Provide opportunities for you to make decisions about the support and intervention services?  
5.28 1.13 5.13 1.63 0.56 .585

9. Provide enough time to talk so you don’t feel rushed?  
6.00 0.91 5.34 1.46 3.09 .007

10. Plan together so they are all working in the same direction?  
6.00 1.03 5.29 1.50 2.93 .009

11. Treat you as an equal rather than just as the parent of a client with disability?  
6.00 0.91 5.11 1.61 4.16 .001

12. Give you information about your son/daughter that is consistent from person to person?  
5.29 1.11 5.18 1.43 0.43 .676

13. Treat you as an individual rather than as a “typical” parent of a person with a disability?  
5.94 0.99 5.24 1.58 2.99 .008

14. Provide you with written information about your son/daughter’s progress?  
4.78 1.35 5.05 1.74 -0.85 .405
15. Tell you about the results from assessments?  
   5.11  1.37  5.39  1.54  -0.87  .399

16. Give you information about the types of services offered at the organization or in your community?  
   4.71  1.21  4.52  1.82  0.63  .536

17. Have information available about your son’s/daughter’s disability (e.g., its causes, how it progresses, future outlook)?  
   4.06  1.44  3.84  1.94  0.63  .538

18. Provide opportunities for the entire family to obtain information?  
   4.89  1.32  4.03  1.95  2.75  .014

19. Have information available to you in various forms, such as a booklet, kit, video, etc.?  
   4.41  1.12  3.79  1.98  2.29  .036

20. Provide advice on how to get information or to contact other parents (e.g., organization’s parent resource library)?  
   3.94  1.14  4.08  2.04  -0.50  .624

4.4.4 The Partnership Orientation Measure (POM)

Families reported an overall average score at 84% scale maximum, indicative of a trend towards their rating services as could not have been better. This rating was statistically significantly greater than the mean score for a comparative sample ($M = 4.04$, $SD = .64$); $t(18) = 7.49$, $p = .000$ (two tailed). Comparative data were not available for the subscales.

Family perceived the PBTs greatest strength to be their focus on promoting collaboration (at 87% scale maximum). Considerations here included the extent to which the PBT members worked jointly with the family by identifying strengths, needs, and goals, and how they incorporated the family input into data collection and plan development. Further considerations included how the PBT members promoted shared responsibility and ownership for the child’s support plan.

Families rated the PBT relatively strongly for their encouraging approach (at 86% scale maximum). This facet of their work included consideration of how PBT members promoted and inspired family members during the decision making process involved in developing the support plan, how they encouraged family members to speak up, to make their own decisions, to draw on their own knowledge, experience and expertise, and to exercise choice in the planning process.

Families rated the PBT relatively strongly for their sensitivity and responsiveness (at 86% scale maximum). This facet of their work included consideration of how PBT
members asked questions or made statements that demonstrated an awareness of the needs, attitudes, and feelings of the family, and acknowledged different perspectives. It also included consideration of how the PBT members conveyed empathy, how they checked to make sure the family was happy with the assessments and programs, and how they responded positively to the family, making changes or adaptations to the programs or processes as needed. This facet also included consideration of the extent to which PBT members were honest and sincere, and genuinely warm and caring.

Families also rated the PBT relatively strongly for their focus on strengths (at 85% scale maximum). This dimension of the service evaluation focused on the extent to which PBT members recognised, acknowledged, and built upon the existing knowledge, skills and abilities of family members, in contrast to adopting a deficit approach.

Family members reported the PBT as strong in their use of effective communication (at 84% scale maximum). This included consideration of the extent to which PBT members asked open-ended questions, elicited tangible examples, restated statements to check for accuracy, and asked for clarification where family comments were unclear. Consideration was also given to the extent to which PBT members acknowledged and reflected the emotional dimension to comments and responses made by families, and how clearly and sensitively PBT members conveyed their suggestions, recommendations, and any concerns when talking with families.

Families reported that PBT members were focused on promoting skill development (at 81% scale maximum). Consideration here included the extent to which the PBT members promote new and existing family abilities. This could have involved explaining and/or modelling steps in the problem-solving process (e.g., defining a priority need, collecting information, setting goals, and monitoring and evaluating progress), as well as describing, training, modelling, and reinforcing specific techniques and interventions.

Families reported that PBT members were resourceful and shared information (at 77% scale maximum). Consideration here included the way in which the PBT members located and provided information about additional supports, services, and relevant resources. It also included consideration of how PBT members supported families to make choices and find solutions to their own problems, independent of the PBT.

Table 4.31 Partnership Orientation Measure scores reported by parents in receipt of services from the Positive Behaviour Team (n = 18)

<table>
<thead>
<tr>
<th>Item</th>
<th>PBT parents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
</tr>
<tr>
<td>Focus on strengths</td>
<td>5.11</td>
</tr>
<tr>
<td>Promotes collaboration</td>
<td>5.22</td>
</tr>
<tr>
<td>Encouraging</td>
<td>5.17</td>
</tr>
<tr>
<td></td>
<td>Mean</td>
</tr>
<tr>
<td>--------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Sensitive &amp; responsive</td>
<td>5.17</td>
</tr>
<tr>
<td>Uses effective communication</td>
<td>5.06</td>
</tr>
<tr>
<td>Promotes skill development</td>
<td>4.83</td>
</tr>
<tr>
<td>Resourceful &amp; shares info.</td>
<td>4.61</td>
</tr>
<tr>
<td>Average</td>
<td>5.02</td>
</tr>
</tbody>
</table>

4.5 Family interviews

The results of the family interviews are reported below. While the interviews were conducted using a semi-structured interview schedule, the findings are organised according to seven themes that were extracted from these data overall. The themes were: family expectations of the PBT, family experiences of working with the PBT, the PBT process, intervention and support activities, the most important experiences of the PBT, family recommendations concerning staffing of the PBT, and the most needed services more generally as reported by families. When reporting data in support of the themes, comments made by families, and paraphrasing of comments, are provided in italics.

Family expectations of the PBT

When asked about their expectations of PBT involvement, families commented on expectations relating to both their family member with disability and others in the family, including themselves. Typically, families wanted an intervention that made their son or daughter stable, calmer, and happier; a happier kid who’s not always in trouble. A number of families commented on the importance of their son or daughter getting skills and being more independent. As one parent stated, to know that one day he might do more on his own.

Parents frequently commented specifically on the importance of their son or daughter developing communication skills (being able to say what she/he wants) and anger management skills (being able to say what she/he feels and to keep control when it’s hard), for use at home and at school. Families frequently commented on the need for 1:1 counselling for their daughter or son, commenting that she/he needs to debrief, and I can’t do that for her/him, she/he doesn’t want to talk to me, she/he needs someone outside the family to talk to. A number of parents commented on the need for their daughter or son (mostly sons) to have a mentor - someone who stays around for the next few years while he grows up. Nearly all families commented on how important it was to get support so their daughter or son had friends - other kids away from home to spend time with on a regular basis.

In regard to their own needs, families frequently commented on wanting the PBT intervention to make me feel stress free, and be more happy. A common desire was that the PBT intervention would result in less fights in the family. Most families made reference to the desire to feel more confident, both in relation to supporting their daughter or son and in relating to other services, such as schools.
Families experience of working with the PBT

Families consistently reported that the home-based service was just what they needed, and an essential part of the PBT service. They commented that the home-based delivery was important for keeping things personal to the family and maintaining privacy. They also noted that this form of service meant that clinicians could see what it was like and the strategies were about what was practical. It was about help in the situation where people live. Families frequently made contrasts with other services they had received, where they had to go to see an expert who didn’t really know what it was like at home, or where they had to tell their whole story in a group. Neither of these scenarios were seen by families as preferred or effective options. Rather these were spoken of as additional sources of stress that they didn’t need. Several families clearly stated we don’t want another course to go to. Families also commented on the cost of going to other programs and this was not in their budget.

Families reported favourably on the team visits. They commented that if one doesn’t know the answer the other one usually has some ideas. Families also commented that they work together, so you don’t have to fill in the gaps for them. Families reported positively about situations in which team members had gone out with them and their child; going out to places we all need to go together. They indicated that this helped with strategy development and they felt that the suggestions that were made were made by people who really understood what it was like for them.

Families appreciated the telephone contact between visits. They commented that this was an important source of support and also was a good way to remind them about strategies and to change strategies where necessary. Some families indicated that it would have been helpful for the PBT to have observed what happened at the weekend, while other families said that it was important to have a few boundaries, where on the weekend they could just be a family without professionals on the door step.

The PBT processes

Most families wanted something to happen sooner. They had typically been waiting a long time for the service and were desperate for things to be different. Those families that had been involved with the PBT for a longer period spoke about their frustrations in the early stages, but many also commented that they later understood why it took a while to conduct the assessments and start a plan.

However, most families asked that the PBT not take too long with the assessments. A number of the families reported that they needed more support with the written assessments and forms, and some asked for the questions to be simpler. Some families expressed some concern that assessments looked at the past and they wanted to look at the future.

Here it should be noted that as part of ongoing family engagement, PBT staff actively talked to families about their difficulties with the sustained (i.e., longer than anticipated by many families) assessment process. In many cases some short-term intervention, particularly safety planning, was appreciated. However, it was the experience of the PBT that families usually required support to work through a collaborative assessment and intervention planning process. It was this collaborative and prolonged assessment experience that many families found it difficult to adjust
to, as their previous experience and consequently their expectations were aligned with processes involving them as the recipient of practitioner expertise, rather than as co-creators of insight and support plans.

Some families expressed the need to know more about what’s coming next, where is this going, and what to expect. Families that were near the end of the process typically commented that they could now see why the assessments were needed and why it had taken so long. However, those in the early phases commonly expressed frustration it was taking so long to get really started.

Families reported positively about the PBT working with other services that were involved with their family, especially schools and respite services. Families said it was important for the PBT staff to see their child everywhere, because behaviour was everywhere. Some families noted that the PBT had brought them together with other services for the first time, or where they had not been able to speak with other services for a long time, especially with references to schools. Families valued the role of the PBT in providing advocacy and mediation.

**Intervention and Support Activities**

Families valued both the way in which PBT services were provided, specific activities and resources, especially information about what services were available and how to access them. This was despite all families having been involved with the service system for many years. Some families commented that they had a good LAC who helped, and others said that the PBT seemed to know more about who to contact. Families commented positively about opportunities to talk and get counselling, and some expressed the desire for further counselling just for parents. A number of families indicated that they could keep going if they just had someone to listen to them.

Families commented on how the PBT had made them take the time needed to reflect; not hurried, like in groups – where I can’t get a say. Families frequently commented on how the PBT had built their confidence.

Most families commented on the essential need for respite, both out-of-home and in-home. School holiday programs that were able to take their child were noted as being in short supply. Some families commented that they (the program) took him a few years ago, but never again. Families expressed a desire for more information about networks and groups they or their child could join. A number of families commented that it’s the sibling(s) who needed more support and connections outside the family.

Families commented on the use of video. Video observation was central to assessment, the planning of support, and the coaching of parents in intervention strategies. The use of video was found useful in developing shared understandings between family members and PBT staff, and provided an important focus of collaborative problem solving and the monitoring of progress across different environments (home, school, and respite). Most families indicated that the video was very helpful. Parents remarked that it made it easy to see the family in the picture and for the first time really see what was happening, seeing the triggers like never before. Families commented on how important it was to know how I react. A few
families said they were a bit worried about the video, but soon got used to it. One family said it was just like having ‘Super Nanny’ come to the home.

Families identified a range of specific strategies that they had found helpful. Those most commonly remarked upon were: having a timetable; having a written plan; having a plan that could go to school; communication cards; cue cards; pictures - lots of pictures, a social story to use. Families valued having things to show teachers at school, things to show staff at respite, and things to show other family members. Families commented on the value of drawing the family tree and talking about where people fitted in. They commented on drawing circles of interest, to help plan things they could try.

Families commented on the fact that they learnt not only how to record behaviour, but also how to make sense of the records (with comments that professionals in the past had got them to keep records, but never explained how to make sense of them). Families commented that they now knew how to teach skills, whereas before they just yelled. Being able to teach and reward good social skills was frequently cited by parents as a positive experience of the PBT. Many parents also commented that they had learnt how to work together as parents – how to be on the same page like never before. A number of families commented on how they had learnt so much about Autism and this was important to know so they could better understand their son.

Families, especially those towards the end of the PBT process, commonly stated they wanted a long-term plan, to know what would come after PBT, a safety net to make sure it didn’t go backwards. A few families commented that they wanted more than they had previously from LAC, as it just wasn’t enough to keep going. Many families highlighted the need for occasional professional support, beyond their PBT involvement. Typically people highlighted the need for access to a speech pathologist or a psychologist.

**Most important experiences**

When reflecting on the PBT involvement with their family and the intervention, families highlighted a number of experiences that they considered to be of particular importance. In conversation, they noted how these had been of benefit to them and how they believed that these experiences could also be of benefit to other families in a similar situation.

Families frequently commented on how, as a consequence of the PBT involvement they were working better together as a family; understanding each other better; communicating more; and learning to let go of the bad things from the past and look to the future with hope. A number of parents commented on how they were learning to stay calm, learning self-control, learning self-reflection. One parent said it was very important to have developed the understanding that when you are sick and can’t keep going; when you need a rest, and it’s OK to ask for help.

Parents frequently commented on how PBT involvement was helping them to develop the skills necessary to handle him/her when we are in public and how to react in a crisis. One parent commented that it had been of great benefit to learn how I react in a crisis. Parents frequently commented on how the PBT were helping them generate more things to do with my child – ideas, ideas, ideas. A number of
parents highlighted how important it was to get him/her back to school and to get me talking to the teacher again.

Staff for the PBT

When asked about the desirable attributes for PBT staff, families consistently commented that they were looking for people who were caring, patient, non-judgemental, and open minded. A number of families emphasised that it was important that PBT staff were approachable and that you know you can contact them and it won’t be a hassle. Families said it was important that staff showed that they listen to you and believe you. They stated that it was important for PBT staff to be reliable – people who do what they say and follow-up. One parent described the need to have people who come prepared to get their hands dirty, implying the importance of being involved with the family and incidents as they occur. Families frequently commented that it was important that PBT staff were people who know what it’s like to be a parent under pressure and who are able to relate to all the family (mothers, fathers, siblings and extended family, as well as the person with disability).

Many families commented on the importance of working with staff who demonstrated knowledge and skills. Families said that PBT staff needed to be qualified in what they do, and one family said it was important that they are not just nice do-gooders. Several families commented that staff were knowledgeable but not know-it-alls and that this was important. One parent stated, staff need to be real people who know the right questions to ask in a sensitive way. Most families made comments along the lines that PBT staff needed to be people who know people with disability; and people who know Autism well. Several families made comments to the effect that PBT staff need to be people who know enough so they can plan things outside the book, and not just stick to the recipe. As one parent put it, you don’t want someone who is just running the same workshop for the 100th time.

Most needed supports and services

When asked to comment on what families need most, parents typically commented that its hard work, stress all the time; so you need time out; you need understanding. A number of parents commented that they needed understanding in the community; not having to explain him/her in public all the time. Respite was frequently cited as a major need. Also, several parents commented that he/she will need a home of his own in the future and we need to plan for that now.

Parents commented on the importance of intervention services working at home and at school – so it all happens together. Several parents commented that it was important to have schools where the teachers know how to handle him/her, and which recognised he/she has special needs and can’t just be left in the class or the playground on his/her own. On this point, several parents commented that if they want him to go to a mainstream school, then the teachers need training and support.

Families were seeking services outside of work hours, so my husband can come too – they don’t understand at work that he needs time off to be involved. A number of families commented that they needed someone to telephone when it is tough and you don’t know what to do – someone to remind you about the strategies and help you use them. Several parents said it would be good to have a hot line for support – not more referrals.
A number of families commented they had been waiting a long time for something like the PBT, waiting years for a service like this, and that they needed it much earlier. A number of families commented that all families are different and have their own way of doing things; packages don’t work and that the individualised service of the PBT was what was so important.

Families commented on the importance of receiving services from specific disciplines, which they recognised as having knowledge and skills relevant to their needs of their family member with disability, and their own needs. Families typically made reference to the need for speech pathologists, occupational therapists, psychologists, and social workers. A number of families made the comment that they wished their LAC had been a social worker. And again, several parents said it was important for LACs to have more information, so they know who to send us to. A number of parents commented on the need to get a good psychiatrist, to get the medication right and keep it right or change it when it was wrong.

### 4.6 Staff assessments

#### 4.6.1 Personal Wellbeing Index, 4th Edition

Staff completed the personal Wellbeing Index, the results of which are given in Table 4.32. Comparisons are also made with an Australian normative sample.

Analyses indicate that staff were reporting their average sense of personal wellbeing and quality of life (79% scale maximum) at a level statistically significantly above that to be expected of typical Australians (75% scale maximum), though the effect size is only small and as such is clinically unremarkable (d = .39, r = .19). Their overall rating of life as a whole (77% scale maximum) was comparable with that to be expected of typical Australians (77% scale maximum). On the basis of these results it could be concluded that staff were successfully maintaining homeostasis, and there was no evidence of them being at risk of mental ill-health. These assertions are consistent with the results reported below for the Human Services Survey (section 3.6.2) and Occupational Stress Inventory (section 3.6.3).

The results suggest that staff were reporting their personal wellbeing, in order of priority from the level of greatest satisfaction to relative least satisfaction, with respect to personal safety, their standard of living, their future prospects, sense of philosophical/religious fulfilment, personal relationships, their health, sense of achievement, and connections to community.

Notably, staff reported their personal wellbeing at a subscale level at a level significantly above that to be expected of typical Australians with respect to their satisfaction with their future prospects (a small to medium effect size; d = .58, r = .28), personal safety (a small to medium effect size; d = .45, r = .22), and connection to community (a small effect size; d = .34, r = .17). However, none of these were clinically remarkable. All other ratings were as might be expected for typical Australians.
Table 4.32 Difference between Personal Wellbeing Index (PWI) scores for PBT Staff (n = 20) and normative data for the Australian population (n = 2200+) (Cummins, 2005)

<table>
<thead>
<tr>
<th>Item</th>
<th>PBT Staff</th>
<th>Australian Norms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Standard of living</td>
<td>8.05</td>
<td>1.05</td>
</tr>
<tr>
<td>Health</td>
<td>7.70</td>
<td>1.42</td>
</tr>
<tr>
<td>Achievement</td>
<td>7.70</td>
<td>0.80</td>
</tr>
<tr>
<td>Relationships</td>
<td>7.75</td>
<td>1.29</td>
</tr>
<tr>
<td>Safety</td>
<td>8.45</td>
<td>1.09</td>
</tr>
<tr>
<td>Community</td>
<td>7.65</td>
<td>1.37</td>
</tr>
<tr>
<td>Future</td>
<td>7.95</td>
<td>0.89</td>
</tr>
<tr>
<td>Philosophy/religion</td>
<td>7.95</td>
<td>1.43</td>
</tr>
<tr>
<td>Average PWI</td>
<td>7.90</td>
<td>0.76</td>
</tr>
<tr>
<td>Life as a whole</td>
<td>7.65</td>
<td>1.31</td>
</tr>
</tbody>
</table>

4.6.2 Human Services Survey

Staff reported their level of emotional exhaustion to be relatively low, according to the standardised interpretation of scores. Their ratings were, on average, statistically significantly lower than ratings to be expected of staff in human services.

Similarly, staff reported their level of depersonalisation to be relatively low, according to the standardised interpretation of scores. Their ratings were, on average, statistically significantly lower than ratings to be expected of staff in human services.

Staff reported level of personal accomplishment at a level within the average range expected of human service workers. There was no statistically significant deviation from the normative sample.

The results on the Human Services Survey would indicate staff are not reporting any symptoms commonly associated with burnout syndrome. Furthermore, the results suggest that they are not currently at risk of burnout syndrome. These findings are consistent with the results of the Personal Wellbeing Index reported above (section 3.6.1), and the Occupational Stress Inventory, reported below (section 3.6.3).
### Table 4.33 Difference between Human Services Survey scores for PBT Staff (n = 20) and normative data (n = 3400+) (Maslach & Jackson, 1996)

<table>
<thead>
<tr>
<th>Item</th>
<th>PBT Staff</th>
<th>Comparison HSS Norms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Emotional exhaustion</td>
<td>15.05</td>
<td>9.28</td>
</tr>
<tr>
<td>Depersonalisation</td>
<td>1.45</td>
<td>2.09</td>
</tr>
<tr>
<td>Personal achievement</td>
<td>37.65</td>
<td>4.03</td>
</tr>
</tbody>
</table>

Clinical interpretation: Low Emotional Exhaustion ≤16; Low Depersonalisation ≤6; Low Personal Achievement ≥39.

### 4.6.3 Occupational Stress Inventory Revised

Overall, staff self-reports on the Occupational Stress Inventory were clinically unremarkable. The average rating of stress on the Occupational Roles domain was statistically significantly below the average to be expected. However, this rating remained within the range to be interpreted as normal. The average rating of stress on the personal Strain domain was statistically indistinguishable from the average score to be expected, and was within the range to be interpreted as normal. Similarly, the average rating on the Personal Resources domain was statistically indistinguishable from the average score to be expected, and was within the range to be interpreted as indicative of an average level of coping resources. These scores are consistent with the findings of the Human Services Survey, reported above.

At a subscale level, there was some indication that staff’s reported levels of occupational stress was statistically significantly below the average (e.g., Role Overload, Role Insufficiency, Role Boundaries) and that their coping resources were greater than the average (e.g., Social Support). However, all these scores still fell within the range to be interpreted clinically as normal.

### Table 4.34 Difference between Occupational Stress Inventory Domain T-scores based on staff self-report (n = 20) and comparative data (n = 909) for which the mean T-score was 50, SD 10 (Osipow & Spokane, 1999)

<table>
<thead>
<tr>
<th>Item</th>
<th>PBT Staff OSI Domain T-Scores</th>
<th>Comparison OSI Norms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>1. Occupational roles</td>
<td>44.15</td>
<td>7.29</td>
</tr>
<tr>
<td>2. Personal strain</td>
<td>47.78</td>
<td>7.06</td>
</tr>
<tr>
<td>3. Personal resources</td>
<td>51.93</td>
<td>5.50</td>
</tr>
</tbody>
</table>
Table 4.35 Difference between Occupational Stress Inventory Subscale T-scores based on staff self-report (n = 20) and comparative data (n = 909) for which the mean T-score was 50, SD 10 (Osipow & Spokane, 1999)

<table>
<thead>
<tr>
<th>Item</th>
<th>PBT Staff OSI Subscale T-Scores</th>
<th>Comparison with OSI Norms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>1. Role overload</td>
<td>43.50</td>
<td>4.63</td>
</tr>
<tr>
<td>2. Role insufficiency</td>
<td>43.35</td>
<td>6.53</td>
</tr>
<tr>
<td>3. Role ambiguity</td>
<td>47.30</td>
<td>6.88</td>
</tr>
<tr>
<td>4. Role boundary</td>
<td>45.00</td>
<td>8.84</td>
</tr>
<tr>
<td>5. Responsibility</td>
<td>46.90</td>
<td>7.93</td>
</tr>
<tr>
<td>6. Physical environment</td>
<td>47.15</td>
<td>6.35</td>
</tr>
<tr>
<td>7. Vocational strain</td>
<td>49.60</td>
<td>10.07</td>
</tr>
<tr>
<td>8. Psychological strain</td>
<td>47.10</td>
<td>6.50</td>
</tr>
<tr>
<td>9. Interpersonal strain</td>
<td>47.80</td>
<td>6.65</td>
</tr>
<tr>
<td>10. Physical strain</td>
<td>46.60</td>
<td>8.06</td>
</tr>
<tr>
<td>11. Recreation</td>
<td>51.25</td>
<td>10.16</td>
</tr>
<tr>
<td>12. Self-care</td>
<td>52.75</td>
<td>8.95</td>
</tr>
<tr>
<td>13. Social support</td>
<td>53.45</td>
<td>7.17</td>
</tr>
<tr>
<td>14. Rational/cognitive coping</td>
<td>50.25</td>
<td>8.52</td>
</tr>
</tbody>
</table>

4.6.4 Measure of Beliefs About Participation in Family-Centred Services

Staff reported an overall belief in adopting a family-centred approach to support for their clients. They gave an average level of endorsement of the approach at 78% scale maximum, indicative of strong agreement with the proposed features of a family centred approach. The total score and subscale scores were all comparable to the views expressed by staff in the comparative group, with the exception of their views concerning self-efficacy to implement the approach. Staff expressed a statistically significant higher level of endorsement of their own preparedness to implement a family centred approach, compared to the views expressed by the comparative sample of US service providers. A comparison of staff and family responses on this scale is presented at section 3.7.5.
Staff reported that they believed there would be few if any negative outcomes to the implementation of a family centred approach to service provision. On average, they reported 86% endorsement of the perceived absence of negative outcomes. Questionnaire subscale scores did not indicate any issues of particular importance to staff with respect to potential negative outcomes. Overall, staff did not endorse any concerns that the approach would lead to less time being spent in direct services to the child, that service providers might have difficulty sharing roles with families during the intervention process, that service providers might need to sacrifice professional integrity, that the approach might not meet the needs of parents, or that service providers might have difficulties working directly with families and other service providers.

Staff surveyed reported a relatively high level of endorsement (on average, 87% scale maximum) of the principles identified as central to family centred services. The strongest level of endorsement was given to the principle of Encouraging the involvement of all family members is a good thing, which was rated at 91% scale maximum. Strong endorsement was also given to it is important to consider the needs of all family members in service delivery (e.g., parents, siblings, grandparents), it is important to attend to family priorities for goals and services (even where these priorities differ a lot from the priorities of service providers), parents should always have the ultimate responsibility for making decisions about their son/daughter’s support services, and it is essential to encourage and have family members choose how much they want to be involved in making decisions about their son’s/daughter’s services. All these principles were rated at, or above 85% scale maximum.

Staff provided the highest level of endorsement (on average, 91% scale maximum) with respect to their belief in their own capacity (self-efficacy) to work within and implement a family centred approach. They indicated that they intended to participate in services in a family-centred way, that they were confident they would be able to do the things expected of them according to a family-centred approach, that they would be able to work with others in a family-centred way, and that they had the skills and abilities needed to participate in a family-centred approach. All of these were endorsed at or above 88% scale maximum.

Staff endorsed the potential benefits of the family-centred approach on average at 80% scale maximum. Staff reported a relatively strong belief that a family-centred approach will be more beneficial than a traditional approach to service delivery, that in a family-centred approach, families will “follow through” better with treatment plans because they are partners with service providers, that participating in services in a family-centred way is essential. All of these were endorsed at a level greater than 85% scale maximum. Relatively high levels of endorsement were also made with respect to a family-centred approach would make service delivery effective because everyone on the team would be working toward the same goals, that family-centred services increasing the efficiency of service delivery by improving communication among service providers and families, that as compared to traditional practice, service providers using a family-centred approach will be more satisfied with the care they provide. These facets of the family centred approach were endorsed at or above 75% scale maximum. The lowest level of endorsement was given to the proposition that family-centred service will reduce service providers’ stress because the responsibility for decision-making will be shared between parents and service providers. This was endorsed at only 64% scale maximum.
It was with respect to their beliefs in the practical feasibility of implementing a family-centred approach to service provision that staff expressed their greatest concern. On average, they endorsed items concerning the practicalities of implementation at only 54% scale maximum. This rating was comparable with the views expressed by the US sample, which expressed endorsement on average at only 53% scale maximum.

Staff were most concerned that service providers’ lack of familiarity, experience, or training in matters related to family-centred service will affect the ideal practice of family-centred service, that in a family-centred approach, families will be required to take on responsibilities they would rather have service providers perform, that parents’ lack of awareness of expectations of them (according to principles of family-centred service) will affect the ideal practice of family-centred service, and that family-centred service will take more time to implement than traditional service delivery. All these were rated at or below 50% scale maximum. Relatively less concern was expressed with respect to service providers’ preferences, desires, or opinions regarding their role in the delivery of services will create obstacles affecting the ideal practice of family-centred service, that parents’ lack of understanding of what family-centred service really means will affect the ideal practice of family-centred service, and that compared to traditional practice, family-centred service will increase the work of service providers. All these were rated at or below 67% scale maximum.

Table 4.36 Difference between Measure of Beliefs About Participation in Family-Centered Services subscale scores reported by PBT staff (n = 20) and a comparison sample (King et al., 2003; n = 324)

<table>
<thead>
<tr>
<th>Item</th>
<th>PBT Staff</th>
<th>Comparison Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>1. Benefits</td>
<td>5.62</td>
<td>0.51</td>
</tr>
<tr>
<td>2. Practical feasibility</td>
<td>3.81</td>
<td>0.82</td>
</tr>
<tr>
<td>3. Self-efficacy to implement</td>
<td>6.39</td>
<td>0.48</td>
</tr>
<tr>
<td>4. Principles</td>
<td>6.12</td>
<td>0.54</td>
</tr>
<tr>
<td>5. Absence of negative outcomes</td>
<td>6.05</td>
<td>0.79</td>
</tr>
<tr>
<td>6. Overall belief</td>
<td>5.44</td>
<td>0.44</td>
</tr>
</tbody>
</table>
Table 4.37 Difference between Measure of Beliefs About Participation in Family-Centered Services item scores reported by PBT staff (n = 20)

<table>
<thead>
<tr>
<th>Item</th>
<th>PBT Staff</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td><strong>1.</strong> Service providers will have difficulty working with families or other service providers in implementing a family-centred philosophy.</td>
<td></td>
<td>5.55</td>
<td>1.43</td>
</tr>
<tr>
<td><strong>2.</strong> Family-centred service means that service providers will sacrifice their professional integrity.</td>
<td></td>
<td>6.40</td>
<td>1.27</td>
</tr>
<tr>
<td><strong>3.</strong> As compared to traditional practice, service providers using a family-centred approach will be more satisfied with the services they provide.</td>
<td></td>
<td>5.30</td>
<td>1.34</td>
</tr>
<tr>
<td><strong>4.</strong> Parents should always have the ultimate responsibility for making decisions about their son’s/daughter’s support services.</td>
<td></td>
<td>6.00</td>
<td>1.38</td>
</tr>
<tr>
<td><strong>5.</strong> A family-centred approach will reduce the quality of services for people with disability (because less time will be spent providing direct services to the person with disability).</td>
<td></td>
<td>6.55</td>
<td>.69</td>
</tr>
<tr>
<td><strong>6.</strong> In a family-centred approach, service providers will be unsure how to share roles with families.</td>
<td></td>
<td>5.65</td>
<td>1.09</td>
</tr>
<tr>
<td><strong>7.</strong> Participating in services in a family-centred way is essential.</td>
<td></td>
<td>6.05</td>
<td>1.36</td>
</tr>
<tr>
<td><strong>8.</strong> Parents’ lack of understanding of what family-centred service really means will affect the ideal practice of family-centred service.</td>
<td></td>
<td>4.70</td>
<td>1.72</td>
</tr>
<tr>
<td><strong>9.</strong> A family-centred approach will be more beneficial to people with disability than a traditional approach to service delivery.</td>
<td></td>
<td>6.20</td>
<td>.70</td>
</tr>
<tr>
<td><strong>10.</strong> It is important to attend to family priorities for goals and services (even when these priorities differ a lot from the priorities of the service providers).</td>
<td></td>
<td>6.10</td>
<td>.79</td>
</tr>
<tr>
<td><strong>11.</strong> In a family-centred approach, families will “follow through” better with intervention &amp; support plans because they are partners with service providers.</td>
<td></td>
<td>6.10</td>
<td>.91</td>
</tr>
<tr>
<td><strong>12.</strong> Family-centred service will reduce service providers’ stress because the responsibility for decision-making will be shared between parents and service providers.</td>
<td></td>
<td>4.50</td>
<td>1.357</td>
</tr>
<tr>
<td><strong>13.</strong> I have the skills and abilities needed to participate in a family-centred approach to service.</td>
<td></td>
<td>6.15</td>
<td>.671</td>
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14. Compared to traditional practice, family-centred service will increase the work of service providers.  
15. Family-centred service will take more time to implement than traditional service delivery.  
16. It is important to consider the needs of all family members in service delivery (e.g., parents, siblings, grandparents).  
17. A family-centred approach will make service delivery effective because everyone on the team is working toward the same goals.  
18. Encouraging the involvement of all family members is a good thing.  
19. A family-centred approach will not meet the needs of parents.  
20. I am confident that I am able to work with others in a family-centred way.  
21. Service providers’ preferences, desires, or opinions regarding their role in the delivery of services will create obstacles affecting the ideal practice of family-centred service.  
22. In a family-centred approach, families will be required to take on responsibilities they would rather have service providers perform.  
23. Family-centred service will increase the efficiency of service delivery by improving communication among service providers and families.  
24. Service providers’ lack of familiarity, experience, or training in matters related to family-centred service will affect the ideal practice of family-centred service.  
25. It is essential to encourage and have family members choose how much they want to be involved in making decisions about their son’s/daughter’s services.  
26. I intend to participate in services in a family-centred way.  
27. I am able to do the things expected of me according to a family-centred approach.  
28. Parents’ lack of awareness of expectations of them (according to principles of family-centred service) will affect the ideal practice of family-centred service.
4.6.5 Comparing staff and family ratings on the Measure of Beliefs about Participation in Family-Centered Services

Overall, staff and family members were in agreement about their beliefs concerning participation in family centred services. Where there was some evidence of statistically different scores (e.g., Principles and Practicable Feasibility), the effect sizes were small and the differences clinically unremarkable.

At a subscale level, some trends of note included: Negative outcomes – parents rated the possibility of service providers having difficulties working with families less than did staff, and staff rated the possibility of service providers having to sacrifice their integrity less than did parents (in both instances, evidenced by lower scores); Benefits – parents gave a higher endorsement than staff to the propositions that family centred services will reduce service providers stress due to shared decision making, and that family centred services will increase efficiency; Practicable feasibility – families were more inclined to give higher endorsement to the proposition that family centred services would take more time to implement than traditional services, and that service providers’ lack of familiarity, experience, or training in matters related to family-centred service will affect the ideal practice of family-centred service (in both instances, evidenced by lower scores); Self-efficacy - Families gave higher endorsement than did staff to the propositions that I have the skills and abilities needed to participate in a family-centred approach to services, and I intend to participate in services in a family-centred way. However, in all instances, though showing statistical differences in scores, these finding are clinically unremarkable.

Table 4.38 Difference between Measure of Beliefs About Participation in Family-Centered Services subscale scores reported by parents (n = 18) and PBT staff (n = 20)

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<tr>
<th>Item</th>
<th>Parents</th>
<th>Staff</th>
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<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>1. Benefits</td>
<td></td>
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<tr>
<td></td>
<td>5.92</td>
<td>.63</td>
</tr>
<tr>
<td>2. Practical feasibility</td>
<td>3.89</td>
<td>1.06</td>
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<tr>
<td>3. Self-efficacy to implement</td>
<td>6.00</td>
<td>0.77</td>
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<tr>
<td>4. Principles</td>
<td>6.16</td>
<td>0.68</td>
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<tr>
<td>5. Absence of negative outcomes</td>
<td>6.00</td>
<td>0.88</td>
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<tr>
<td>6. Overall belief</td>
<td>5.48</td>
<td>0.47</td>
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Table 4.39 Difference between Measure of Beliefs About Participation in Family-Centered Services item scores reported by parents (n = 18) and staff (n = 20)

<table>
<thead>
<tr>
<th>Item</th>
<th>Parents</th>
<th>Staff</th>
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<tbody>
<tr>
<td>1. Service providers will have difficulty working with families or other service providers in implementing a family-centred philosophy.</td>
<td></td>
<td></td>
<td>-6.28</td>
<td>.000</td>
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<tr>
<td>2. Family-centred service means that service providers will sacrifice their professional integrity.</td>
<td>6.22</td>
<td>6.40</td>
<td>-4.55</td>
<td>.000</td>
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<td>3. As compared to traditional practice, service providers using a family-centred approach will be more satisfied with the services they provide.</td>
<td>5.67</td>
<td>5.30</td>
<td>-1.76</td>
<td>.095</td>
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<td>4. Parents should always have the ultimate responsibility for making decisions about their son’s/daughter’s support services.</td>
<td>6.00</td>
<td>6.00</td>
<td>-2.53</td>
<td>.020</td>
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<tr>
<td>5. A family-centred approach will reduce the quality of services for people with disability (because less time will be spent providing direct services to the person with disability).</td>
<td>5.89</td>
<td>6.55</td>
<td>-1.75</td>
<td>.097</td>
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<td>6. In a family-centred approach, service providers will be unsure how to share roles with families.</td>
<td>5.78</td>
<td>5.65</td>
<td>-2.01</td>
<td>.059</td>
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<td>7. Participating in services in a family-centred way is essential.</td>
<td>5.78</td>
<td>6.05</td>
<td>-1.78</td>
<td>.861</td>
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8. Parents’ lack of understanding of what family-centred service really means will affect the ideal practice of family-centred service.

9. A family-centred approach will be more beneficial to people with disability than a traditional approach to service delivery.

10. It is important to attend to family priorities for goals and services (even when these priorities differ a lot from the priorities of the service providers).

11. In a family-centred approach, families will “follow through” better with intervention & support plans because they are partners with service providers.

12. Family-centred service will reduce service providers’ stress because the responsibility for decision-making will be shared between parents and service providers.

13. I have the skills and abilities needed to participate in a family-centred approach to service.

14. Compared to traditional practice, family-centred service will increase the work of service providers.

15. Family-centred service will take more time to implement than traditional service delivery.
16. It is important to consider the needs of all family members in service delivery (e.g., parents, siblings, grandparents).

17. A family-centred approach will make service delivery effective because everyone on the team is working toward the same goals.

18. Encouraging the involvement of all family members is a good thing.

19. A family-centred approach will not meet the needs of parents.

20. I am confident that I am able to work with others in a family-centred way.

21. Service providers’ preferences, desires, or opinions regarding their role in the delivery of services will create obstacles affecting the ideal practice of family-centred service.

22. In a family-centred approach, families will be required to take on responsibilities they would rather have service providers perform.

23. Family-centred service will increase the efficiency of service delivery by improving communication among service providers and families.

24. Service providers’ lack of familiarity, experience, or training in matters related to family-centred service will affect the ideal practice of family-centred service.
25. It is essential to encourage and have family members choose how much they want to be involved in making decisions about their son’s/daughter’s services.

26. I intend to participate in services in a family-centred way.

27. I am able to do the things expected of me according to a family-centred approach.

28. Parents’ lack of awareness of expectations of them (according to principles of family-centred service) will affect the ideal practice of family-centred service.

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<tr>
<td>6.11</td>
<td>1.02</td>
<td>5.95</td>
<td>.95</td>
<td>-1.76</td>
<td>.095</td>
<td></td>
</tr>
<tr>
<td>6.33</td>
<td>0.91</td>
<td>6.60</td>
<td>.50</td>
<td>-2.53</td>
<td>.020</td>
<td></td>
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<tr>
<td>6.00</td>
<td>0.84</td>
<td>6.55</td>
<td>.51</td>
<td>-1.75</td>
<td>.097</td>
<td></td>
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<tr>
<td>2.83</td>
<td>1.38</td>
<td>3.35</td>
<td>1.69</td>
<td>-2.01</td>
<td>.059</td>
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4.7 Staff interviews

The results of the staff interviews are reported below. While the interviews were conducted using a semi-structured interview schedule, the findings are organised according to five themes that were extracted from these data overall. The themes were: what PBT staff believed families needed most; the key resources most valued by PBT staff; additional resources that PBT staff believed that they needed; key features and suggested enhancements to the PBT process; and promoting staff health and staff retention. When reporting data in support of the themes, comments made by staff, and paraphrasing of comments, are provided in bold.

4.7.1 What families need most

PBT staff identified a range of issues impacting the health, wellbeing, and quality of life of their clients. Among those things commonly mentioned by PBT staff were the need of families to be listened to and respected for their own experience and expertise. The importance of families gaining a sense of control over their circumstances and being in control of the intervention process were frequently highlighted. These comments were consistent with the approach of and evidence in support of the efficacy of family centred practice.

PBT staff noted that families appreciated honesty from service providers, especially about limitations of the service system and limitations of the intervention process. Comments indicated that families needed hope. However, some families had been promised miracle cures in the past and that when introducing interventions it was important for practitioners to be open about what needed to be done and what realistically could be achieved and over what time period.

PBT staff had observed that some families benefited from learning skills to better enable them to negotiate with professionals such as teachers, medical practitioners, and allied health professionals; how to ask questions and get the information or services they need. They noted that families often expressed the experience of being powerless. Given these issues, PBT staff expressed the view that families needed access to advocacy services. Such services included advocacy with respect to service provision. However, there was also an apparent need in some instances for advocacy and mediation both within families, and between families and their neighbours. In some instances PBT staff undertook these roles. However, they identified these roles as worthy of consideration for a discrete service or to be identified as a service that was available through existing structures such as LAC or Community Teams (for which purposes some additional training might be needed).

It was suggested by many PBT staff, it was possible that many families would benefit from long-term case management support. It was indicated that this might be effectively delivered through the Local Area Coordination (LAC) service, but that such a service might benefit from specialist back-up and clinical consultation support. In the context of discussing the relationship between the need for on-going support from the Disability Services Commission generally, and episodic support provided by the PBT in particular, it was suggested that LAC support for some families needed to be on-going and not just a response to crisis situations. Regular review of Person Centred Planning might provide a structured and accountable framework to support this long-term involvement.
It was observed that families would benefit from greater social connections, especially with other families. While issues of confidentiality and the time families had available did limit the extent to which PBT could connect families, it was noted that strategies needed to be developed to foster networks among parents and siblings – people who will listen and to whom they can relate on a personal level; circles of support; to know they are not alone.

PBT staff reflected that families appeared to benefit from learning skills to use functional analysis to help understand their child’s behaviour and to develop meaningful strategies. It was noted that families also benefited from gaining knowledge and skills concerning how to teach skills in a structured way using everyday situations and opportunities. They noted that families also need support to develop problem solving skills for new and novel circumstances as they arise, together with coping strategies to promote personal mental health.

It was noted that possibly one of the most important issues for families to grasp was that it’s not all about the child and that many issues relating to parents as individuals and parents as a couple also need to be addressed if effective long-term change is to occur. Several PBT staff commented that the families with which they had been working needed strategies to better look after themselves. For these reasons, it was suggested that some might benefit from a family centred plan, similar to the PCPs developed for individuals with disability. Here it was noted that outside of the PBT involvement there was no service that could support such a process, so even if the PBT developed it there would be no on-going review beyond the PBT involvement. Here though, further consideration could be given to the role of the LACs, as their services are designed to ‘consider the family as a whole’.

On a practical level, PBT staff frequently commented on the need families had for access to respite services. Such services were considered to provide both a means of defusing potentially dangerous situations at home where the family’s capacity to cope had reached crisis point and providing a foundation to maintain quality of life for parents and siblings alike. It was noted that parents were much more able to cope where they had time to be alone as a couple, and where parents were able to spend time with other siblings. In turn, other siblings were much more supportive of their family member with a disability where they had predictable opportunities to be with their parents. Concerning respite, both out-of-home and in-home respite were considered helpful depending upon the individual family.

Practical home help was also noted to be an issue for a number of families, especially larger families and single parent families. This encompassed cooking and cleaning. Home maintenance was also an issue for some families in terms of time, skills, and finances.

Concerning finances, PBT staff observed that many families lived in poverty. The financial pressures limited their access to services and limited participation in the community more generally. These financial pressures were observed to compound families’ experience of stress and in turn limit their capacity to cope with the support of their family member with disability. However, this was not always the case, and there were families that were described as having considerable resources. These, however, were in the minority.
4.7.2 Key resources – things most valued by PBT staff

PBT staff frequently commented that among their most valuable resources was the time they had to spend with families and build relationships. This extended to comments about the frequency with which they could meet with families (at least weekly), the time they could spend with families (often several hours), and the duration of their involvement with families (many months at a time, with up to 18 months or 2 years in some circumstances). Staff noted that this time was not a luxury, but essential to success with the families. They noted that while they were conscious their service needed to be time-limited, they believed they had support from their management to take the time necessary to do the job well. Some comments suggested that the public sector funding environment supported them in taking the time needed and that they found it hard to imagine how private practitioners could afford to provide such services.

PBT staff commented on the importance of being flexible to meet family needs, but of having clear philosophical and process-based structures to support their work. Staff commented on the importance of the ‘three pillars’ informing the delivery of services: Applied Behaviour Analysis, Family Systems Theory, Functional Communication. The IABA training was highlighted by many as essential to their work. The availability of the on-line IABA modules was considered a valuable resource. The structure of the ‘Introduction to services meeting’ and the supporting documentation, together with the staged approach to assessment, formulation, implementation, and closure were noted by staff as helpful, both for them and the families. However, some comments suggested that there needed to be a better way to explain the process to families in the documentation that was currently available.

Staff commented on the challenges of the trans-disciplinary approach, but affirmed it as an essential element of the PBT service and a major contributor to successful interventions. Staff valued the opportunity to have training in assessment and intervention techniques that were not necessarily part of their profession’s traditional way of working. However, some staff did express concern about the ethics of practising outside of their immediate area of expertise and the need to support such trans-disciplinary work though professional supervision.

The structured case conferencing system was highlighted as an important element of the PBT process which maintained professional integrity and quality assurance. On-site line management with both regular individual meetings and an open-door policy were also viewed as critical components of the PBT system. Some staff, however, were also seeking supervision in their particular area of professional practice, for which purposes there were currently no formal structures in place. Staff commented on the value of ready access to the experience of their colleagues through interdisciplinary consultation among team members, and, in particular, the advantages of working in multi-disciplinary pairs for home visits.

Working in multi-disciplinary pairs for home visits was seen as an important part of the way the PBT delivered services. It provided families with the multi-disciplinary support they required and ensured that therapists and families were all working from the same page. PBT staff noted that it provided practical support for visits, where, in addition to case conferencing with families, the pairs provided the opportunity for one team member to provide dedicated time to the parents and another to spend dedicated time with the person with disability. Team members also commented on
the value of the post-visit discussions that took place in the car on the way back to the office. These in-car sessions provided for immediate case conferencing and planning to take place, as well as de-briefing where visits had been stressful.

The level of experience among team members was also considered an important asset. It was noted that while it was good to have new graduates involved that these staff might be more effectively involved as interns or on secondment from other teams to gain experience, rather than necessarily being part of the team and tasked with the responsibility of an intervention.

On a practical level, the PBT spoke positively about the availability of vehicles, especially where flexibility was needed to be responsive to family needs. Staff noted that video had become an increasingly important part of their work both for assessment and intervention. For this reason, access to video cameras and laptop computers were essential. Training in the use of video as an educational tool and in the use of video editing software were also requested. Staff also noted that with the emphasis on creating communication aids, access to software such as BoardMaker, a colour printer, and a laminator were essential. Staff noted the importance of access to library resources to keep current in the knowledge essential to implement evidence-based practice.

4.7.3 Additional resources needed

PBT staff commented on how well they had been resourced with training in the beginning phases of the program. However, they cautioned that a close audit needed to be kept on the currency of their knowledge and skills and also who in the team had been provided with training. It was noted that with new members joining the team, it was difficult to have everyone up to date. While formal courses in some areas were only available periodically, there was a need to have written and on-line material to help induct new staff and to provide access to review material for existing staff. Again, the IABA on-line modules were frequently given as an example of a useful resource.

Training that staff identified as potentially important to have access to included: family systems training, solution focused therapy, motivational interviewing, person-centred planning, applied behaviour analysis, family partnerships training, and functional communication. Hanen training for speech pathologists was considered useful, but it was noted that given the limitations imposed by Hanen, this training was not currently available in a way that was conducive to trans-disciplinary team work. PBT staff were seeking induction into the ‘bigger picture’ of the DSC and the state-wide strategy; to know where you and your work fits into the bigger picture.

PBT staff reported a need to review the referral information that was available to other services and families. Staff believed that they now had a better understanding of how the PBT would work and what it could offer and that these new insights needed to be reflected in a revision of the information that was currently available about the service. Clear diagrams and plain language were thought to be essential to the design of such material.

In terms of professional resources, PBT staff expressed a desire to have available on the team the discipline of occupational therapy. Staff also expressed a need for support from nursing and potentially the option for psychiatry consultation. Here it was noted that a significant number of their clients were on medications to address
behaviour and a range of medical conditions, and that they needed advice concerning drug side effects, contra indicated polypharmacy, and the need for medication reviews.

The involvement of social trainers was discussed by some team members in the context of being able to provide follow-up support to programs. However, the relationship between social trainers and the other professions remained a point of debate. Administration support was also raised, but it was unclear as to what functions such a person might perform.

A number of staff commented on the need for additional IT and AV resources. Additional video cameras were requested, given the increased use of video in assessment and program implementation. Video conferencing, for use with both families and other professionals, was requested for consideration. Staff noted the relatively high proportion of families that had access to VOI facilities on their home computers, but that DSC IT policy prevented the use of technology such as SKYPE. However, further information was needed to clarify this situation. There were several requests to investigate how the current IT limitations could be overcome to allow for video conferencing with families. Video conferencing was seen as potentially very useful, given many families had reported that telephone contact between visits was very helpful for both psychological support and active problem solving or refining strategies in new situations.

PBT staff commented on the potential advantages of being able to refer to respite with the confidence that a family will get a place in a timely way when needed. Several staff commented that they often identify a potential crisis during a home visit and that having immediate access to respite (that night or at least that week) could make a substantial difference to a family and their ability to maintain their family member with disability at home in the longer-term. This was especially the case during the early phase of an intervention.

PBT staff commented on the importance of flexible working hours. Comments indicated that PBT staff felt it important to be available when families could see them, and also to be available to conduct observations and model program implementation at times that were relevant to families (which could potentially include the weekends). Current procedures which provide for extended hours (Monday to Friday, 7am to 6pm) were still, in the view of some staff, unnecessarily limiting. Here though it should be noted that current DSC procedures do allow for people to work outside of standard hours, based on the needs of individual families and clients: though weekend work is discouraged for a variety of reasons including staff health, industrial considerations, and ethical considerations such as the management of professional boundaries.

4.7.4 Key features and enhancements of the PBT processes

PBT staff commented that they were very reliant on the detail and quality of referral information in order to make decisions concerning acceptance to the service, the initial allocation of staff, and the early phases of the assessment and intervention. Some suggestions were made with respect to the need to revise the referral documentation in light of the experience gained in the initial phases of PBT operation. Also, give the critical role of LACs in the referral process, some staff proposed that LACs be provided with specific training in PBT referral (in one instance, an on-line introduction to PBT was suggested) and possibly in conducting a
limited number of screening assessments on behalf of the PBT. However, specific details of such assessments were not provided. Also, subsequent discussion with LACs indicated that they would prefer a briefer referral form with a supporting process conducted by the PBT (e.g., an interview and file review with the LAC) to gather additional information and clarify family circumstances and needs.

Staff noted that developing cultural competence, especially for working with indigenous families and migrant families, could be an important part of the team’s in-service program. However, it was noted that such training was available generically and that it might be an option for staff to access this individually.

PBT staff commented on the need to achieve a better match between families and the staff allocated to maximise rapport. It was noted that initial staff allocations were typically based on the needs of the family identified in the referral information and who was available to take on a new client. Pragmatic limitations were acknowledged, but a desire to work on a ‘matching strategy’ was expressed. No further details were, however, forthcoming.

Concerning time lines for involvement, it was generally agreed among staff that 9 months was too short for most families and that 2 years was possibly the maximum desirable length of time for an intervention. However, it was also acknowledged that most, if not all families referred to PBT would require some on-going contact with specialist services. Consequently, there was a need to develop a post PBT support strategy. It was noted on repeated occasions that there was a need to allow sufficient time for embedding gains; don’t be too hasty to move on until the family is feeling confident with their new gains. And again, it’s not just achieving the gains importantly, it’s also about consolidation and sustaining them. There was general consensus that weekly visits are important generally, though more so at the beginning and less so towards the latter stages of the maintenance phase.

PBT staff acknowledged that many families were looking for some immediate response that made a difference. Consequently, many families struggled with the relatively long assessment phase. Staff affirmed the need for thorough assessment, but generally agreed they also needed to find something for families to do early in the process, even if this needed to be refined or revised in light of assessment findings. It was also noted that families might benefit from the development of an individualised timeline at the beginning of the process, with identifiable milestones that were regularly reviewed with families every few visits. For any documentation prepared for families, plain language and avoiding jargon were considered critical.

Staff valued the process supports associated with the PBT implementation. However, there was a view that the current checklists needed to be rationalised in light of experience to date. These checklists needed to be sufficiently prescriptive to maintain quality but flexible to allow for the needs of individual families. Staff expressed the view that there needed to be more discussion about the minimum data set to be gathered pre and post intervention and which tools they should use.

In the early phases of involvement, it was noted that there was a need to better explain to families the PBT process and not to assume that all was understood at the end of the ‘introduction to service meetings’. PBT staff observed that often families needed to revisit the information covered at the introduction to services meeting. Having clearer written and visual documentation would help this process. Also, it
was identified that there was a need work with the family in the early phase to identify who and what other services needed to know about the PBT intervention and what they need to know.

PBT staff identified the need to place increased emphasis on actively seeking parental insight and fostering this. They emphasised the need to continue to increase efforts to engage families in goal formulation more actively, and noted the need to help families develop realistic goals that were objectively measurable with respect to both progress and attainment. All these comments are consistent with the implementation of a family-centred approach to service provision.

Staff noted the need to closely monitor anxiety, stress and depression among family members. It was noted that referral for focused CBT for individuals could be better incorporated into the PBT process, possibly involving the parent’s GP and a referral via Medicare to an external psychologist.

Towards the end of PBT involvement, it was noted there was a need to better prepare families for cessation of PBT involvement and to have them connected to other services that would provide on-going support. It was also identified that there was a need to develop comprehensive summary notes, designed for different audiences (the person with disability, families, schools, other service providers, future health professionals, etc.). It was noted that families needed clear guidance as to how to instigate a re-referral and how they could gain access to other support services.

It was noted that it was important for LACs to be involved throughout the process, and not just at the point of referral. LACs provided the family with long-term stability of service relationships. PBT staff considered LACs fundamental to the post-PBT involvement planning. The possibility of engaging LACs in person centred planning as part of the PBT closure strategy was discussed by several staff.

4.7.5 Promoting staff health and staff retention

PBT staff identified a range of strategies that promoted staff health, which contributed to staff retention, and which could be used as incentives at the time recruiting new staff. Among these strategies, staff highlighted the fact that they felt they had the time needed to do the job properly. Several staff commented on previous positions where they had felt pressured by management to bring therapy services to a close prematurely so as to meet administrative performance standards. Staff reported positively on the structured case conferencing and the availability of individual supervision.

Staff noted that the regular ‘big team meetings’ were important for keeping focused on working as a team and reinforced trans-disciplinary practice. The ‘big team meetings’ also provided an important way of staying connected, monitoring fatigue, and looking after each other. Staff noted that individual supervision provided an important opportunity to not only discuss professional issues, but also issues related to work-life balance.

Some staff however, would have like additional access to discipline specific supervision. Some staff also noted the need to gain access to professional development opportunities to maintain generic professional skills and, in some instances, professional registration. Being able to attend and present at conferences
was viewed as an important way of maintaining connections with professional colleagues working in other areas.

Staff noted that for a team comprised of relatively experienced and senior clinicians, there were limited opportunities to ‘act up’ or take on a leadership role. It was suggested that these opportunities were important for success planning. Some staff suggested that opportunities for short-term secondment to other teams might address this desire. However, with the instigation of multiple regional teams, such opportunities might be more readily available. Staff also expressed the opinion that secondment could also enable staff to maintain professional skills that they might not otherwise have an opportunity to use in the PBT. It would also be a way of both taking PBT skills to other teams (e.g., Community Teams) and bringing back to the PBT fresh ideas. Opportunities to supervise discipline specific students was also seen as a way of satisfying the desire of senior staff to realise opportunities for professional leadership.

Flexible working hours were considered an important way of both being able to deliver client services and provide family friendly hours of employment. Some staff commented that flexible hours were partly an attraction to consider private practice, which was where others of their colleagues of a similar level of experience were currently heading. Some staff commented on the importance of being able to work part-time. Some indicated that the opportunity to work of an evening or of a weekend would be of advantage to both their clients and their own family life. Current DSC procedures do allow for the authorisation of work outside of usual hours, though some staff were unclear about these procedures and the grounds for requesting such authorisation. Some staff were looking for work closer to home to minimise travel. Flexible working hours and travel time were raised as particularly important for many staff who had family responsibilities.

Pay parity with professional staff in other agencies was commented upon by some staff. Reference was made on several occasions to pay grades in the Health Department, which were believed to be better than those for DSC. In particular, given staff were relatively experienced, a number of staff believed they might be financially better off in private practice and that this might be a longer-term career move. These issues are currently subject to an active review by the DSC.

4.8 Stakeholder interviews

The results of the stakeholder interviews are reported below. They are organised according to the three major stakeholder groupings: Local Area Coordinators, Community Teams, schools, and respite services. When reporting data, comments made by staff and paraphrasing of comments are provided in italics.

4.8.1 Local Area Coordinators (LACs)

Local Area Coordinators (LACs) described families supporting children and young people with disability as having a diversity of needs requiring diversity of response from a diversity of support services. Following from this strong theme of diversity, they highlighted the need for continuity in service supports, which they conceptualised as a long-term single point of contact providing support (emotional), information, and negotiation (with other services). The issue of the need for support when negotiating with other services was highlighted. In the current context of the
PBT review, such comments were accompanied by references to negotiating access to respite, vacation care, and preventing exclusion from school and day services as a consequence of the person with disability’s behaviour. It was when negotiations with such services failed that LACs saw a heightened risk of family breakdown and the need for out of home placement. It was at this point that they sought referral to the PBT.

These issues were seen to reach a critical climax during the teenage years with parents struggling to support older children. LACs also noted that while the PBT catchment had to some degree addressed the need of younger parents, there were many older (aged) parents who were supporting adult sons and daughters at home, and that these older parents also required services. Here though they noted that the capacity of many of the older parents might not have been sufficient to take on an intervention and that out of home solutions remained important (e.g., access to respite and the option of a group home placement).

LACs noted the challenge supporting families to be part of the community and to access generic services, but recognised the need for specialist services. Here it was noted that even within the context of the specialist (disability) service system, expertise and the capacity to respond to the needs of people with severe and persistent challenging behaviour was extremely limited, and as a consequence there was a great need for a specialist tertiary referral service such as the PBT. LACs saw the PBT as both a service to which they could refer, but also expressed a wish for access to a consultancy service through the PBT – for ideas about strategies they could try prior to making a referral or while making and awaiting the processing of a referral.

Supports targeted at the needs of siblings were highlighted. These were discussed in the context of two distinct groups. The first group consisted of siblings who were themselves children in the family home. Many of these siblings were seen as at risk of harm, or longer-term trauma. Here there was a need to ensure that specialist interventions could be delivered with a focus that was sufficiently broad and encompassing so as to acknowledge and address the psycho-social and practical needs of siblings. Secondly, it was noted that many older siblings were themselves carers and that specialist interventions needed to acknowledge and take into account that their needs were sometimes different from those of parents, though there was no precise articulation of these needs. Further investigation of this issue appears warranted.

With respect to parents’ needs and involvement with other services, a recurrent theme expressed by LACs was that parents perceived service staff (e.g., respite staff, day support staff, school staff) as lacking the skills necessary to understand and respond appropriately to their son or daughter. It was suggested that breakdowns in school and respite placements were more about staff training and capacity to cope rather than client behaviour. The issue of understanding people on the autism spectrum, in particular, was highlighted. To address the staff development needs of personnel in other services, it was noted that specialist services working with families, such as the PBT, needed to integrate their work with the other services with which the family was involved.

LACs noted the value of specialist services such as PBT focusing on both the person and their behaviour (through skills development, enhancing independence, and
management of the environment) as well as working on issues associated with parental confidence and skills. They noted the importance of work which addressed issues associated with parental relationships and how it was critical to get the parents working together.

LACs, while acknowledging that the PBT had been positioned as a tertiary response for families most in need, commented that PBT was wasted as a crisis response. They suggested that in many instances families needed this service much earlier; when parents have the ‘head space for intervention’. The LACs commented that it would be of great benefit to many families with the expertise and mode of operation available more widely through the community teams. Again, a number of LACs requested access to a consultancy service via the PBT, without the need for a full family referral.

LACs noted that the PBT was staffed with senior and experienced practitioners, and that this level of expertise was fundamental to their effectiveness. They commented that mature and skilled staff were particularly well received by families, and that even where younger and seemingly less experienced staff made similar suggestions families were more inclined to take note of the more mature practitioners.

It was noted that PBT was very effective at getting mums and dads on the same page, and bringing parents together. The value of the focus on building family capacity (knowledge, skills and psycho-social adjustment, confidence and mental health) was of particular value. This was seen as complementary to skills based interventions for the person with disability, but critical to long-term success.

It was recognised that there was a need for thorough assessment of the person with disability, family members, and the context of the family unit, and that this needed to take time. It was acknowledged that the limitations of previous interventions could have been due to ‘quick fix’ attempts. However, it was emphasised that many families had experienced the initial 3 months of assessment as frustrating, and that some had reported to LACs that they were still waiting for something to happen. Having a few ideas of things to try immediately were important for families, even if these were generic strategies requiring later refinement.

LACs noted that families valued the team approach adopted by the PBT. They commented that families found that this increased their confidence and feeling of support. There were some comments suggesting the value of having a good match between the PBT members and the family, though how this was achieved was unclear. It was noted that some families, and fathers in particular, might have benefited from greater contact with male staff and that some families had hoped that their sons in particular could have had contact with a male therapist.

The availability of the staff, in terms of work outside of the usual working hours was seen as valuable. LACs reported that families found this to be important, in a similar way that they might have had the option of attending a GP at an evening clinic. This was seen as important for involving fathers in particular in the intervention, as well as meeting with siblings after school.

Among the things that the LACs highlighted as valuable was the PBTs message to parents that behaviour has a cause or a reason and that understanding the cause or reason was a vital first step to developing a solution and that this was possibly why previous attempts to simply control the behaviour had been ineffective in bringing
about any sustained change. The LACs noted that the PBT would **hang in as long as they are needed**. This was recognised and **respected by parents**, many of whom had previous experience of **short term programs** (6 weeks to 6 months) that had failed to bring about long-term change. The **development of communication aids** for use at home, school, and in respite were also valued highly.

It was noted that the PBT worked where the person and their family was: home, school, respite. This was considered a positive contrast to other services that expected families to go to them, attend at a time that imposed difficulties on the family, or which failed to grasp the diversity of environments in which the family lived their lives (and across which strategies needed to be developed). The support and training that was provided to other services that were involved with the family were seen as vital to success. Here it was noted that the PBT not only worked with current service providers, but in some instances had enabled parents to reconnect with services that had in the past been of support. Promoting connections with lost family members had also been noted as beneficial to some families, increasing their social connectedness (and resources), and healing old wounds.

Some LACs identified the need for some families to have access to **training in passive self-defence** techniques. This was particularly the case where there was assault behaviours enacted by the person with disability involved. **Home safety audits** were seen as something that could be approached more systematically, with most families benefiting from such audits.

LACs highlighted the value of being **actively involved** in the PBT assessment and intervention implementation process. While acknowledging the workload they already carried, those LACs who had been an active part of the PBT process including **attending family meetings and case reviews** saw the benefit of this **integrated service approach**, rather than simply referring the family to PBT and **getting a report at the end**. In support of this, having a **clear time line at the outset** that **identified key milestones** and points at which they needed to be involved would assist LACs to more effectively plan their work load and involvement. At minimum, LACs expressed **formal involvement at least every 6 months**, with some form of **case review meeting** with the PBT. In some instances, **more regular but less formal briefings** would have been welcomed, such as an **e-mail to summarise what had been discussed and planned during home visits over the previous month**.

In short, the LACs reported the PBT to be a valuable part of the service system for the families with which they were working. They affirmed many positive experiences of families. They would like the option for consultancy prior to referral, a more integrated level of involvement during the process, and an identified role for LACs in the closure of PBT involvement. LACs were generally supportive of the idea for incorporating a **person-centred planning process** (PCP) into the PBT closure phase, which they as LACs would coordinate.

4.8.2 Community Teams

Community Teams reported that not all families referred to Community Teams required the intensity of the PBT. However, many families required **prolonged engagement**, well beyond what Community Teams could do within their existing (time limited) service structure. They noted that current Community Teams were not resourced for prolonged engagement; i.e., **beyond a few months at most**. Community
Teams expressed the view that many of the families would benefit from/require active involvement for several years at a time, and still require re-referral.

Community Teams commented on the value of the multi-disciplinary processes adopted by the PBT. They commented that they were not resourced to provide an integrated service such as this. Some further commented that they had not been prepared (trained) for the trans-disciplinary approach, which they recognised as requiring a specific skill set.

Community Teams commented on what they perceived to be relatively long assessment timelines. While acknowledging the need to conduct thorough assessment, the view that a faster engagement with families might be beneficial was expressed. Leaving families with something tangible to try at the end of the first visit was seen as important. They commented that the timelines needed to be better explained to families, as many families expected a much quicker engagement and action process, based on their experience with previous services. There was also a need to revisit the plan on a regular basis, so families could see where they were at in the process. One comment was that ‘...the PBT know what they are doing, but families also need to know what’s happening and when’.

The view was expressed that more could be made of the existing assessments already on people’s files. Also, it was suggested that Community Teams or LACs could be trained to conduct some assessments, early in the referral process. Also, there were some comments to suggest more thought was needed prior to leaving forms for parents to complete, as some parents might have found the paperwork to be an additional stress.

Community Teams noted the value of working across environments. They highlighted the value of involvement with schools and respite services in particular.

Community Teams noted the importance of working in a way that allowed parents to work on their own issues. They commented that they often wanted to do this, but their resources would not allow for this form of engagement, which focused their attention on the child with disability. They commented that among the several barriers to success was the reality that many families have major internal systemic problems that require intervention, and mental health issues for individual parents.

Community Teams noted that some families had previously responded well to programs, but lacked the resources to embed and sustain the interventions. They commented that in some instances the PBT could benefit from the early re-introduction of existing strategies, and complement these with the sustained support available through the PBT, rather than having to do prolonged assessment and developing new programs.

Community teams highlighted the benefits of having capacity to gain access to respite in the short-term, as a circuit breaker. They noted the positive effect of strategies related to communication aids. They also noted the effectiveness of assisting families to reconnect with previous services and old family friends, so as to build the family’s social capital; and coping capacity.

Community Teams noted the high proportion of their clients who presented with Autism and associated behavioural problems. They commented that situations were sometimes compounded by a relatively late diagnosis of Autism and consequently
delays in access to therapy services. It was suggested that the PBT could benefit from building upon the knowledge and information accumulated by the former Home Based Autism Service (HBAS). Here it should be noted that the PBT was based upon resources from the HBAS, plus additional funding. The HBAS service model was different in its intent, and whilst utilising best practice principles of intervention, did not individualise interventions in the way that was desired for the PBT. Information from the HBAS approach was integrated into the service model, as appropriate – e.g. hands on intervention with families around routine and behaviour management occurs in the context of family goals and relevance to a particular family context.

It was noted that for longer-term support to be effective, LACs and Community Team staff needed to have a good understanding of the strategies developed by the PBT. It was commented that there would be benefit in developing strategies to ensure continuity of service, especially for LACs, but also to identify Community Team staff who could be involved at the point of discharge from PBT. However, further consideration would need to be given as to how these re-referrals to Community Teams might be managed. Good structure for closure reports was recommended. Here it should be noted that the PBT uses a structured format for closure reports with most families. These are complemented by relevant and accessible resources/materials to help families sustain strategies that assist in behaviour management and optimal family functioning.

Capacity building for Community Teams was considered an important part of the longer-term strategy. This was referred to in the context of the disciplines available on Community Teams (lack of Speech Pathology and OT services) and the skills base of Community Teams (currently focused on uni-disciplinary engagement). Here it should be noted that services are currently being reviewed with an intention to have PBTs supported by primary, short term services. This would mean that the multidisciplinary mix would be across all teams. Furthermore the DSC has recently commenced recruitment of speech pathologists and OTs for allocation to community teams.

There was some discussion concerning the development of a model of service that recognised families referred to PBT typically have longer-term support needs. It was proposed that some form of step-down service might be of benefit: PBT + CT+LAC > CT+LAC > LAC > Independence.

Community Teams reported the benefits of PBT services, and how they complemented existing services. Community teams expressed a view that with some additional resources (e.g., speech pathology) they might be able to undertake some of the work of the PBT, but did recognise that the structure and PBT process were distinct from their own and geared towards high intensity services for a small but high needs group. Community Teams were seeking clarification as to their role in the support of families following PBT involvement. They expressed some concern that families might have heightened expectations that Community teams could not meet.

4.8.3 Schools & Respite Services

Schools and respite services expressed concern about a seemingly growing number of children whose behaviour posed a serious barrier to their accessing services and inclusion even in specialist services. One school principal, in a special school, identified that over half of the students in any one of his classes were potentially at
risk of exclusion at some point, as their behaviours were at best disruptive to the class and more commonly would place other students and teachers at risk of harm. However, all those interviewed emphasised that they would do whatever it took to avoid exclusions.

It was suggested that many of the school psychologists appeared under prepared by their professional training for developing support strategies for children with complex behaviour support needs. It was noted on several occasions that these specialists themselves expressed fear and an inability to continue to support these children at school. Furthermore, it was noted that schools and respite services lacked access to other allied health disciplines integral to a multi-disciplinary approach. The disciplines consistently identified were speech pathology (the lack of access to communication aids and advice on effective communication strategies was repeatedly raised) and occupational therapy (equipment and sensory integration assessment and advice). There were also calls for additional access to nursing (advice on medication and monitoring side effects, especially when children were subject to medication changes) and social work (to support family liaison).

It was commented that LACs were a useful resource. However, the variability in their knowledge and skills meant that while some were invaluable when supporting children with challenging behaviour, others had little if any professional contribution they could make. The timing of referral to PBT and the extent to which PBT follow-up was necessary was therefore potentially influenced by the varying skills and experience of the LACs.

For effective involvement in schools in particular, being able to embed specialist with class teachers and teacher’s aides for prolonged periods were seen as vital. This provided for thorough assessment, the development of strategies that were ecologically valid (and practical), the modelling and refinement of intervention. The support and confidence building this provided for teachers and aides was noted as particularly important. The embedded work of the PBT was contracted with the traditional allied health consultancy model, which was deemed ineffective for those students identified as having severe and pervasive behavioural disturbance.

The approach whereby the PBT specialist worked both with the core team (principal, class teacher, aide, and parent) in a planning and consultancy mode and directly in the classroom was seen as important. In high school, it was noted that it was important to meet with others apart from just the student’s home room teacher – all subject teachers and those who might work with the student in the yard all needed to be consulted. Conducting direct observations in the class (in contrast to just asking teachers to record data) and spending time with the aides was repeatedly highlighted as a positive if PBT involvement. Building skills among aides in particular to record behaviour observations and interpret patterns in behaviour were also considered valuable activities. As one principal commented, “we had good behaviour records, but did not know what to do with them”. A further basic skills that was identified as being needed was how to do a functional assessment and then use the results to develop a meaningful program.

It was noted that PBT staff provided a vital bridge between services and home for both schools and respite services. This was especially important where relationships were strained and communication had broken down. As one principal commented, “we knew what happened at school, but not at home; we needed a 24/7 view of the
student to understand him and what we needed to do”. As another put it, “behaviour support is a 24 hour consideration; we need to make a 24 hour difference in the child’s life, and not just in a single setting”.

The approach of the PBT was characterised as “a fresh approach to ask ‘why does the student behave this way’ and not just ‘how do we stop the behaviour and get him on task’”. Also, comments suggested an approach that was characterised by ‘having a long-term vision for the child; do what you can do in the immediate present and look to the future with hope’. People commented that it was reassuring to have a key contact person and to know you were drawing on the collective wisdom of the whole team.

It was noted that not only did the focus child benefit from the intervention, but that staff learnt new ways to work with other children in the service or school. As one principal put it, “one child was referred, but seven children benefited and in addition to the class teacher, 5 EAs also learnt a lot”. And again, as another service provider commented, ‘most of our families would benefit from the support of a PBT program’.

Comments suggested that staff were also equipped with new insights with which to challenge the perspective of other client’s students and parents, to help them to be more accommodating of the focus child. This helped to build a more welcoming community for the child (and his/her parents), whereas in the past they might have been ostracised. In the school setting, it was noted that the work of the PBT contributed to building the child and the parents’ social network in the school community.

Services, though initially wary of the use of video, generally came to see video as an extremely useful observation tool and a means of reviewing strategies and progress. Other intervention approaches that were highlighted included: Social Stories; building friendship networks at school and away from school; routine cards and visual timetable; communication cards; cuing techniques such as phrases that were particularly meaningful for the individual, such as “use your church voice”; pictorial signs around the school (helped other students too) traffic light strategy (stop, think, do).

It was noted that approaches need to work with the emotional context of the class from the child’s perspective, take on board the school’s program objectives, and develop the program to fit within the school’s resources. An often repeated comment was that focused one-on-one work with the student is needed – it’s not a luxury.

It was noted that intervention in schools was problematic for a variety of reasons including the availability of teachers and aides. It was noted that often asking them to stay back after 4pm worked insofar as it did not disrupt the teaching day, but that teachers were often too tired to participate fully in sessions at these times. No viable solutions were posed during the current consultation.

Key indicators for involvement of specialist services such as the PBT were noted to include: disruption at home, family breakdown, parental separation and divorce, death in family, sibling conflict, new siblings, on-set of puberty, pending transition to a new school, or leaving school.

Approaches adopted by the PBT that were noted to assist the process included: an effective partnership approach, in which people worked together (case conferences
were repeatedly identified as very useful – especially where these brought parents and service providers together as they had not done so previously); they were described as being unlike other allied health professionals, they were actively engaged in trying and modelling strategies, and they did not just ‘give advice’; building on existing Individual Educational Programs (IEPs), rather than setting up parallel systems or programs; having clear behavioural targets to inform strategies, and not just generic programs; having instructions pitched with individual teachers and aides in mind; PBT staff were observed to be thoughtful and respectful; they were honest when they didn’t know the answer; comments suggested that PBT staff gave agency staff a sense of control in an out of control situation. The availability of telephone consultation was noted as important, as was the PBT initiating telephone follow-up and not just waiting for a crisis call. This enabled proactive fine tuning to programs in response to the changing needs of the child.

Services would have liked a graphic timeline or representation of the various phases of the involvement to assist them in conceptualising the process. However, they emphasised the importance of being flexible, not ‘process driven’. Services would have been open to recommendations concerning their respective organisations’ learning and resource needs more broadly; services commented on the need for thorough assessment, but wanted more immediate strategies/things to try.

Services were overwhelmingly positive about their involvement with the PBT. Comments included: “I was blown away with the work they did”; “I had not seen an intervention work so well before”; and “if I could buy this service, I would”. Importantly, most service providers commented that the families involved in the program were fragile, that there was a need for on-going support, and that most of these children will need life-span services.
Chapter 5 - References


Impact, effectiveness, & future applications of PBT in WA


Chapter 6 - Appendices

Appendix 2. Positive Behaviour Strategy, DSC Statewide Specialist Services, 2010
Appendix 3. Human Research Ethics Approval: RMIT University
Appendix 4. Human Research Ethics Approval: Deakin University
Appendix 5. Procedure for reporting observation or suspicion of situations involving neglect or abuse of persons with disability
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Appendix 10. Consent Form for Staff
Appendix 11. Interview Schedule for Staff


PBT Model of Service Delivery
Updated 01-04-2011

PBT Mission
"To encourage lasting, positive behaviour change and improved quality of life of the person with a disability and their family by increasing the capacity of the person, their environment and support systems."

Referral Behaviour

Desired Outcomes of Key People
- Consumer, family, school/ work, other

Maintenance
- Supporting families to reflect and problem solve to maintain positive change
- Identifying potential supports and resources for future needs

Review
- Links between factors
- Goals
- Implementation of plan

Implementing the plan
- Family/system/client development and practice of specific skills

Developing a Plan
- Identifying strategies required to achieve overarching goals
- What supports are required

Assessment
- Thorough functional assessment of:
  - The Behaviour
  - Communication
  - Systemic influences, particularly family functioning, beliefs and interactions
  - Hypothesis Testing

Collaboration with family and other systems to explore:
- What's going on? Making links
- Supporting the family and systems to create their own understanding, why the behaviour occurs, factors that influence, what might help

Short term discreet intervention to support:
- Safety planning
- Engagement of parents
- Skills required to enable systemic discussions

Systemic Formulation
- Family, other systems & PBT develop a shared understanding of the fit of the behaviour – why it occurs in a systemic context (conceptualisation is circular, not linear)

Team Members engage with families to facilitate greater awareness of why behaviour exists and what changes they can make to achieve lasting positive behaviour change.

Team Members engage in collaboration with family/Team

Goals
- Developed in collaboration with family/Team

Impact, effectiveness, & future applications of PBT in WA

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Appendix 2. Positive Behaviour Strategy, DSC Statewide Specialist Services, 2010

The Way Forward

Function
- Accommodation
- Family
- Individual

Team Structures
- Team Leader
- Psychologists
- Behaviour Consultants

Team Leader
- Behaviour Support Specialist
- Behaviour Support Officer

Service
- Referral/Intake
- Primary Response
- Intensive Focus
- Maintenance

* Areas of Project Focus
ABST - Accommodation Behaviour Support Team
PBT - Positive Behaviour Team

Footnote: The Accommodation Function offers intervention to support people who live in accommodation group homes provided or funded by the Commission. The Family Function offers intervention focussed on family outcomes. Individuals may or may not be living with family and has family support. The Individual Function offers intervention focussed on individual and involvement of support systems. Individual may be living independently or living with family and has little of no family involvement. They are likely to have individual accommodation option with mental health and justice involvement.

Note: The Family Positive Behaviour Team has been reviewed by McVilly, 2010. The Accommodation team will be reviewed after PBT services have completed the consolidation process.
Appendix 3. Human Research Ethics Approval: RMIT University

27th January 2009

Keith McVilly
Building 201, Level 4
School of Health Sciences
RMIT University

Dear Keith

A&SBETAPP 60 – 08 MCVILLY Impact, effectiveness and future of Positive Behaviour Support teams in the provision of community support services

Thank you for submitting your amended application for review.

I am pleased to inform you that the committee has approved your application for a period of 2 years to January 2011 and your research may now proceed.

The committee would like to remind you that:

All data should be stored on University Network systems. These systems provide high levels of manageable security and data integrity, can provide secure remote access, are backed up on a regular basis and can provide Disaster Recover processes should a large scale incident occur. The use of portable devices such as CDs and memory sticks is valid for archiving; data transport where necessary and for some works in progress.

The authoritative copy of all current data should reside on appropriate network systems; and the Principal Investigator is responsible for the retention and storage of the original data pertaining to the project for a minimum period of five years.

Annual reports are due during December for all research projects that have been approved by the Human Research Ethics Sub-Committee.

The necessary form can be found at: http://www.rmit.edu.au/browse;ID=sop7y1u3kp66w

Yours faithfully,

Diana Donohue
Chair, Science Engineering & Technology Portfolio
Human Research Ethics Sub-Committee ‘A’

Cc Chair SET HRE-SC ‘B’: Barbara Polus School of Health Science
Appendix 4. Human Research Ethics Approval: Deakin University

DEAKIN UNIVERSITY
Human Ethics Research
Office of Research Integrity
Research Services Division
70 Elgar Road Burwood Victoria
Postal: 221 Burwood Highway
Burwood Victoria 3125 Australia
Telephone 03 9251 7123 Facsimile 03 9244 0581
research-ethics@deakin.edu.au

Memorandum
To: A/Prof Keith McVilly
School of Psychology

cc:
Deakin University Human Research Ethics Committee (DU-HREC)

Date: 08 December, 2009
Subject: 2009-175
Impact, effectiveness and the future of positive behaviour support teams in the provision of community support services
Please quote this project number in all future communications

The application for this project was considered at the DU-HREC meeting held on 07/12/2009.

Approval has been given for A/Prof Keith McVilly, School of Psychology, to undertake this project from 7/12/2009 to 7/12/2012.

The approval given by the Deakin University Human Research Ethics Committee is given only for the project and for the period as stated in the approval. It is your responsibility to contact the Human Research Ethics Unit immediately should any of the following occur:

- Serious or unexpected adverse effects on the participants
- Any proposed changes in the protocol, including extensions of time.
- Any events which might affect the continuing ethical acceptability of the project.
- The project is discontinued before the expected date of completion.
- Modifications are requested by other HREC’s.

In addition you will be required to report on the progress of your project at least once every year and at the conclusion of the project. Failure to report as required will result in suspension of your approval to proceed with the project.

DU-HREC may need to audit this project as part of the requirements for monitoring set out in the National Statement on Ethical Conduct in Human Research (2007).

Human Research Ethics Unit
research-ethics@deakin.edu.au
Telephone: 03 9251 7123
Appendix 5. Procedure for reporting observation or suspicion of situations involving neglect or abuse of persons with disability

Matters discussed between family members and the research staff are considered to be private and confidential. Only aggregated data will be reported to the Disability Services Commission (DSC), not identifying any individual families or individual family members.

However, in instances where the research staff observe, or suspect the possibility of any situation involving neglect or abuse, this will need to be reported to the appropriate authorities.

The procedure whereby situations involving the observation or suspicion of neglect or abuse will be reported, will be in accordance with procedures already established by the Disability Service Commission and consistent with the Partnerships in Protection policy framework and operational guidelines (August, 2008).

1. All reports will be made directly to the Team Leader of the Positive Behaviour Team and/or the Regional Manager.

2. For formal allegations, the Team Leader and/or the Regional Manager will instigate a consultation with the Social Work Supervisor, who will instigate a formal notification (to the Director General) within 24 hours.

3. Thereafter, the Partnerships in Protection procedures will be instigated, including the preparation of a Serious Incident Report (within 7 days), and a Partnerships in Protection Action Plan (within 2 to 3 weeks). The Partnerships in Protection Action Plan is reviewed bi-monthly by the Partnerships in Protection Panel, unless otherwise agreed.
Appendix 6. Plain language statement for families

Family member participation information statement

[Information for family members using support services provided by the Positive Behaviour Team of the Disability Services Commission of Western Australia]

**Project Title:** Impact, effectiveness and future applications of Positive Behaviour Support Teams in the provision of community support services

**What is the study about?**

We want to know:

- How the Disability Services Commission’s new Positive Behaviour Team is helping families to support people with disability at home and in the community.
- The things that the Positive Behaviour Team does which are helpful to families.
- The things families would like changed about the services the team provides.

The differences that having the support of the team makes to your family and to the quality of life experienced by your family member with a disability.

We want to use this information:

- To help improve services.
- To make these type of services available to more people in similar circumstances to you and your family.

(2) Who is carrying out the study?

The study is being conducted by **Dr Keith McVilly**.

Dr McVilly is a Clinical Psychologist, experienced in working with people with disability and their families and a Senior Lecturer in Disability Studies at RMIT University, Melbourne, Victoria.

(3) What does the study involve?

Dr McVilly will be reviewing the work of the Disability Services Commission’s new Positive Behaviour Team.

The Disability Services Commission (DSC) regularly evaluates the quality of its services through the routine review of non-identifiable records of families and individuals who register with DSC. This is part of the normal practice of the Commission and already forms part of your signed agreement / consent to receive services provided by the Disability Services Commission.
However, we are asking for your agreement and signed consent to participate in a larger evaluation, and to provide information that will identify you and your family to Dr McVilly. This it totally your choice.

If you do not want to participate in the full evaluation of the Positive Behaviour Team, you do not have to sign an additional consent form and none of the information provided to Dr McVilly by the Positive Behaviour Team will identify you or your family.

If you do agree to participate in the full evaluation and sign the consent form:

You will be given an opportunity to meet personally with Dr McVilly on several occasions while you are being supported by the Positive Behaviour Team and after the PBT has finished working with the you and your family. Though you can still decide at any time that you do not want to meet with Keith. It remains totally your choice.

- The Positive Behaviour Team will be able to talk with Dr McVilly about your situation in a way that might identify you, and refer Keith to talk with other services that the PBT is working with to support you.

Dr McVilly will be able to access records maintained by the Positive Behaviour Team that identify you and your family.

(4) How much time will the study take?

If you agree to participate:

- Dr McVilly will offer to visit you on 2 or 3 occasions while you are involved with the Positive Behaviour Team.

Dr McVilly will offer to visit you on one occasion after you have finished with the team.

You can choose to meet with Dr McVilly at your house or meet him at an office of the Disability Services Commission – whichever is best for you. Each meeting could take about 1 hour.

(5) Can I withdraw from the study?

- Being part of this research is voluntary; it’s your choice. That means you can decide if you want to join in or not.

- If you decide to participate, you can still withdraw at any time.

- Your agreement to participate or decision to withdraw will in no way affect the services you receive from the Positive Behaviour Team.

You can say ‘no’ to meeting with Dr McVilly and still get support from the Positive Behaviour Team.

(6) Will anyone else know the results?

- Information collected as part of the study will be kept private and confidential.
• Information will be stored securely for 5 years and then destroyed.

• Only members of Dr McVilly’s research team will see individual information. They will write reports about the research to give to the Disability Services Commission and to publish in journals and talk about at conferences, but will not mention anyone’s name or where they live. This means that you will not be identifiable in the reports.

However, if the researchers are aware of any situations in which you or your family member(s) might be in danger these will need to be reported to the Disability Services Commission.

(7) Will the study benefit me?

There are no direct benefits to you for participating in this study. However, telling us about your experience of working with the Positive Behaviour Team will help the Disability Services Commission to improve the service for other families in the future. Taking part should not have any risks or discomforts for most people. However, there might be some inconvenience related to the interviews, but these should be minimal. You can choose the time and place.

(8) Can I tell other people about the study?

Yes. You can talk about the study with anyone, including your Local Area Coordinator (LAC) or a family advocate.

(9) What if I want more information?

If you have any general questions, you can ask your Positive Behaviour Team (PBT) Contact Person at the Disability Services Commission or the PBT Leader, Craig McIver (Tel. 08-9329 2300). Alternatively, you can contact Dr Keith McVilly at RMIT University (Discipline of Disability Studies, RMIT University, Tel. 03-99257362).

(10) What if I have a complaint or concerns?

This study has been reviewed by the University Human Research Ethics Committees of the researchers involved. Any person with concerns or complaints about the conduct of the current research can make confidential contact with: **RMIT University Human Research Ethics Committee: Tel. 03 9925 2251.** You can also contact the Disability Services Commission Consumer Liaison Officer, Fran Tyler (Tel. 08-94269244).

(11) What do I do next?

If you say “NO”, and do not want to be part of the research just tell your key contact person with the Positive Behaviour Team. You don’t have to do anything else.

If you say “YES”, and do want to be part of the research you need to sign the consent form.

This information sheet is for you to keep
Appendix 7.  Consent form for families
Prescribed Consent Form for Persons Participating In Research Projects
Involving Interviews, Questionnaires or Disclosure of Personal Information

College: Science, Engineering & Technology
School of: Health Sciences (Discipline of Disability Studies)
Name of participant(s): 
Address of Participant(s): 

Project Title: Impact, effectiveness and future applications of Positive Behaviour Support Teams in the provision of community support services

Name(s) of investigator: Dr Keith R. McVilly
Phone: 03 99257362

Family member participation consent form

[This Consent Form is for family members involved in support services provided by the Positive Behaviour Team of the Disability Services Commission of Western Australia]

1. I have received a statement explaining the interview/questionnaire involved in this project.

2. I consent to participate in the above project, the particulars of which - including details of the interviews or questionnaires - have been explained to me.

3. I authorise the investigator or his or her assistant to interview me or administer a questionnaire.

4. I acknowledge that:

   (a) Having read Plain Language Statement, I agree to the general purpose, methods and demands of the study.
(b) I have been informed that I am free to withdraw from the project at any
time and to withdraw any unprocessed data previously supplied without
effecting any services that I receive.

(c) The project is for the purpose of research. It may not be of direct benefit
to me.

(d) The privacy of the personal information I provide will be safeguarded
and only disclosed where I have consented to the disclosure or as
required by law.

The security of the research data is assured during and after completion of the study.
The data collected during the study may be published, and a report of the project
outcomes will be provided to the Disability Services Commission of Western
Australia. Any information which will identify me will not be used.

Participants’ Consent

Signature(s) of Participant(s) & Role in Family (e.g., Mother, Father, Sibling):

.................................................................................................................. Date: ..............

.................................................................................................................. Date: ..............

.................................................................................................................. Date: ..............

Signature of Witness:

.................................................................................................................. Date: ..............

Name of witness: ........................................................................................................

Where the person is under 18 years of age, has a Guardian, or a Person
Responsible to assist in decision making (e.g., a family member or advocate), they
must also sign this form, for it to constitute valid consent

Complaints about this project may be directed to the Executive Officer, RMIT Human
Research Ethics Committee, Research & Innovation, RMIT, GPO Box 2476V,
Melbourne, 3001.

The telephone number is (03) 9925 2251. Web: http://www.rmit.edu.au/rd/hrec
Appendix 8. Interview schedule for families

Family interview guide

Family ID _________________________________

1. Participants:
Mother    Father    Brother    Sister    Other

2. At what phase of the PBT process is your family?
Assessment    Intervention    Maintenance    Closure

How long have you been involved with the PBT?

How did you find out about the Positive Behaviour Team (PBT)?

How did you become involved with (referred to) the PBT?

How would you describe the work of the PBT?

What are / were your expectations; what are you hoping the PBT will achieve for:
your son / daughter or sibling with a disability?
you, personally?
other members of the family (e.g., your partner, other children, etc)?
the family as a whole?

To what extent do you think the PBT is achieving these expectations?

What are the most important things the PBT has done for you and your family?

What else would you like the PBT to do, or try to do for your family?

Is there anything you particularly enjoy or would highlight about your involvement with the PBT?

Is there anything you particularly don’t enjoy about your involvement with the PBT?

How would you describe the support the PBT provides to you and your family member with disability at your home and elsewhere (e.g., at school, day service / activity centre or workplace)?

How would you describe the contact you have and the support you receive from the PBT in between home visits?

How would you describe the information provided to you by the PBT, about the services they provide to your family?
What do PBT staff need to do their job (effectively)?

What are the core attributes for staff recruited to the PBT; what sort of people should the PBT employ?

How would you describe your experience of the Referral process?

How would you describe your experience of the Assessment & Intake process?

How would you describe your experience of the Intervention process?

How would you describe your experience of the Maintenance process?

How would you describe your experience of the Closure process?

What other services do you and your family currently access?

How would you compare PBT services to those of other services you access or have previously accessed?

What is the most important service your family needs now / in the future (which might or might not be provided by the PBT)?

What do you think families supporting a person with disability at home need most?
Appendix 9. Plain language statement for staff

Staff member participant information statement

[This information sheet is for staff members involved in support services provided by the Positive Behaviour Support Team of the Disability Services Commission of Western Australia]

Project Title: Impact, effectiveness and future applications of Positive Behaviour Support Teams in the provision of community support services

(1) What is the study about?

We want to know if, and if so how, the Disability Services Commission’s new Positive Behaviour Team is helping families to support people with disability at home. We want to find out about the things that the Positive Behaviour Team does which are helpful to families and any things families would like changed about the services the team provides. We would like to know about the differences that having the support of the team makes to families and to the quality of life experienced by family members with a disability. We want to use this information to help improve services and to make them available to more people in similar circumstances. To assist with this evaluation, we also want to know about the staff providing the services; about things that help you in your work and about some of the challenges or potential stressors you encounter when doing your job.

(2) Who is carrying out the study?

The study is being conducted by Dr Keith McVilly. Keith is a Clinical Psychologist, experienced in working with people with disability, their families and support staff. He is a Senior Lecturer in Disability Studies at RMIT University, Melbourne, Victoria and has previously conducted similar organisational evaluations.

(3) What does the study involve?

Dr McVilly will be reviewing the work of the Positive Behaviour Team. This will include reading information about families which is collected by the team and assessments conducted by the team as part of their service provision. He will talk with team members at meetings and provide opportunities for staff to meet with him individually. He will also be meeting with individual families, where families provide explicit consent to do so. This is consistent with the usual way in which the Disability Services Commission evaluates the quality of its services.

(4) How much time will the study take?

Staff will be involved in the study in a number of ways, including during ordinary meeting times, in individual interviews conducted during the usual working hours and by way of introducing Dr McVilly to families. Your participation will be within your usual working hours and be counted as hours worked.

(5) Can I withdraw from the study?

Most of your involvement in this study will be as part of your usual duties. However, you will not be required to meet with Dr McVilly individually if you do not wish to do
so. Also, there will be a number of questionnaires that you will be offered an opportunity to complete. You will not be required to complete these if you do not want to do so. Completing questionnaires about yourself will be voluntary. Choosing not to complete questionnaires, or not to meet with Dr McVilly, will in no way affect your employment with the Positive Behaviour Team.

(6) Will anyone else know the results?

Information collected as part of the study will be kept private and confidential. Information will be stored securely for 5 years and then destroyed. Only members of the research team will see the information. They will write reports about the research to give to the Disability Services Commission and to publish in journals and talk about at conferences, but will not mention anyone’s name or individual position in the Positive Behaviour Team. This means that you will not be identifiable in the reports. However, if the researchers are aware of any situations in which there has been a possible breach of the law, these matters will need to be reported to the Disability Services Commission and any other appropriate authority.

(7) Will the study benefit me?

There are no direct benefits to you for participating in this study. However, telling us about your experience of working with the Positive Behaviour Team will help the Disability Services Commission to improve the service for families in the future. Taking part should not have any risks or discomforts for most people. However, there might be some inconvenience related to the interviews, but these should be minimal.

(8) Can I tell other people about the study?

Yes. You can talk about the study with anyone, including your DSC Staff Grievance Officer or industrial representative.

(9) What if I want more information?

If you have any questions, you can ask the PBT Team Leader, Craig McIver (Telephone: 08-9329 2300) or A/Manager IFS, Jacki Hollick (Telephone: 08-94269728). Alternatively, you can contact Dr Keith McVilly at RMIT University (Discipline of Disability Studies, RMIT University, Tel. 03-99257362).

(10) What if I have a complaint or concerns?

This study has been reviewed by the University Human Research Ethics Committees of the researchers involved. Any person with concerns or complaints about the conduct of the current research can make confidential contact with: RMIT University Human Research Ethics Committee: Tel. 03 9925 2251

(11) What do I do next?

If you say “NO”, and do not want to be part of the research, please simply decline to return questionnaire as and when they are distributed or to decline any offer for an individual interview. You don't have to do anything else.
If you “YES”, and do want to be part of the research you need to sign the consent form.

This information sheet is for you to keep
Appendix 10. Consent form for staff

Prescribed Consent Form for Persons Participating In Research Projects

Involving Interviews, Questionnaires or Disclosure of Personal Information

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College: Science, Engineering & Technology

School of: Health Sciences ( Discipline of Disability Studies)

Name of Participant:

Address of Participant:

Project Title: Impact, effectiveness and future applications of Positive Behaviour Support Teams in the provision of community support services

Name(s) of investigator: Dr Keith R. McVilly

Phone: 03 99257362

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Staff member participant consent form

[This Consent Form is for staff members involved in support services provided by the Positive Behaviour Team of the Disability Services Commission of Western Australia]

1. I have received a statement explaining the interview/questionnaire involved in this project.

2. I consent to participate in the above project, the particulars of which - including details of the interviews or questionnaires - have been explained to me.

3. I authorise the investigator or his or her assistant to interview me or administer a questionnaire.

4. I acknowledge that:

   (a) Having read Plain Language Statement, I agree to the general purpose, methods and demands of the study.
(b) I have been informed that I am free to withdraw from the project at any
time and to withdraw any unprocessed data previously supplied without
effecting any services that I receive.

(c) The project is for the purpose of research. It may not be of direct benefit
to me.

(d) The privacy of the personal information I provide will be safeguarded
and only disclosed where I have consented to the disclosure or as
required by law.

The security of the research data is assured during and after completion of the study.
The data collected during the study may be published, and a report of the project
outcomes will be provided to the Disability Services Commission of Western
Australia. Any information which will identify me will not be used.

**Participants’ Consent**

**Signature of Staff Member:**

................................................................. Date: ..............

**Signature of Witness:**

................................................................. Date: ..............

**Name of witness:** .................................................................

Where the person is under 18 years of age, has a Guardian, or a Person
Responsible to assist in decision making (e.g., a family member or advocate), they
must also sign this form, for it to constitute valid consent

Complaints about this project may be directed to the Executive Officer, RMIT Human
Research Ethics Committee, Research & Innovation, RMIT, GPO Box 2476V,
Melbourne, 3001.

The telephone number is (03) 9925 2251. Web: http://www.rmit.edu.au/rd/hrec
Appendix 11.  Interview schedule for staff

Staff interview guide

Staff ID: _________________________________

Gender:    Female   Male

Employment Status:  Permanent  Contract (& time)  Casual

Employment Fraction: Full Time  Part Time

Average hours worked per week:

Travel time to work:

Profession:

Qualifications:

Time since graduation from original degree / professional qualification:

Time with the Positive Behaviour Team (PBT):

Previous appointments and approximate time in previous positions:

Why did you come to work with the PBT?

How would you describe the work of the PBT?

What are your expectations; what are you hoping the PBT will achieve?

To what extent do you think the PBT is achieving these expectations?

What are the most important resources you have available to support your work?

What resources do you wish you had available to support your work?

Is there anything you particularly enjoy or would highlight about your work with the PBT?

Is there anything you particularly don’t enjoy about your work with the PBT?

What do you think families supporting a person with disability at home need most?

How would you describe your induction to the PBT?

How would you describe your in-service / professional development opportunities within the PBT?

How would you describe the co-ordination and communication processes within the PBT; how information is circulated, meetings are conducted, etc?
How would you describe the way in which staff health is supported / managed within the PBT?

What is the supervision process and what has been your experience of supervision (personal and professional)?

How would you describe the way in which the PBT works with and operates in relation to other areas of the Disability Services Commission?

How would you describe the way in which the PBT works with and operates in relation to other services, outside of the Disability Services Commission (e.g., other government agencies and non-government / community services)?

How would you describe your experience of the *Referral* process?

How would you describe your experience of the *Assessment & Intake* process?

How would you describe your experience of the *Intervention* process?

How would you describe your experience of the *Maintenance* process?

How would you describe your experience of the *Closure* process?

How would you describe your work in the various settings in which you provide services: at schools; day services / activity centres or workplaces)?

What you consider to be the key indicators of eligibility (suitability) for the services offered by the PBT?

What are the key indicators of preparedness for transition from one phase of the service to the next?

How would you compare PBT services to those of other services with which you have previously worked?

Have you been surprised by anything as the PBT has evolved?

How do the various disciplines on the PBT contribute and work together; and what facilitates or hinders these processes?

What do PBT staff / the team need to do their job effectively?

What do you, personally need to do your job effectively?

What are the core attributes for staff recruited to the PBT?

Would you recommend the work of the PBT to other practitioners?

Where do you see your longer-tem professional career going?

What might cause you to leave the PBT?

What might encourage you to stay with the PBT?
Appendix 12. Goals nominated by families

- To learn to manage her anger more appropriately
- To live independently with a female housemate
- Obtain alternative employment to X (supported employment service)
- To learn to pay bills
- To have her own bank account in order to save money for holidays
- To join a bike riding club
- To have the opportunity to engage in more stimulating activities
- To keep clothes on at home & reduce head banging
- For resolution of where X is to live in order to establish safe accommodation
- To develop a post school plan for X to keep her stimulated & as engaged with community as much as possible
- All the teenagers in the family to get on together
- To be able to go out as a family
- Masturbation to cease completely
- X to experience less pain
- X to get off the floor when asked
- Full night sleep for everyone
- A reduction in X's swearing and threats;
- A reduction in X's physical violence towards others;
- A reduction in X's irrational talk;
- The family to go out together for outings;
- To develop a more positive mother-son relationship
- To be treated as an adult
- Reduction in aggressive behaviour; increase in compliance; increase in recreational activities/interests
- For X to not need constant one on one attention
- For X to do what he's told to stay safe (eg don't run)
- For X to not hurt other people or himself as he gets older and bigger
- For X to not need constant one on one attention
- For X to do what he's told to stay safe (eg don't run)
- For X to not hurt other people or himself as he gets older and bigger
- Things to be more fair at home between X and X (brothers)
- Less bullying at school
- Not being sent to his room as much
- People to be nice to him,
- To have things for himself,
- To spend time with X
- others to listen more when he's speaking
- X and X (brothers) to get along - no violence
• Increased overall coping skills of the family
• Family to have a general acceptance of each other
• Family to have a general acceptance of each other
• X to stop hitting himself
• X to stop pushing around X and X (siblings)
• To understand why the aggressive behaviour occurs
• Strategies to avoid the aggression
• For X to communicate in other ways than aggression
• For X’s self care skills to improve so he has some independence Especially toileting, showering, mealtimes
• X to develop skills to effectively manage emergency/crisis situations (in connection to X’s behaviour) if and when they arise
• X to implement strategies to promote X’s independence skills
• Establish a regular routine of doing family activities together
• X to be able to access the community with support eg Going to the shops, medical appointments if needed
• X to further access respite options eg Day programs
• The family to be able to go out together on outings in the community X to be re-assessed for autism
• X to increase his independence with daily living skills eg Showering
• X to transition from the bus into the home safely and quickly
• Reduce intensity of self harm behaviour by 50% in 6 months
• Reduce prompts by 50% for toileting using mum’s baseline
• Reduce access to food to stop crumbing by 50% eg Take food away, limit access
• Increase sitting time for evening meal to 5 minutes
• Future planning re: accommodation via written plan/draft
• Increase X’s communication abilities
• Increase access to the community
• Increase engaging activities for X at home
• X to display positive behaviour (getting along well with mother and sister)
• Increased compliance (X to more often follow instructions)
• less hitting, kicking, carrying-on (occurring as infrequently as once per month)
• To enhance toileting skills
• For X to understand and follow the steps involved in using the toilet at home for urinating and bowel movements
• To reduce hands in pants in public
• For to understand the appropriate place to masturbate (in his bedroom with the door shut)
• To further develop positive parenting practices
• To develop and use alternatives to physical punishment (redirection, planned ignoring, quiet time, providing positive attention, rewards)
• To enhance the parental relationship
• To increase X and X’s communication skills and develop their listening skills/assertiveness skills
• To find better ways to deal with his anger, rather than using violence
• To learn to compromise a little
• X complying more with instructions given (by mother)
• Mother having increased interactions/conversations with X
• X to talk softly/calmly rather than shouting and turning taking with talking
• Not to have "ground-hog day"
• X to have reduced stress levels
• X to have fun with X (sibling), more happy times together
• Reduce aggressive behaviour which includes biting, scratching, pinching, pulling hair, and head-butting
• Reduce spitting
• Reduce nose blowing
• Improve communication between school and family
• Identify new rewards and consequences for school use
• To spend more one-on-one time with mum
• Family as a whole to do more fun things together as evidenced by scheduling family fun time together once per week
• X to feel more calm/relaxed/still as evidenced by a decrease in score on the stress DBC subscale
• Fewer headaches and scheduling more time to self
• X to spend more quality time with the kids as evidenced by scheduling 15 mins quality time with them 2 times per week
• X, X and X (siblings) to treat each other with respect as evidenced by using manners and saying nice things about each other
• X and X (siblings) to spend more quality time together as evidenced by scheduling quality time together once per week
• Increase compliance
• Increase appropriate attention seeking behaviour
• Improve the quality of life with more balance
• X to be more manageable
• Decreasing her violence towards others
• Increasing her communication
• X being more obedient (listening and following instructions)
• X and X (parents) to have no stress
• X to be able to recognise pain and tell people she is in pain
• X to successfully and safely move from home into independent living with support
• X to come home to visit and continue to be a valued member of the family
• X to receive appropriate professional help with regard to his sexual feelings/behaviour towards his young sister
• Increase skill level and confidence
• Reduce levels of aggression
• Increase X’s engagement in pleasant activities
• X to listen and follow instructions
• X to “start talking” (explained to father that this was not within our capability, but we would be able to assist with X’s communication)
• To improve X’s communication skills to reduce behaviour linked to communication
• To increase X’s independence skills
• For X (sibling) to have someone to talk to about X
• To reduce the number of aggressive episodes
• X to talk to someone about how he is feeling
• X’s behaviour to improve so that he could possibly remain at home
• X would like the bullying at school to stop
• X to initiate play more appropriately and to play more gently with siblings as evidenced by parental reporting
• The children to consistently go to bed when directed by parents and to remain in their bed for entire night as evidenced by parental reporting
• X to comply with parent’s instructions in relation to sharing with siblings, putting and keeping seat belt on, as evidenced by parental reporting
• X to decrease tantrums from 1-2 times a day to 1-2 times a week, and stop swearing as evidenced by parental reporting
• X to use only the toilet for pu and bm No toileting in inappropriate places;
• X to cease eating and drinking non-ingestible substances;
• X to reduce his destructive behaviours of tearing paper;
• X to cease running off whenever he has the opportunity
• Reduce X’s distress (less crying, hitting head)
• Increase enjoyable activities jumping on the trampoline, swimming in the pool or going on his scooter
• Increase family participation in community activities
• For X to express distress in a more appropriate way - which would lead to
• Increase activities with him, decrease ‘aimless’ activities such as wandering around
• To improve family relationships
• To be able to have some 'normality' at home eg Not having a bare house
• To communicate better with X
• For X to participate and be included in social situations (eg, school, family, community)
• For X to not answer back/ react when asked to do things
• For X to get into a routine
• To expand interests for family, and for family to spend time together
• For X and X to have strategies to manage X’s behaviour when he says no
• For X to not have meltdowns in the mornings and for him to go to school
• For X to learn to his full capability / potential at school
• For X to be able to go to shopping centres without him having to buy something every time
• For X to have better coping strategies for when X has a meltdown at the shopping centre
• Decrease X’s aggressive & tantrum behaviour
• Decrease obsessive behaviour (eg pouring water on couch & bed, searching for food) decrease running, escaping and introduce a routine
• For X to be compliant
• For X to accept ‘no’ without questioning and having a tantrum
• For X to stop stealing food and eat when allowed to
• X’s attitude
• X respecting others
• Preparing him for adulthood and X’s concerns with issues related to this eg, feasibility of a license,
• X’s approaching drinking age, sex/sexual issues, moving out, general self-care/daily living skills, money/budgeting skills
• Assistance with anger management and social interactions
• Reduced aggression and improved social skills
• Stop aggression towards siblings
• Develop more understanding of spoken language
• For X to learn to express his frustration more appropriately
• Teach X about his anxieties and ways to deal with them
• To be able to go out as a family
• To be able to go out as a couple
• For X to have one outside activity
• For X to engage in more physical activity
• House to be more calm- talking calmly, less demands, accept what others’ say, respecting each others’ wishes
• X to speak more calmly (less aggression) and listen more before reacting
• X to have a better relationship with X
• Increase family social participation in community (without outbursts)
• X to use independent skills at respite and school
• Respite and school to better understand and reinforce/praise X’s independent skills in an appropriate manner
• Respite and school to use appropriate behaviour management strategies (including consequences)- increase consistency between home, school and respite
• X to better understand his role as a sibling (vs parent- set limits with X)
• X (parent) to decrease need to use excuses or explain X to others
• X (parent) to give in less to X (not be frightened to say “no”)
• Increase balance for the family - X and X (parents) to have more time to self
• Reducing X’s aggression towards others
• X and X (siblings) to spend more quality time together
• Reduce family stress
• X to stop “attacking” X (sibling) and leave him alone and not interrupt X (sibling) completing his homework
• X to sit down at the table to eat
• X to walk with X (sibling) together when they are out and not to run away
• Reduce sexualised behaviours between children
• Reduce aggressive behaviour from children
• Increase consistency between parents
• Establish an understanding of typical children’s behaviour and developmental stages
• Facilitate problem solving about whether X to stay or leave the home
• Increased compliance with reduction in physical and verbal aggression