



Positive Behaviour Framework

Substantive Equality

Project 4

Disability Services Commission

Statewide Specialist Services

Positive Behaviour Teams

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Substantive Equality Project Number 4: Positive Behaviour Teams

Executive summary

The Disability Services Commission (the Commission) is committed to providing information, support and services that are culturally sensitive and responsive, free from racial discrimination, and result in equitable outcomes for all people with disability in Western Australia including people from Aboriginal¹ and culturally and linguistically diverse (CaLD)² backgrounds, their families and carers. In so doing, the Commission is committed to implementing the Government's Policy Framework for Substantive Equality (PFSE) for services funded and provided by the Commission. This report is the fourth project undertaken by the Commission and aims to evaluate the compliance of the Positive Behaviour Team (PBT) service with the principles of substantive equality.

The Positive Behaviour Teams sit within the Positive Behaviour Services Branch of the Commission's Statewide Specialist Services Directorate. The teams commenced operation in 2008 and are situated in the Myaree office (South) and the Joondalup office (North). Both PBTs provide services within the Perth Metropolitan area.

The feedback informing this report was collected from interviews with Aboriginal families and families from CaLD backgrounds who have experienced the service, interviews with the PBT staff who provide the service, two group workshops held with agencies that specifically work either with Aboriginal or CaLD communities and one workshop held with staff from two Local Area Coordination (LAC) districts.

This evaluation finds that the Positive Behaviour Teams are offering high levels of support to families/carers and people with disability who sometimes display challenging behaviours who are from Aboriginal and CaLD backgrounds. On all the evidence available, this program has a high level of acceptance and is delivering positive outcomes for people with disability and their families/carers. The Positive Behaviour Support model was seen by all informants contributing to this report as a contemporary, clearly defined, and generally, a culturally secure service. Its strengths are its:

- flexibility in application

¹ The Commission uses the term Aboriginal in preference to Indigenous due to the expressed preference of Aboriginal people for this term during recent policy consultation processes. The term is used to include both Aboriginal and Torres Strait Islanders who live in Western Australia.

² Culturally and linguistically diverse' refers to the wide range of cultural groups and individuals that make up the Australian population. It includes groups and individuals who differ according to religion, race, language or ethnicity from those whose ancestry is Anglo-Saxon, Anglo-Celtic, Aboriginal or Torres Strait Islander. For ease of reference, CaLD is commonly used as an abbreviation for culturally and linguistically diverse. http://www.omi.wa.gov.au/omi_terminology.cfm

- the ability to work with families and individuals over an extended period of time
- the personal and professional attributes of its staff
- the quality management approach taken to service delivery and design.

Whilst the program received strong support, there were nonetheless a number of recommendations that have been made to further strengthen this service. These recommendations mainly focus on increasing accessibility to the Positive Behaviour Teams in a more culturally secure practice framework for people from Aboriginal and CaLD backgrounds. These recommendations require few resources to implement, however they have the potential to significantly impact on the capacity of the PBT approach to increase access and responsiveness to the needs of Aboriginal and CaLD individuals and their families/carers.

Recommendations

1. Broaden access to the PBT services

1.1 That the referral source be broadened from the LAC program to include other government and specialist agencies working with CaLD and Aboriginal families.

1.2 That the PBT service build stronger working relationships with these agencies to increase their awareness and knowledge about disability and the Positive Behaviour Services and for the PBT service to gain skills and knowledge about working with CaLD and Aboriginal families.

2. Improve written information on the service

2.1 That the family flyer for CaLD and Aboriginal families be rewritten in plain English and include more graphics. Family stories on the information sheet would ideally be of a culturally similar family and translated into the most common first languages of CaLD families.

3. Use of formal assessment tools

3.1 That consideration be given to the current use of formal assessment tools, with clear guidelines to be developed for their use with CaLD and Aboriginal families and exploration of the availability and/or development of culturally appropriate assessment tools.

4. Cultural guides for families

4.1 That the preparation checklist for PBT staff include the prompt for staff to explore support options for families which may include a community/cultural guide to safeguard the family's cultural beliefs and values.

5. Length of assessment

5.1 That the PBT further consider flexibility in how the Positive Behaviour Team works with families from CaLD and Aboriginal backgrounds by introducing interventions/practical support earlier and/or delaying formal assessments when these actions would assist in engaging the family.

6. Maintenance and follow-up

6.1 That families who have limited informal and formal support be offered an extended maintenance stage and scheduled periodic follow-up.

6.2 That LAC and PBT work together to develop explicit and agreed roles and expectations for both PBT and LAC staff in terms of family support post PBT intervention.

7. Diversity in PBT Staff, relationships with Aboriginal and CaLD agencies, access to cultural expertise/knowledge

7.1 That PBT consider using provisions of the Equal Opportunity Act 1984 (sections 50(d) and 51) to target applicants from Aboriginal and CaLD backgrounds in order to increase cultural diversity.

7.2 That the PBT service consider accessing Aboriginal cultural advice and practice support by engaging an Aboriginal practice consultant (either contractual or permanent).

1. Introduction

This project is part of the Disability Services Commission's commitment in implementing the Policy Framework for Substantive Equality (PFSE). The PFSE was designed to ensure that services are accessible to all Western Australians and are responsive to the different needs of the State's diverse community.

The Commission's Substantive Equality Statement of Commitment for People with Disabilities aims for policies, programs and services that deliver equitable outcomes, equal opportunity and culturally secure services to CaLD and Aboriginal individuals and families. The concept of "substantive" equality differs significantly from our general understanding of the concept of equality. Typically the term equality prescribes equal treatment of all people regardless of circumstances. This type of formal equality fails to take into account the accumulated disadvantage of generations of discrimination or the disadvantage faced by groups in a service system that fails to recognise different needs (often without realising that this is occurring).

The concept of substantive equality encompasses the following understandings, that:

- Rights, entitlements, opportunities and access are not necessarily distributed equally throughout the community.
- Equal or the same application of rules to unequal groups can have unequal results.
- Where services cater to the dominant, majority group, then people who are not part of the majority group and have different needs may miss out on essential services.³

Substantive equality involves achieving equitable outcomes as well as equal opportunity by promoting sensitivity to the different needs of "client" groups and by eliminating systemic discrimination in policies, programs and services. Systemic discrimination occurs when practices discriminate unfairly in their effect, impact or outcome irrespective of the intention. It is discrimination that is embedded in the policies and practices of an organisation. While often unintentional and appearing neutral, the effect is to exclude people from particular indigenous and ethnic groups from full participation in the organisation at all levels and from accessing services in a fair and non discriminatory manner.⁴

Services that have a strong commitment to substantive equality are:

- Culturally responsive, free from discrimination and developed in partnership with Aboriginal and CaLD people with disabilities, their families, carers and communities.
- Tailored to the unique needs and local contexts of individuals.
- Provided by staff who understand, respect and value cultural diversity.

³ DSC Substantive Equality Statement of Commitment for people with Disabilities 2006

⁴ibid

- Built on and work with existing services provided to Aboriginal and CaLD communities.
- Developed using strategies to address additional needs and vulnerabilities arising from people facing double discrimination or multiple issues such as unemployment, poverty, lack of suitable housing, poor health, domestic or family violence.⁵

This project seeks to evaluate the compliance of the Positive Behaviour Team approach with the principles of substantive equality. In other words, how well the PBT service adapts to, or develops, specific approaches to meet the needs of Aboriginal and CaLD families who have needs related to the sometimes challenging behaviours of a family member. This report provides project findings and proposals for the PBT service based on substantial qualitative data and demographic data gathered from:

- family experiences of receiving the service
- the source/s of referrals (LAC)
- staff experiences of delivering the service
- CaLD and Aboriginal agencies feedback on the service
- Annual Client Data Collection (ACDC) 2009/10
- ABS (census 2006 WA)
- Positive Behaviour Team Client Data 2007-11.

Definitions

Aboriginal: People who identify as Aboriginal or Torres Strait Islanders. The term Aboriginal is used for ease of reading throughout this document and refers to both Aboriginal and Torres Strait Islanders.

Culturally and Linguistically Diverse (CaLD): Refers to the wide range of cultural groups and individuals that make up the Australian population (Office of Multicultural Interests). It includes groups and individuals who differ according to religion, race, language or ethnicity from those whose ancestry is Anglo-Saxon, Anglo-Celtic, Aboriginal or Torres Strait Islander.

The Australia Bureau of Statistics (Census 2006) considers a person to be from a CaLD background on the basis of :

- Individual's place of birth (non-main English speaking country⁶)
- parent's place of birth (non-main English speaking country⁷)
- speaking a language other than English at home
- English proficiency.

⁵ DSC Substantive Equality Statement of Commitment for people with Disabilities 2006

⁶ Non-Main English Speaking Country excludes people born in Canada, Ireland, New Zealand, South Africa, United Kingdom and United States of America.

⁷ Ibid

The Commission's Annual Client and Service Data Collection online database (ACDC) collects the following information to define the cultural and linguistic background of a non-Aboriginal service user:

- service user's place of birth (non-main English Speaking Country⁸)
- speaks a language other than English at home
- requires an interpreter.

There is a recognised risk of underreporting inherent in the ACDC collection in that it does not include the parents' place of birth. Within the Positive Behaviour Teams, a service user is considered to be from a CaLD background if they (or their parents) were born overseas in a non-English speaking country.

Cultural competence: The specific knowledge and skills acquired in working with a specific community. The ability of agency staff to respond in a culturally responsive manner to the CaLD and Aboriginal people to whom they provide services.⁹

Cultural security: Cultural security refers to delivering services in such a manner that the cultural rights, views, values, and expectations of Aboriginal and CaLD people are not compromised and to ensure that Aboriginal and CaLD people are afforded the same service outcomes as other citizens¹⁰

2. Brief description of the Positive Behaviour Service

The mission statement of the Positive Behaviour Teams is

“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 PBT aims to work in partnership with families/carers to:

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

The Positive Behaviour Teams are an interdisciplinary mix of professional staff including Clinical Psychologists, Speech Pathologists, Occupational Therapists and Social Workers who are experienced in positive behaviour support. There are two teams based at the Joondalup and Myaree Commission offices.

⁸ ibid

⁹ Equal Opportunity Commission, 2005, Understanding the Policy Framework for Substantive Equality Key Terms.

¹⁰ ibid

To access this service, a person must be:

- eligible to receive Disability Professional Services funded or provided services¹¹
- aged 6-25 years
- located in the Perth metropolitan area
- living in a family situation
 - the family/carers must be able and prepared to invest the time and effort required
 - the family/carers intend to continue caring for the person for at least the next 12 months.

It is a condition of acceptance of referrals to PBT that the referring agency will work collaboratively with PBT staff concerning safety and child/consumer protection issues.

Challenging behaviour is defined as

“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.”¹²

The three primary ‘pillars’ of support provided to families and individuals are:

1. .Positive Behaviour Support (examples of the type of outcomes worked towards)

- That carers can read early warning signs effectively.
- That there is consistency in management.
- That strategies and support are put in place to reduce possibility of anxiety.
- That carers can identify potential triggers and potential influence on raising anxiety.
- That carers are able to reflect on triggers and identify further support required.

11 Disability means 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 Services Act 1993)

12 Emerson, E., Cummings, R., Barrett, S., Hughes, H., McCool, C., & Toogood, A. (1988). Challenging behaviour and community services: Who are the people who challenge services? *Mental Handicap*, 16(1), 16-19.

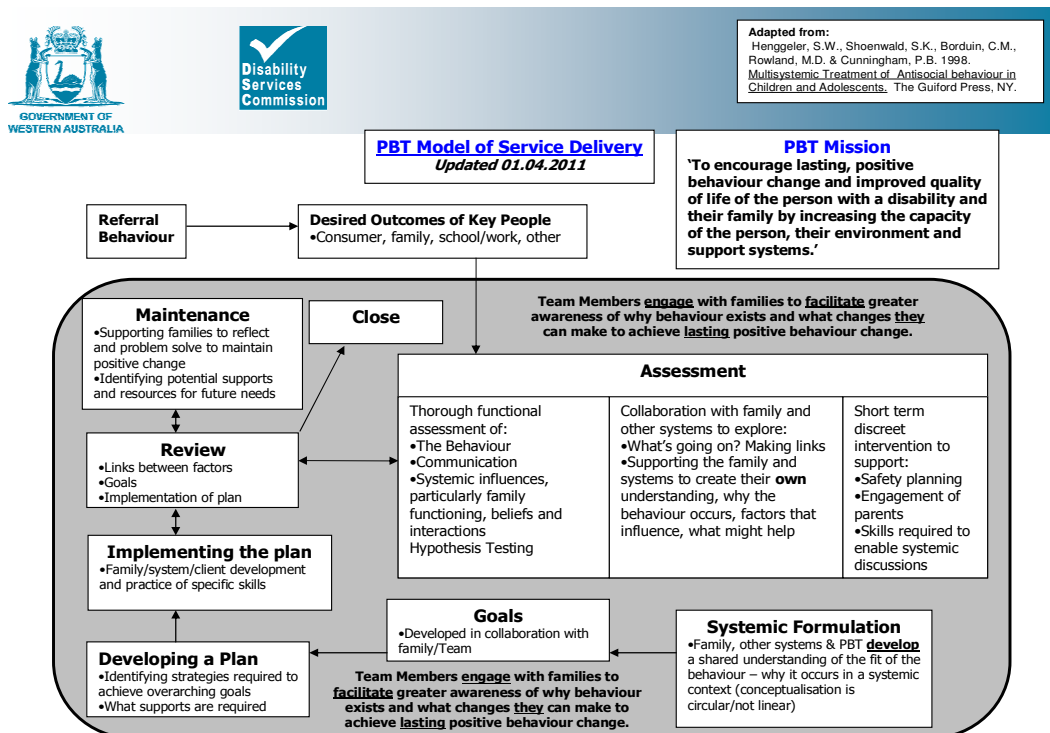
2. Family Systems Approaches (examples of outcomes)

- Carer perspective changes from avoiding and being fearful of behaviour to planning for what support is required.
- Separation of the person's identity from their behaviour.
- Support driven not behaviour driven.
- Family and school relationships challenged to work more cohesively.
- School support now focused on the individual's gifts, what the person needs and how to meet those needs in place of reacting to behaviour.

3. Interventions to support functional communication (examples of outcomes)

- Detailed exploration of communication processing needs and introductions of visual support if required
- Verbal skills improved

The model of service is described diagrammatically as



3. Project methodology

3.1. Project scope and consultations

This project aims to evaluate the capacity and effectiveness of the Positive Behaviour Teams to provide culturally secure responses to the needs of Aboriginal people and people from culturally and linguistically diverse backgrounds. The project team in consultation with the Substantive Equality Implementation Committee (SEIC) agreed that four major stakeholder groups would need to be part of the project inquiry into how well the PBT delivers culturally secure services to families from culturally diverse backgrounds. They included:

1. the Aboriginal and CaLD families who had received a service from the team
2. the staff who delivered the service to the families
3. specialist Aboriginal and CaLD agency representatives
4. representatives from the LAC program, the primary source of referrals for families to the PBT. (See appendix 3 PBT/SE Project Outline).

3.2. Qualitative data:

Eleven families (nine families from CaLD¹³ backgrounds, one Aboriginal family and one foster family with an Aboriginal foster child) were interviewed by the project officer in their homes. (Refer to appendix 4 for questions)

Sixteen PBT staff were interviewed individually in their workplace. (See appendix 5 for questions)

Three workshops were held with:

1. **Ten representatives from six CaLD agencies**
2. **Twelve representatives from ten Aboriginal agencies** and
3. **Twelve LACs from two metropolitan districts** (North and South). (See appendices 6-8 for participants and workshop questions).

All of the stakeholders were taken through a series of questions which after analysis/synthesis fell into two major categories of information

1. What works well in the PBT service.
2. What could be developed to improve the PBT service for families from Aboriginal and CaLD backgrounds.

13 The Positive Behaviour Team refers to CaLD as service users (or their parents) who were born overseas in a non-English speaking country.

All three groups (agency representatives, PBT staff, and families) involved in providing feedback gave us invaluable information on what the current strengths of the PBT service are when working with people from CaLD and Aboriginal backgrounds as well as highlighting areas in which further development could significantly improve access, cultural security and outcomes for these groups.

Common themes ran through all of the stakeholder groups. Using the family feedback as the most important primary source of information, key themes were identified. These key themes are strongly supported in much of the feedback from the other stakeholder groups and they form the basis of the seven major recommendation areas that come out of this project.

3.3. Demographic Information

3.3.1. General population

Western Australia's population is drawn from rich and varied cultural, linguistic and historical traditions. An estimated 1,959,088 people live in Western Australia (Australia Bureau of Statistics (ABS) 2006 Census). Approximately 3% of Western Australia's population indicated an Aboriginal descendant, 12% were born overseas in a non-main English speaking country¹⁴ and 18% spoke a language other than English at home.

3.3.2. Profile of Commission service users

According to the Commission's Annual Client and Service Data Collection (ACDC) online information system, the Commission assisted 21,652 Western Australians with disability in 2009-2010. Of these, 6,082 accessed the Community Aids and Equipment Program (CAEP) only, and these people were removed from further analysis as the CAEP program does not report background information on client characteristics.

Of the remaining 15,570 service users, 9.0% were identified as Aboriginal and 9.6% as coming from a CaLD background.

Table 1 Percentage of Aboriginal and CaLD service users 2009-2010.

	All service users* (accessing provided and funded services metro and country)	People receiving Commission provided services who meet PBT access criteria (living in metro area, with family and aged between 6 to 25 years)	People who received a PBT service
Total	15,570	3,602	53
Aboriginal	1,402 (9.00%)	171 (4.75%)	1 (1.90%)
CaLD	1,491 (9.60%)	260 (7.22%)	6 (11.30%)

* ACDC 2009-2010 (Excluding people who access only the Community Aids and Equipment Program)

The results show that in percentage terms, people from a CaLD background are receiving PBT services at a rate higher than either the identified CaLD population of

¹⁴ Non-main English proficiency country excludes people born in Canada, Ireland, New Zealand, South Africa, the United Kingdom and USA.

service users under ACDC or the subgroup of people who meet the access criteria for this service and are potentially eligible for PBT services.

The situation is reversed for Aboriginal people, with only one individual receiving a PBT service in the year 2009/10 and a total of two referrals since the start of the PBTs four years ago. (Note that all referrals to the service for Aboriginal and CaLD individuals and families have been accepted). The low referral rate for Aboriginal people raises a number of concerns which will be addressed later in this report.

4. Analysis of issues

The themes identified in this report emerged from the multiple consultation processes. The members of the Behaviour Support Consultation Team independently read the feedback from family and staff interviews and identified themes. Key themes were considered to be those that were raised by multiple families. Families interviewed came from the following backgrounds; Aboriginal, Arabic Muslim, Bangladeshi Muslim, Somali Muslim; Chinese, Ethiopian Muslim, Chinese Singaporean, Burmese English, Serbian, and Chinese Vietnamese. The key findings are not recorded in order of importance. They were all raised as important issues by families and supported by the other stakeholders. Themes that were particular to specific groups (CaLD, Aboriginal, LAC or PBT staff) are also included in this report.

4.1. Access to PBT services.

At present the only formal way a family can gain a referral and ultimately access to the PBT is through the Local Area Coordination (LAC) service. A family must have a formal connection with the LAC, meaning they are eligible for and receiving LAC support. Of considerable importance in the referral process is the quality of the LAC/family relationship. Without significant knowledge of the family's needs as well as knowledge of the PBT, service appropriate referrals cannot be made.

Seven of the eleven families interviewed were referred to the PBT by the LAC and commented on their excellent relationship with the LAC. Two families found their way to the service through contact with other Commission staff, one family through the school (and then the LAC) and one family, who did not have a strong relationship with the LAC, spent considerable time searching for the right support for her son and eventually found out about the PBT while reading through some information in another disability-related service.

Families without good LAC connections have little chance of finding out about this service and having an appropriate referral made. Families with limited or no connections to LAC currently have no opportunity for appropriate referral to the PBT. PBT staff expressed the view that opening up the referral process to specialist agencies would see an improvement in the numbers of referrals for people from CaLD and Aboriginal backgrounds (see Appendix One, point 18.)

“...I think that the place most Asian families will be made aware of their child’s disability is in the school system and so that is where the PBT information should be targeted...”

“... I did not give up searching for help for my son...many others would have given up after two years! I got such a bad run-around for several years I don’t think many families would go through this ...Schools I think are the best places to get information from for parents ...especially Asian parents...”

“...I had no idea such a service existed. It would be good to know about such a service and not have to rely on the LAC to let you know (when they think it may be the right time)...”

“...many people from CaLD backgrounds would not be aware of this service or other DSC services so I think they (PBT) should consider other ways to let people know about the service...”

Families felt that there was limited information about disability-related services and support (including the PBT) in the communities that they are part of and that the Commission should target their information at places like schools and community agencies.

During the process of consultation, feedback from specialist CaLD service providers suggested that the provision of knowledge and information to CaLD agencies about PBT and disability in general would support attitudinal changes within agencies and build their capacity to better inform and support their clients who have a family member with a disability,.

“...I don’t think many Asian families would seek help for a problem...the family tries to deal with it...in Asian culture it is shameful to have a child with a disability and the families would try and hide it from the community...”

CaLD Services Workshop

There appear to be access issues for families from Aboriginal backgrounds. PBT data shows that only two families were referred in the four years that the PBT has been in operation. These two referrals were accepted into the service and at the time of writing were still receiving support and feedback, indicating high levels of satisfaction with the service.

“...the team worked well with my whole family...the kids look forward to them coming to the home and working together...the whole family has improved a lot...they understand my family’s need 100%...the team should stick to what they are doing, it’s great...”

“...the PBT staff are very aware of his needs and are actively searching for an Aboriginal mentor...they (PBT) are very aware of his cultural background and are keen to enhance his cultural knowledge through giving him experiences that are culturally valued...the team are really good to work with they are open, communicate well, there are no issues at all...”

Both, however, had comments to make about why they felt so few Aboriginal families were in the service.

“... his (the Aboriginal boy in foster care) biological family would not have agreed to a referral for several reasons; they lived a life of poverty and chaos and disability was not one of their priority needs, they did not recognise their son as having a “disability” and they would not have trusted any government service or even known of the existence of the Disability Services Commission...”

“... You should have more information at the Aboriginal Medical Service. Derbarl Yerrigan Health Service have information with Aboriginal pictures on them ...they need to know about this service(PBT) and tell other families like mine so they can find out what is wrong with their child... Aboriginal people have shame often about disability and they will often only use the AMS. AMS needs a lot more disability information...I went there for years and they could never tell me about what was wrong with my son...the school helped me find out...”

The Commission’s formal and public response to meeting the needs of Aboriginal people with disability, their families and carers (see appendix 6) recognises that “along with European settlement came dispossession of land and culture, negative discrimination and disruption of kinship ties”.¹⁵

The legacy of a history of discriminatory and often inhumane treatment of Aboriginal people by the State is that many Aboriginal people may be unwilling and distrustful of Government services. The lack of referrals coming from the LAC may well be partially explained by the lack of trust Aboriginal people have of Government agencies; however the reverse of this explanation for very low referrals may well lie in the difficulty for Government services in successfully engaging with these families.

Knowledge of, and skills in, culturally sensitive engagement strategies are as essential to the referral agency as they are to the PBT service. Many Aboriginal people who have a disability also experience multiple disadvantages such as poverty, poor health, lack of education, unemployment, justice issues and substance abuse as a result of the poor treatment they received in the past.¹⁶

Aboriginal people with disability face far greater disadvantage and vulnerability to that experienced by many non-Aboriginal people with disability and consequently require greater efforts to engage and support them. Strategies of engagement and support that may work well with other cultural groups need to be modified or changed for this population to take into account not just their cultural needs but the multiple disadvantages faced by families from Aboriginal backgrounds.

The Commission’s Policy and Practice Plan 2006 - Access for Aboriginal and Torres Strait Islander People with Disabilities - states a commitment to ensuring access to services for people from Aboriginal backgrounds and to providing services that are culturally secure. An essential element in making this happen for Aboriginal

¹⁵ Access for Aboriginal and Torres Strait Islander People with Disabilities -Policy and Practice Plan April 2006

¹⁶ ibid

communities is building on and working in partnership with existing services provided to Aboriginal communities.¹⁷

If people with disability from Aboriginal backgrounds are “choosing” to access services from specialist Aboriginal providers and if the LAC is experiencing difficulties in reaching out to this community (as described in the LAC workshop), then it follows that the PBT service needs to connect with those specialist services to reach this population. The PBT service also needs to continue working closely with the LAC program as it attempts to connect with the Aboriginal community.

Recommendation 1. Broaden the access to the PBT services.

1.1 That the referral source be broadened from the LAC program to include other government and specialist agencies working with CaLD and Aboriginal families.

1.2 That the PBT service build stronger working relationships with these agencies to increase their awareness and knowledge about disability and Positive Behaviour Services and for the PBT service to gain skills and knowledge about working with CaLD and Aboriginal families.

4.2. Information provided on the service

Families generally found that they could read the written language used in the ‘Information for Families’ sheet, however they found some of the concepts difficult to comprehend. The need for translated resources was also identified as a major theme coming out of the PBT staff interviews (see Appendix I, points 11 &13).

Several families stated that although they could read the ‘information for families’ flyer, they did not understand some of the language and/or concepts used in the flyer. One parent commented

“... I did not know what a ‘speech therapist’ or ‘clinical psychologist’ was; where I came from we had only social workers... there are no other people to help you...”

“... positive behaviour what does this really mean? I thought they must be judging me as a poor, a negative parent ...I thought I was a very positive parent already not a negative parent...”

Eight of the families interviewed were very positive about the staff and their efforts to communicate clearly. PBT staff explained the written information and this was very helpful. They especially appreciated the use of pictures and other visual resources.

¹⁷ ibid

“...They were always very nice and they even used some of our language in his communication book...They always checked everything with me ...every single word they wrote they would check with me...They also checked everything with “A” and they talked to him a lot and taught him many things as well...”

“...if I could not understand or answer some of the questions the PBT staff helped me ...it was fine ...”

All families interviewed had a functional level of spoken English language competency (their own assessment and that of the study author, who interviewed them). However, most needed help to understand the written language used in the assessment documents as well as assistance to understand the meaning and concepts from a cultural perspective.

“...The PBT staff explanations of the service were quite clear but the documents were a bit difficult (to understand)...”

“... You should have information translated into other languages as even when the words can be read the message can still be difficult to understand due to culture...”

“...your “mission” what it aims to do should be written in other languages... some concepts need to be translated not just words...”

“...translated materials would help families whose English is not as good as mine. It takes me a lot longer to understand English writing...my first language is Chinese and it takes me twice as long to read and understand English...”

Recommendation 2. Improve written information on the service

2.1 That the family flyer for CaLD and Aboriginal families be rewritten in plain English with more graphics. Family stories on the information sheet would ideally be of a culturally similar family and translated into the most common first languages of CaLD families.

4. 3. Use of assessments

There was some inconsistency in the use of the formal assessment tools (questionnaires) with families from CaLD and Aboriginal backgrounds. Some families were told that they had to complete questionnaires despite them stating they would rather not. Others cannot remember any formal assessment being offered. Some families completed them willingly, others reluctantly, and some did not know of their existence.

The inconsistent use of formal assessment tools is supported by feedback from interviews with the PBT staff. There is evidence of a lack of clarity about when and with whom these assessments should be used in the PBT staff feedback (see Appendix 1, point 16). Is it left to the staff member’s discretion? Do families have a

say in their use? How relevant are these assessments to people from diverse cultural and linguistic backgrounds?

If the relevance of these assessment tools cannot be clearly explained and understood by the family or they simply do not wish to complete them, should they? How much of a “say” does the family have in this partnership model?

Clear guidelines for use of the assessment tools for the PBT staff need to be developed and communicated to assist staff and families to make ‘good’ decisions. Above all, information should be collected in ways that match the families’ preferences if an open and trusting relationship is to be developed.

“...The PBT staff insisted that we do the questionnaires but they did offer to help us...I raised some issues about the type of questions we were asked and how they were not culturally appropriate ...”

“...I did not want to do all the paperwork stuff and definitely not the genogram... the team respected my decision and found other ways to work with us ...”

“...The questionnaires are very intense and the interpretations of the results by the staff may not be valid for our culture ... the tests are not culturally valid; we need tests that are suited to our culture...”

“...Some of the questions were very personal and I didn’t quite know how they would help my son. I struggled to see how they related to the problem we had. Clearer and better explanations of how the questions fit into the goal of solving our problem would be good...”

“...My English is quite good, however the questionnaires were very difficult to understand because of my culture. I needed a lot of help from the staff to answer these and they (the staff) were very helpful and we went through them together...”

“...I really wanted to provide all the information that the staff wanted/needed to help us as I was very desperate and really needed help for my son. Most of the questions asked of us seemed OK once they were explained and we could discuss what my understanding was and how my culture influenced my answers...”

“...There were too many questions in the paperwork and many repetitions which was annoying ...it was quite stressful to have so many questions...they were a bit overwhelming and made me feel stressed and depressed at times...”

Six families found the questionnaires were difficult to understand but went on to state that PBT staff were very helpful and sensitive to their culture when trying to explain the meaning of questions. Generally people were happy to answer questions asked in a verbal or written context once they were clear about how this was going to assist their child/family, although most believed that too many questions were being asked.

Some of questions asked by the staff and asked in the formal assessment tools resulted in two people feeling ‘bad’ about their parenting style. Within their own culture their parenting style/practices are seen as ‘good’ or ‘appropriate’, however they felt negatively judged by PBT staff when responding to some of the questions about discipline and safety. The need to consider how to construct these questions

in a culturally sensitively manner is very important and is seen by families as a demonstration of respect for their cultural values.

“... Some of the questions about smacking children upset me, they asked do I smack my child and it made me angry as this was the way all of us were taught right from wrong. I do not think it is bad to smack when a child is very naughty but this question made me feel like I was being judged as a bad parent. They annoyed me with some of the questions...”

“...the staff were very respectful and easy to understand but the questions were a bit overwhelming and made me feel stressed and depressed at times...I could not see how they related to my life...this may be a cultural thing...”

Recommendation 3. Use of formal assessment tools

3.1 That consideration be given to the current use of formal assessment tools, clear guidelines developed for their use with CaLD and Aboriginal families and exploration of the availability and/or development of culturally appropriate assessment tools.

4.4 Cultural Guides for families

Several families talked about the need for someone who understood their culture and language to be with them for some or all of the service duration to safeguard their cultural beliefs and values. These families described the introduction to the service as confusing and the ending of the service as rushed and unsatisfactory. This need for cultural support was also a significant need that came out of the staff interviews (see point 20 PBT Staff Interviews). Staff stated that such a person could provide a “cultural bridge” between family and staff.

“...The family should be able to invite/involve a community leader as a cultural advocate for the family. ... A family may be fearful or too respectful and say nothing for fear of losing the service. The model is very good but I feel that it is very daunting at the start that you have to “sign up” to 12 months or more. This could put people off so early in the service...”

The use of a cultural support or guide by the family, independent of the Commission and preferably from the same community as the family, to meet their identified need (having someone with them who understands their culture and language) has previously been found to be helpful.¹⁸ Services that encourage families to identify a cultural guide have found that this strategy helps facilitate communication and understanding between staff and families. Examples of cultural guides include community leaders, members of the clergy, and business leaders from the family’s cultural group or other identified individuals who speak the family’s primary language and have knowledge and experience of their culture.

It must be noted that a cultural guide is quite distinct from an interpreter or linguistic guide in that they are from the same culture as the family (and may also as a result share a common language) but their main area of expertise and support comes from their common cultural background and understandings not from shared linguistic

¹⁸ Educational Research and Improvement Centre Digest (August 2001) EDO-PS-01-4.

/language knowledge. Interpreters (linguistic guides) will have language skills in both the family's primary language and the service provider's language but not necessarily have a shared cultural heritage.

Cultural guides/support can play several roles ¹⁹:

- Assist families in understanding service information, processes and procedures in a culturally sensitive and responsive manner.
- Provide staff with insights concerning community beliefs, values and communication style.
- Act as facilitators to bring families and staff closer together to reach desired outcomes.

Families with strong working relationships with their LAC may feel the LAC is best placed to perform this role, however a cultural guide would ideally be from the same or similar cultural background as the family, be prepared to invest significant time, and be independent of the Commission. Families may choose to involve the LAC, and/or a cultural guide, or neither, depending upon their needs. The issue here is that families need to be informed that they can choose from these options to support/safeguard their cultural beliefs, values and practices.

Balancing this need was the acknowledgement made by families that the PBT staff made every effort to be culturally sensitive and to accommodate the families cultural needs/practices.

“...The staff appeared very aware of our cultural needs... it feels like I have known them for years...they are very good at what they do and always aware of my family's cultural values...”

“...They have been a lifeline for me...they are very flexible and willing to help no matter what...”

“...The PBT staff was excellent and they really got to know us as they spent a lot of time with us...”

“...The time they spent with us allowed them to get to know us and about our culture and how we like to do things. It was not just about culture they were considerate about what would work for my family as well...”

Recommendation 4. Cultural guides for families

4.1 That the preparation checklist for PBT staff include the prompt for staff to explore support options for families which may include a community/cultural guide to safeguard the family's cultural beliefs and values.

¹⁹ ibid

4.5. Flexibility in the assessment stage

The service duration (between nine months and eighteen months) was seen by all families as a very positive feature of the PBT service, although most felt that the assessment stage was too long. PBT staff also commented positively about the length of the service, however most staff, in contrast to the families, felt that a lengthy assessment stage was essential (see point 2 PBT staff interviews).

The length of time staff and families had together allowed trusting relationships to develop and time for families to learn new ways of managing/parenting their child. Families also appreciated the time staff had to assist them to build better relationships within the family and with other systems such as schools.

“...this approach is very good as we get to know each other well and you feel supported...I would love this type of support to go on for ever...My children are now all very close as we work together with “M”; the children understand about autism since we have had the team and it works better for us as a family. Before this they would run away to their rooms and avoid him or tell me he was getting too much of my time...” (Aboriginal mother)

“...I felt for the first time that someone was taking the time to find out about me, my family and my son...the length of the service is very beneficial as we can all get to know each other...the service looks at the whole of my son’s world, not just the family, but all the other parts of his life...”

“...the time the team spent with us was very good as we got to know each other, we got close and it was very emotional to say goodbye...I would like that kind of support again it was very good for my family and my son...”

Most families commented, however, that the assessment period lasted too long and that they would have preferred intervention to start earlier.

“...the assessment stage is too long and they need to do or start doing something earlier for many families...”

“...I thought they would be doing more intervention but they only seemed to do assessments...that went on for about 12 months and the service finished quite quickly...we had no maintenance or review stage and the intervention stage was too short...”

“...the length of the service was daunting to start with and the first three months of assessments were intimidating for us but over time it became better as we got to know each other...more time should be given to sitting and talking and getting to know each other before all the paperwork and questionnaires are expected to be done...”

“...I think that other families from my culture would find it (the assessment stage) very difficult, that amount of paperwork and so many questions. It’s because I have been here over 20 years and my English is very good that it was OK for me...”

Recommendation 5. Length of assessment.

5.1 That the PBT further consider flexibility in how the Positive Behaviour Team works with families from CaLD and Aboriginal backgrounds by introducing interventions/practical support earlier and/or delaying formal assessments when these actions would assist in engaging the family.

4.6. Maintenance and follow-up

More time spent in maintenance and follow-up after the completion of the service is a common theme throughout the family interviews and was also a major theme coming out of the PBT staff interviews (see point 15 PBT Staff Interviews). Although the service was highly appreciated for the overall length of time it devoted to families, many felt that they needed some contact in the year/s following the official end of the service to help them stay on track and maintain, over the longer term, the gains that they had achieved.

Many families from CaLD and Aboriginal backgrounds have minimal connection with government and other generic services in their communities due to issues such as lack of trust, fear of officials, lack of knowledge about services, financial hardship, transport difficulties, and language and access issues. Many families from CaLD backgrounds have also often lost family and friendship networks as they have been left behind in their countries of origin. Families identified the need for more time to be spent in maintenance and follow up which, given the multiple disadvantages faced by many families from CaLD and Aboriginal backgrounds, is well justified.

“I did not understand the end of the service...it did not end properly and I don't know why...they need to finish the service properly and say good bye, this is the end of your service...I did not have a final meeting and I don't know why.”

“At first I did not understand the service and said that it would not work for my son...how could talking to me most of the time help my son? Why didn't they work with my son?”

The staff seemed to explain the service well and the written material seemed fine, however the service did not turn out to be what I had expected it to be...The time of completion of the service should be agreed to by both sides – family and staff. The assessment went on for 12 months and then the service finished quite quickly.”

“...There should be follow-up. Families are just cut off at the end of the service... the time of completion of the service should be agreed by both sides –the family and the staff...”

“...some after-service contact with the PBT would be very good to have. This would help to keep me on track and give me support...there are times when I feel I am doing this all on my own and I might not do things the way I should...their contact would help to keep me doing things properly... contact maybe once a month by phone or visit would encourage me and make me feel more positive...”

“...Follow-up from the team would be really helpful for us – as they already know us we would not have to tell our story all over again...It was a very good team and having better follow-up would make it a better service. I think the team should contact families perhaps three times a year to see how things are going and help again if needed. It (the service) would not need to be so long as they already know us well...”

“...if I didn’t have these two ladies to support me I would still be in denial and we would be going backwards...you feel supported and you wish this type of support could go on forever...”

Families talked in very positive terms about how the PBT staff assisted them with “sorting out problems” with the schools their children were attending and helping them to get appropriate respite from agencies; however contacts with other community based support were not mentioned. The ability to maintain the gains that the family makes through working with the PBT service (its longer term sustainability) are greatly reduced when systems of support within their community are not available or accessed .The building of social capital (supportive networks) for these families is essential to ensure sustainability of positive outcomes, however very time consuming. Questions that need to be considered by the PBT service include:

- Where does the building of social capital/support networks for families fit into the PBT model?
- Is this role currently the responsibility of the LAC, the PBT staff or both?
- Are the LACs aware of this need?
- Are the LACs able to deliver on this need? (See Appendix 2 points 10 and 11)

The relationship between the PBT staff, the LAC and the families was raised as an area needing further development by the PBT staff (see point 19 PBT Staff Interviews).To effectively support families from CaLD and Aboriginal backgrounds during the service and in the follow-up period once the service has ended, the roles and responsibilities of all parties need to be clear.

Recommendation 6. Maintenance and follow- up

6.1 That families who have limited informal and formal support be offered an extended maintenance stage and scheduled periodic follow-up.

6.2 That LAC and PBT work together to develop explicit and agreed roles and expectations for both PBT and LAC staff in terms of family support post PBT intervention.

4. 7. Diversity in PBT staff

When families were asked the question, “Do you have any suggestions on how the PBT service could better meet the needs of families from CaLD and Aboriginal backgrounds?”, thirty percent responded that having access to CaLD and Aboriginal staff to assist them and the staff would improve the service. PBT Staff also cited this as very important in their interviews (see Appendix 1 point 17).

“...More training for staff about how to engage with and work with Aboriginal families and children... more cultural knowledge would be useful ...”

“...Having an Aboriginal staff member or consultant on the team to support the staff...”

“...Some bi-cultural workers would be fantastic. I would have loved to have had a Chinese worker...someone who could understand my background more...”

“...There needs to be more cross cultural training for the staff...in general I felt they were trying hard to fit in with our cultural needs...I find that I have to fight hard for my cultural rights to be respected in general...”

Another twenty five percent said that having some male staff would be beneficial for some families. Religious and cultural practices may dictate which sex a parent can or will work with. The need for young males (all of the families interviewed had boys) to have men in their lives is very important for their development. Currently there are no men on the PBT teams North or South and there is a risk that the unintentional message that may be given to the fathers of the families the team works with, is that this is women’s work, reinforcing the existing heavy burden of care on these women.

“...When working with Muslim families and especially Muslim men, there should be some male workers available. Many will not work with a woman ...”

“...Having a male worker may be good for working with young men who are clients - they may be able to get through (to the boys) better...”

“...Encourage more men to be in the service - boys need men...!”

“...Having some men on the team gives dads a message that this is not just women’s work...”

Increasing the cultural diversity within the PBT service may be facilitated by using the provision of sections 50(d) and 51 of the Equal Opportunity Act 1984. Section 50(d) enables organisations to employ people from a particular racial group to deliver a service where it is best provided by a person of the same race.

Section 51 enables agencies to create a more diverse workforce by implementing measures intended to achieve equality. For example, a statement in a job advertisement might be worded to encourage people from Aboriginal and CaLD backgrounds to apply.

4.8. Relationships with Aboriginal and CaLD agencies.

Improving access to cultural expertise can be achieved through fostering the development of working relationships with specialist CaLD and Aboriginal agencies.

The level of difficulty encountered by many government service providers (Appendix 2 points 11, 18 and 25) in engaging families from an Aboriginal background may also warrant PBT staff having access to Aboriginal cultural expertise through engaging an “in-house” Aboriginal practice consultant. This model is effectively used in the Department for Child Protection, where every office has an Aboriginal practice consultant. It is supported in the feedback from the PBT staff (Appendix 1 point17).

The feedback from families referring to the need to have more diversity of staff on the team should not be taken as a criticism of the staff who worked with these families as ninety percent of the families gave very positive feedback about the quality of the staff who worked with them. The following positive attributes about PBT staff came from the families:

- Staff were gentle, culturally sensitive and family sensitive.
- They were aware of cultural needs.
- They were respectful of other cultural practices.
- They understood the families’ needs well.
- Staff taught families new skills/knowledge and assisted them to gain new insights and new ways of doing things.
- Staff taught families how to communicate with their child/person with disability.
- They have excellent listening skills and are good communicators.
- They genuinely wanted to help families in whatever way they could.
- Families felt they learnt a lot from the PBT staff.
- The staff were very experienced.

“...The two workers I have now try hard to understand my culture and I try and explain to them my culture...”

“...It feels like I have known them for years ...they are very good at what they do and always aware of my family’s cultural values...”

“...This is the first time that I feel professionals have listened to me...almost everywhere else I have felt that my son has been discriminated against due to his disability and culture...”

4.9. Access to cultural expertise/knowledge

Research has found that what is as essential as having bicultural workers is to have staff who embrace diversity as an asset and demonstrate a willingness to learn about the experiences and traditions of the individuals whose backgrounds are

different from their own.²⁰ The list of positive comments above from CaLD families about the PBT staff demonstrates that PBT staff have many of the qualities needed to work effectively with families from diverse cultural backgrounds.

Recommendation 7. Diversity in PBT staff, relationships with Aboriginal and CaLD agencies, access to cultural expertise/knowledge.

7.1 That PBT consider using provisions of the Equal Opportunity act 1984 (sections 50(d) and 51) to target applicants from Aboriginal and CaLD backgrounds in order to increase cultural diversity.

7.2 That the PBT service consider accessing Aboriginal cultural advice and practice support by engaging an Aboriginal practice consultant (either contractual or permanent).

5. Conclusion

This evaluation finds that the Positive Behaviour Teams are offering high levels of support to families, carers and people with disability who sometimes display challenging behaviours who are from Aboriginal and CaLD backgrounds. On all the evidence available, this program has a high level of acceptance and is delivering positive outcomes for people with disability and their families and carers. The Positive Behaviour Support model was seen by all informants contributing to this report as a contemporary, clearly defined, and generally, a culturally secure service. Its strengths are its

- flexibility in application
- the ability to work with families and individuals over an extended period of time
- the personal and professional attributes of its staff
- the quality management approach taken to service delivery and design.

Whilst the program received strong support, there were nonetheless a number of recommendations that have been made to further strengthen this service. These recommendations mainly focus on increasing accessibility to the Positive Behaviour Team in a more culturally secure practice framework for people from Aboriginal and Culturally and Linguistically Diverse backgrounds. These recommendations require few resources to implement, however they have the potential to significantly impact on the capacity of the PBT approach to increase access and responsiveness to the needs of Aboriginal and CaLD individuals and their families and carers.

²⁰ Educational Research and Improvement Centre Digest (2001)

Appendix 1

PBT Staff Interviews

Sixteen interviewees were asked a series of questions about working with CaLD and Aboriginal families in the Positive Behaviour Team model of service delivery, (see appendix 8). The PBT service model was used to structure the interview content (see appendix 9).

Analysis of the PBT staff interviews demonstrated that:

1. Staff have a comprehensive understanding of the PBT model.
2. There was consistency in how the service is delivered.
3. There was a high level of consistency from staff in the responses to questions asked in the interview.
4. Staff felt that the PBT model of service delivered an effective service to families.
5. Staff felt that the service could respond reasonably well to the needs of families from Aboriginal and CaLD backgrounds, however with some additional resources and minor adjustments it would be better able to meet the needs of this population.

Staff responses to each question were divided into two categories

“What works well using the PBT model?” and
“What requires further development?” when working with families from CaLD and Aboriginal backgrounds.

The following themes emerged:

What works well using the PBT model?

1. Preparation

Seen by PBT staff as essential prior to the first meeting with a family – specifically gathering information about the family, their circumstances and gaining some basic knowledge of culture and language needs. Staff all made preparations before visiting a family. Staff members engaged in a variety of preparation methods to facilitate the engagement with CALD and Aboriginal families including the following: reading files, arranging interpreters, talking with referrer (typically the LAC), preparing introduction to service packages, asking the family who they want present/where they want the initial meeting and when, researching cultural matters, inviting a worker who is already engaged with the family to the meeting (LAC), and planning approaches and negotiating roles for the initial meeting with co-workers.

2. Timeframe

Having the time available (from nine months up to around 18 months) to get to know family and building trusting relationships is valued and important.
The investment of time in getting to know the family is essential for success.

A PBT staff member who had worked with an Aboriginal family illustrates the importance of having a long timeframe for intervention in the quote below;

“...first visit no show by the family.....we dropped by the house a couple of times when we were in the area ...when we met the mother we yarned... we met with her several times and just yarned/talked to build relationship...didn't really do a direct introduction to service, this came through our conversations with the mother...”

Having enough time available and the flexibility to discuss or have general conversations with Aboriginal families about their interests and concerns is essential for engagement to occur. In addition staff believed a long assessment phase as very important, however acknowledged that families often became “impatient” during this stage of the model.

“...the assessment phase is long and can be exhausting but I think it works really well. The time allows families to reflect. The assessment phase can in itself result in positive changes...”

“...Time is very important and makes a big difference to this model ...listening and looking; making good observations and building good relationships requires time...”

Time was also identified as important in terms of families developing an understanding of their role in the challenging behaviour and learning new ways to respond.

“...time needs to be taken as the “problem” has been internalised into the child and parents need time to reflect on their role in the “problem” with assistance from others ...”

3. Family centred approach

PBT staff talked about how the model allows them to work with each family as a “micro- culture” and that it is the responsibility of the staff to get to know that particular “family culture” and work with it to achieve positive change. When working with CaLD and Aboriginal families, getting to know the individual “family culture” was seen as important as understanding the broader cultural norms/practices of the CaLD/Aboriginal family

“... We try to be as sensitive as possible to find out what is important to the family...” “...we work with parents to explore their family dynamics and beliefs and why they believe certain things occur...we discuss openly their tradition, beliefs, actions and society's expectations...”

“... Staff always check with families about what is going on and should never override the family. If there is considerable disagreement about what is going on then staff need to find new ways to communicate ... the barriers may well be cultural and finding out about how culture may be influencing progress is essential...”

“...Knowledge of what is important and valued by the family is essential...the family's cultural norms are very important and if the plan does not fit the family it won't be implemented...”

4. Working in partnership with the family (co-working with families)

“...Nothing happens without agreement ...” PBT staff agreed that a shared understanding between themselves and the family about what is going on and what will happen next must occur before anything can happen.

A shared understanding must occur between staff and family for the model to be effective. If the family does not believe / understand what is happening or going on in their family then there is little or no motivation to change for the family.

“...Goal setting is and should be family driven... the emphasis is on making sure it works for the family...we need to be very clear that the goals are the family’s not ours...the emphasis is on the family’s ownership of the goals or the intervention will not work and our work will not be understood...”

Staff commented that “... a large part of this process is talking and reflecting together”. Staff frequently acknowledged cultural difference between team members and the family and encouraged open conversation about cultural issues that may affect coming to a “shared understanding”. Staff found “checking in” often with families about their understanding was helpful and promoted a productive working relationship.

“... Joining together PBT and family arrive at a formulation...it’s about understanding as best we can...to develop a shared formulation...”

“... Ideas and strategies are all written down in the family’s words... extended family may be part of the plan if the family wishes this...this is the family’s plan they have worked hard in the prior months to get to this point...”

5. Flexibility

The ability of the model to be non linear and allow staff to negotiate with families is seen as very positive by the PBT staff. Staff and families constantly review what they are doing, how they understand what is going on, adjusting goals to suit the needs and preferences of the family. Flexibility is essential to accommodate the many individual variations in families as well as the cultural practices and beliefs that influence CaLD and Aboriginal families’ ways of functioning

“... The great strength of the PBT approach is its individualised style...every intervention looks different...”

“...what helps is that the professions involved (in the service) are experienced and confident about the PBT process and adjust that process... it is not a straight linear model...”

Many staff members identified flexible practices to build engagement. This was particularly evident in the assessment phase with many assessment tools being available to better match the family’s needs.

“...Some families are not comfortable with formal assessment tools and the team needs to acknowledge this...being flexible is important even if we can’t get all the information we require...”

6. Builds family capacity

PBT staff agreed that the service aimed to build the family’s capacity by developing their confidence, skills and knowledge to manage challenging behaviour in multiple environments across time.

“...We are clear with the family that we are not there to provide the solution and fix their problems...we can support, model, review, troubleshoot, but at the end of the day, it’s the family that needs to make the changes and do the work...”

Staff talk about their diminishing role from the beginning with families,

“...We work alongside the family with frequency of visits slowly decreasing as parents skills increase in managing their child’s behaviour...”

“... We talk to the family about our role from the start... we work alongside the family with the aim of giving the family the skills, problem solving skills...”

Staff worked with families on rebuilding or improving relationships which were problematic with extended family, external agencies and the LAC to increase the chances of families sustaining the changes.

7. Supervision

Many staff interviewed mentioned that they had excellent supervision in various formats and felt very well supported by their peers, co-workers and managers

“...The (peer) supervision process is really helpful and works well for us when we are working with CaLD/Aboriginal families ...it brings together experienced staff and offers the opportunity for growth and learning in a comfortable environment...”

“...peer supervision provides intensive support and is wonderful...there are checks and balances within the system...”

8. Formal co-worker arrangement

PBT Staff always work in pairs with families and this appears to be highly valued by the team. The co-worker model is seen as good support when working with stressed/complex families, a learning opportunity for each of the workers from each other’s knowledge/experience, assists in preventing bias/prejudices developing, allows joint planning and strategising and is useful for debrief after sessions with families

“... It’s great that the co-worker arrangement is a formalised process...this works well as you have support from others...”

“...having two people working together tends to safeguard the family’s needs, wishes and dynamic...”

9. Experienced staff

Having a team of experienced staff was valued as the work is seen as complex and challenging.

“...Building relationships and engaging the family is highly valued in the model...staff need to have high levels of communication and interpersonal skills to build rapport and engage families...this is often more difficult with Aboriginal families...”

“...PBT have employed senior staff and this is one of its strengths...experienced staff are what make the team work...”

10. Continuous review

Reviewing progress occurs throughout the duration of service with the family on an informal basis and formally towards the end of the service. Reviewing progress and understanding with the family is built into the service process and allows staff to regularly check up on whether they are doing the right thing and are on the right track. Families are asked frequently by staff:

“...How is it going? How does it happen? Is it working?... To give staff directions and help them gauge the family’s thoughts and feelings about the process...”

“...Reviewing is an ongoing process that happens every time a family and staff gets together...”

“...Ongoing communication happens throughout the service about how things are working out...reviewing is almost continuous...”

“...PBT staff must be checking in with the family throughout the service ...is this ok? Etc... Needs to be asked continuously...to ensure that there are no potential /hidden barriers...”

Areas identified for further development

11. Availability of and access to translated resources

Almost all PBT staff commented that having the “information sheet for families” translated into several of the most commonly spoken languages other than English would be very helpful for families. Families who can speak English with a reasonable degree of competence often still have significant problems with reading and comprehension of English. The information sheet should not only be translated but some of the concepts and language simplified. Some other resources also need to be translated for example some of the formal assessments and recording sheets.

“...Information and assessment questionnaires are all in English... we need translated documents and information ...DVD of a family’s experience with service...”

“...There’s value in redeveloping the written communication to make it simpler for families...”

“...Use lots of pictures...this is a heavily language-based intervention...”

“...Need a much greater use of pictures and diagrams to explain what the family sees as happening...highly in favour of simplifying information ...”

12. Use of interpreters

Staff wanted to have a better knowledge of the issues associated with using interpreters and to consult with family about the use and the selection of interpreters. Having better access to training and information for the PBT staff in how and when to utilise interpreter services and the considerations that need to be made when selecting an interpreter. Historical, social and political factors all need be considered prior to engaging an interpreter. Families need to be involved in the process of selecting an interpreter.

“... The assessment process can be long and arduous...for CaLD families; more time is needed and an interpreter is essential...”; “...it would be easier to have it (documents) written in their language and use interpreters ...”

13. Simplification of language and information (verbal and written)

Most PBT staff felt that the (English) language used in the written information designed for use by families of both CaLD and Aboriginal backgrounds should be de-professionalised, simplified and where possible told in a “story” format with a greater use of pictorial support. Verbal information (the conversations staff have with families) need to be as concrete as possible using language and concepts that the family can relate to through their own experiences and knowledge. Where this is impossible, supporting resources should be considered such as DVDs and pictorial information.

“...We should use the language of the family...everyday, ordinary language helps...”

“... We need simplified documents to assist families with literacy issues ...questionnaires in other languages ...a DVD of a CaLD and Aboriginal family’s experience of this service...”

“...Currently much written material is used in the assessment stage and we need to consider how to do this differently... we need simpler forms and also other trusted support (people/agencies) to assist...”

14. More time – start of the service

Many PBT staff thought it critical that more time be spent with families from CaLD and Aboriginal backgrounds during the initial stage and during the maintenance stage. Getting to know the family and vice versa needs to occur in an informal manner where conversations about whatever issues the family wished to engage in can happen and the formal introduction to the service can be suspended to either a later time in the development of the relationship, or slowly introduced as the relationship develops in the first few weeks.

“...Currently the service starts with a meeting where we describe how the service works to the family, give them the information sheet plus some other information, families are encouraged to ask questions about the service and then given a week to think over whether this service suits their needs...” .

For people from CaLD and Aboriginal backgrounds this is clearly too rushed when the family is building trust and rapport with the staff member. Inadequate time and attention to language, culture and engagement at this crucial time may result in families who could really benefit from this service declining at this early stage due to fear or anxiety, lack of understanding or misunderstanding about what the service is, or lack of understanding or misunderstanding about how the service might work with them.

“...During the first meeting the mother declined our service offer ...we thought that she may not have understood what the service was about... we went back several times to help clarify what the service was about ...she then decided to take up the service...”

15. More time - the end of the service

Many PBT staff believe that more time is needed towards the end of the service on developing strategies that enhance the chances that the changes achieved by the family can be sustained. This is the time when other agencies (especially the referral source) are invited back to support the family to maintain their achievements and build other and more support networks around them.

The PBT model works on the assumption that there is an LAC working with the family, that the LAC has a good working relationship with the family, that the LAC has the skills to assist the family to maintain and sustain the changes the family has achieved during the PBT service, and that the LAC has the appropriate community knowledge and contact with specialist CaLD and Aboriginal agencies.

Some of the PBT staff did not have confidence in these assumptions.

The LAC representatives participating in one of the workshops (see point 18 in the Workshop Major Themes) also revealed concern about their ability to fulfil these roles given existing workload, limited time for community development activities and difficulty engaging with these communities, especially Aboriginal families.

Not all staff felt confident that the changes the family had successfully implemented by the end of the service would be able to be sustained in the longer term (this was a concern for CaLD and Aboriginal families mainly). Maintenance (sustainability) seemed to be largely contingent on the availability and quality of the family's LAC and other community resources that may, or may not, be able to be accessed.

“... A longer maintenance period would be beneficial for families, being there to support them is essential because gaining support from external agencies is harder for CaLD families...we need to teach them how to do that well before we depart...”

“... Some families require ongoing support ...there is a gap as to how and who will continue to provide this support ...perhaps brief clinics...there is a need for longer maintenance support for high risk families...”

“...We hope that the LAC has a good relationship with the family and check in on them from time to time...”

“...I believe that it’s important that there is some ongoing contact...could be a phone check-in and review of how they are going...LAC may not be the best follow-up person for CaLD of Aboriginal families...may need a CaLD or Aboriginal mentor or agency...”

16. Use of formal assessment tools

There was some inconsistency in responses from staff about this part of the PBT model. Some staff felt very confident in saying that they could use their own judgement about which tools they felt would be useful and others who believed that the use of formalised assessment tools was not negotiable.

The issue of culturally normed tests was also raised as problematic as most, if not all, existing tests were normed on white middle class populations and all are in English. In summary everyone agreed that assessment was a necessary and valuable stage to have in the model but felt they needed more clarity about whether they had to use formal assessment tools in every situation.

“... We should be moving towards assessment tools for Aboriginal families that are evidence based and normed on that cultural group...”

“...Questionnaires are used as pre and post measures however there is some disagreement over how essential these are...there is some pressure to do the assessment questionnaires early on in the service...”

“...Family has the option to choose how and what they would like to complete in the assessment phase...there is a lot of testing...we need to be flexible as to how we do the testing, what tests we give and find alternative ways of getting required information...”

“...The use of questionnaires is the only doubt I have (about the model)...”

“...Not all assessment tools are CaLD or Aboriginal ‘friendly’ so these are not used or given to families...no formal assessments may be used...”

17. Build relationships with CaLD and Aboriginal communities/access to cultural expertise

Greater knowledge of support for CaLD and Aboriginal families and developing their cultural competence skills was seen as a very important for staff to enable them to build better relationships with families as well as improve the families’ capacity to maintain the positive changes over time – assisting in making the outcomes sustainable. Helping the family to build a network from the start of the service with culturally suitable agencies is seen as a benefit to both families and staff.

“...We need to work directly with support agencies (CaLD and Aboriginal) and not just the current referral base of LAC...greater involvement by us in community based functions for both CaLD and Aboriginal communities would assist us in getting good information to these families as well as broadcasting our own experiences(services) with these groups...”;

“... We need to develop relationships with specific Aboriginal and CaLD agencies to enable collaborative work...”

Developing good working relationships with specialist CaLD and Aboriginal agencies would assist in increasing the cultural competence of PBT staff and may result in more successful engagement strategies being developed.

“...Linking the family with others e.g. Aboriginal liaison officer, who can say ‘you can trust this team’ gives us credibility/legitimacy ...”

”... We need access to cultural competence training especially how to engage Aboriginal Families...”

“... A resource list of CaLD and Aboriginal agencies with summaries about what they do would be a useful resource...”

“... Access to Aboriginal and CaLD expertise would assist our engagement with these communities ...”

Having cultural expertise available in the workplace by engaging a person/s with specialist knowledge about Aboriginal and CaLD communities was also seen as a highly desirable resource by the PBT staff.

“...We need access to advisors or consultants from Aboriginal and CaLD backgrounds that are available on request...”

“... Developing a community consultant model or casual employment contract with local respected elders ...to help us work and engage better with families from CaLD and Aboriginal backgrounds...”

“...Having a staff member with connections in specific CaLD or Aboriginal communities...or a link to those representatives in the community...and consulting with those representatives to obtain information relevant to cultural background of families...”

“..Having Aboriginal workers available to consult with or work with who have credibility in that community...”

18. Referral: source and process

Currently all referrals originate from the LACs. The PBT service has the expectation that the LACs:

- Have a good working relationship with and are delivering an active LAC service to Aboriginal and CaLD families in their district.
- Understand the PBT service well enough to give the families a good understanding of the service and its potential benefits.
- Have a good working relationship with the family and thorough understanding of their needs.
- Have the time and skills needed to write up detailed referral information.
- Have a good understanding of and relationships with CaLD and Aboriginal agencies in the community.
- Have linked families to previous services (in relation to the challenging behaviour) which have not been successful.
- Have access to other practical resources that the family may need during the PBT service .
- Have the ability to assist the family to maintain and sustain the positive changes from the PBT service after it has ceased working with the family.

Many staff interviewed felt that a single source of referrals was too narrow for CaLD and Aboriginal families as they don't always have an active LAC service and may not even be aware of the existence of the Disability Services Commission. The data on number of families who access the PBT service from these groups would suggest that this is the case.

In the LAC workshop (see points 11,17,18 26), representatives reported that having the role of sole source of referrals was very demanding on the individual LACs given their current workload and the need for cultural expertise in working with CaLD and Aboriginal families. An example highlighting the importance of good information and good relationships from the start of the referral process was provided by one of the PBT staff.

“...When I contacted the family to let them know that their referral was successful they could not remember the referral and did not feel like going ahead with the service... the LAC had had no contact with the family since the referral was made... they (the family) had no understanding about the service or what any team professionals did (social work, psych, speech therapist) ...they had signed the referral forms but had no clear idea why...”

“...There is a need for ongoing contact between the family and the referrer to ensure the family knows where the referral is up to and stays involved and in control of the process ...”

“...The family should be more informed about the PBT process and if it's suitable for them...some families are unsure what they are agreeing to...whose opinion it is that they need this service...”

19. Developing LAC/PBT relationship

PBT staff felt that their relationship with the LAC could be improved through better communication and opportunities to work together, especially in the early stages of the referral process. LACs need better and more information about PBT to be able to communicate this well to families. There is also a need for clearer understanding

between PBT and LAC about the expectation each held of the others roles, not just in the referral process but throughout the intervention and post intervention period.

“... We should consider joint visits (with LAC) to families who are being considered for referral to the service...”

“...We need to work more closely with LACs especially at the initial stages when a referral is being considered...”

“...The quality of the information provided by the LAC in the referral and the quality of the relationship the LAC has with the family can make a big difference in family’s ultimate decision to either accept or decline the service...”

20. Cultural liaison position

Staff identified that they had on occasion used Commission staff members who had a cultural connection to the family they were working with to build a “bridge” with the family. This strategy for building engagement with particular families can be useful and work well, but it could have an unforeseen consequence of loading a staff member with cultural obligations in addition to their normal duties. The importance of a “cultural bridge” was raised numerous times by the PBT staff as an important need for both the families and for them to work more effectively.

“..We need...trusted support to assist the LAC or another family member who understands the process...”

“... We need more ‘reminders’ to be culturally aware in general...”

“...Link the family with other people from their community who can say ‘you can trust them’...one family had a translator from the same background who doubled up as support for the family...she was able to educate us...”

“...Having a liaison person at the beginning would be good...”

“...Having a trusted person from that community to share knowledge with us... would assist us to work more effectively with families...”

Appendix 2

Workshops: Aboriginal Agencies, CaLD Agencies, and LACs

Three separate workshops were held for each of the groups: CaLD agency representatives, Aboriginal agency representatives and Local Area Coordinators from two metropolitan districts. The workshop format, content and structure for the Aboriginal and CaLD agencies were identical. The LAC workshop had some minor changes to the focus questions asked in the group work sessions to reflect their role in the referral process for the PBT (see appendix 10).

Major Themes

Feedback collated from the three workshops was divided into two categories:

1. “What works well using the PBT model?” and
2. “What requires further development?” when working with families from CaLD and Aboriginal backgrounds.

What works well using the PBT model?

Themes common to all three workshops-(Aboriginal, CaLD and LAC)

1. The whole of the family/holistic approach.

This feature of the PBT model was raised by all groups but was most prominent in the LAC workshop. The CaLD workshop participants agreed that the holistic approach works particularly well across a number of cultures and issues (not just disability). Working with the family system and not just the person who has the challenging behaviour allows the family to see their role in the behaviour. Growth and learning happens in all the family and is not just concentrated on one person (person with the challenging behaviour). Working with the other family members especially the parents enables capacity to be built into the family to assist them in managing both current and future difficult circumstances.

2. Service length and intensity.

All workshop groups agreed that time was fundamental to building good and trusted relationships with families. The PBT model allows for up to 18 months of service. Time enables the PBT staff to get a very detailed and highly individualistic picture of the family and their environment. It allows the family to change, to learn new ways/skills at an achievable/realistic pace. Time at the start of the service “...to get to know each other...” and time at the end to establish a maintenance plan with the family was considered extremely important by the Aboriginal workshop participants.

Themes common to CaLD and Aboriginal workshops

3. The flexibility of the model.

Participants in the CaLD and Aboriginal workshops identified this feature of the model as very positive for the families in their communities. Flexibility around where the service is delivered – centre, home, or other suitable venue. The CaLD agencies felt that having the service available in the family’s home was an excellent feature,

while the Aboriginal agencies felt that being able to have the service away from the home added to a family's sense of having their confidentiality protected.

4. Relationship-driven.

The PBT model places considerable emphasis on positive family engagement and working in partnership with families. Both the CaLD and Aboriginal groups identified these features as important for their communities. The model allows time to build a trusting relationship with the family and develops/progresses at the family's pace with their input, feedback, participation and decisions all being very central to the process.

Themes common to LAC and Aboriginal workshops

5. A strengths-based approach.

The LAC and Aboriginal workshops both felt that the PBT model could work well with families regardless of their existing capacity as it started "...where each family was at with whatever capacity they have...". System/structural failures were often identified as contributors to the families' existing difficulties rather than individual fault/weaknesses/failures. Aboriginal families so often feel that they are blamed for the many difficulties/hardships they experience within the family and community, so a model that starts where they are and builds on the existing strengths of the family is a refreshing change as well as far more likely to have positive outcomes.

Themes identified by the Aboriginal Workshop only

6. Staff consistency.

Having the same staff for the duration of the service was seen by the Aboriginal agencies as a very important aspect of the PBT service. The relationship built up between the family and the staff and the extended family members is crucial to being able to work with the family. Changes in staff during the service could see the whole service breakdown as the relationship is considered at least as crucial as the service itself.

7. The service is free to families.

Aboriginal agencies said that services that have costs to the clients are not affordable by most families that they work with. Even small costs are major disincentives to participation as poverty is a real issue in the lives of many Aboriginal families.

What requires further development in the PBT service?

Themes common to all three workshops-Aboriginal, CaLD and LAC

Through the employment of Aboriginal staff, the use of Aboriginal consultants and the building of working relationships with specialist Aboriginal and CaLD agencies, access to cultural expertise becomes possible. This theme was particularly strongly supported by both the LAC group and the Aboriginal group. The need for good relevant cultural and familial knowledge is critical to the engagement stage of the service with Aboriginal families. The use of Aboriginal expertise is vital for staff to build cultural competency skills and is viewed by Aboriginal families as a sign of respect and understanding of their cultural needs.

Suggestions from the groups about how the PBT service could build cultural expertise included the employment of Aboriginal staff who would be part of the PBT team (not necessarily positive behaviour specialists) and who could provide expert advice and knowledge to assist the team to better meet the need of Aboriginal families. Another suggestion was to contract Aboriginal community consultants, as needed, for staff development/skills training and Aboriginal family advocacy/liaison.

The use of specialist Aboriginal agencies was also considered a worthwhile approach as these agencies have the most contact with the families. Developing working relationships with these agencies could assist the PBT to have access to information and resources about a particular community or family that would make the engagement process with families from Aboriginal backgrounds more likely to succeed. To quote from a participant in the Aboriginal workshop:

“...promotion of the service and the employment of Aboriginal people must travel along together...it is critical for the two to be in place at the same time...one cannot exist without the other...if one is missing then a barrier is created...”

The CaLD workshop also identified access to greater cultural expertise as important for the service to better meet the needs of CaLD families. They stated that as the service:

“... Has a multi-systemic approach to intervention with families perhaps they should consider working collaboratively with specialist CaLD agencies as well...”

The CaLD agency representatives felt that the development of working relationships with their agencies would deliver major benefits to the staff and the families in the service.

9. Staff training in cultural sensitivity and competence.

The need for PBT staff to have access to training to develop cultural competency came through strongly from all three workshops.

“...There is a need to understand that different cultures perceive many aspects of life differently to the dominant Australian cultural view and how this affects their everyday practices routines, expectations, interactions etc...”

Having some knowledge about what these may be prior to making contact with a family, and being armed with some skills to deal with these issues, would improve the overall effectiveness of the service. Some examples of where staff knowledge of culture (including history) would be critical were provided:

“...many families have been the victims of serious trauma in their home countries due to civil wars...this has implications for who is engaged to interpret... and they may be overly cooperative due to fear of consequences rather than true agreement...”

“...some families believe it is disrespectful to question someone in authority...so accurate feedback from family may not be easy to obtain...the partnership/collaborative model may be outside the family norms...”

“...the perception of disability may be very contrary to the view of the PBT model; for example in some African societies, disability is seen as a result of a curse being placed on the family or individual... having a psychologist involved in your life can be seen as evidence that you are ‘mad’ in some African communities”

Particular concepts that are embedded in much of our professional language, both written and verbal, may present barriers for people needing the service. For example the term “out of home placement” may be viewed as a threat to remove the family member; “positive behaviour” may imply that the care the parent is providing for their family is negative. Careful consideration needs to be given in the choice of language used in the PBT written materials, family documents and conversations staff have with families.

10. Working closely with specialist agencies and families.

“...Work with a bridging agency...”

This theme has much in common with the first theme in this section (see point 8.) However, it is more specifically about working successfully with a particular family. The “bridging” agencies’ role is to assist the family and the PBT staff to build a positive relationship through offering assistance with communication and cultural knowledge. The most suitable specialist CaLD or Aboriginal agency would be one that has had an ongoing positive relationship with the family or had a good connection with the family in the past.

The “agency” that has largely been seen by the PBT service as having this type of role with the family is the LAC service. CaLD and Aboriginal agency representatives from the workshops stated that the LAC often did not have a relationship, or had only weak relationships with some of the families.

LAC representatives agreed that specialist agencies may play a more important and functional role in supporting families to “understand” the PBT service and develop good relationships with the PBT staff as families had existing relationships of trust and confidence with those specialist CaLD/Aboriginal agencies and not the LAC.

11. Broadening the PBT referral source.

This was considered of utmost importance by all three workshop groups. Broadening the source of referrals was considered vital for the PBT to improve the access of CaLD and Aboriginal families to the service. Anyone who did not have an effective LAC service (either through informed choice, lack of knowledge about the service or unrecognised need) would have no knowledge of the PBT service or access to the referrer as currently both of these are solely in the domain of the LAC service. Some comments from the LAC workshop included:

“... LAC engagement with Aboriginal families is difficult/problematic ...we don't know how to engage despite having good intentions...”

“ ... LAC is a voluntary service so often LACs do not actively seek Aboriginal and CaLD families' engagement...”

“...LACs don't necessarily know how to work with Aboriginal families...”

Specialist CaLD and Aboriginal agencies should be able to refer families to the program and, with some better information from PBT, could become suitable information and referral sources. Schools were also seen as a well placed community source of referrals as this was often the first and sometimes only formal institution that many CaLD and Aboriginal families came into contact with.

12. Building sustainable networks with CaLD and Aboriginal agencies.

It was generally believed that the Commission and PBT had very little real contact or knowledge of specialist agencies.

The specialist agencies often have ongoing connections with CaLD and Aboriginal families and provide many essential support services to these families. It was also acknowledged that many CaLD and Aboriginal specific services may have little knowledge of disability and the Commission.

The PBT service would benefit from having a more systematic, planned and organised approach to working with CaLD and Aboriginal agencies. Building a knowledge base of specialised agencies that are working with families from CaLD and Aboriginal backgrounds and developing working relationships with those agencies would assist families, agency staff and PBT staff.

Individual Commission/PBT workers often network with specialised agencies when and if they have the time; however they often do this in an ad hoc fashion and the knowledge gained and the network developed is lost to the organisation or service when that staff member leaves the position.

Themes common to Aboriginal and CaLD workshops

13. Increasing the CaLD and Aboriginal communities' knowledge of the services/using plain English.

Both CaLD and Aboriginal agencies groups felt that there needed to be more information in the community, not just about the PBT service but also about the Commission and Local Area Coordination.

Some of the agencies in the workshops had little or no knowledge of the Commission. Suggestions for getting information to the communities included presentations about Commission/LAC/ PBT to the CaLD and Aboriginal agencies (so that they could inform the families); staff attending cultural sharing events in the community or running some of these; and use of Aboriginal and ethnic radio to get information to people who are illiterate or have very little English competency.

The Information for family sheets should use plain English and include stories about other families from similar backgrounds who have benefited from the service.

14. Language needs to be kept simple - no jargon.

Information should be written in conversational language and should not use technical or professional jargon.

The use of paperwork should be kept to an absolute minimum as many families have had negative experiences with paperwork in their country of origin and fear paperwork.

“... Paperwork may be collected out of fear as in many third world countries if you have no paperwork you receive no services ...”

Families may interpret certain words and statements very differently to what is intended. For example “out of home placement” may be seen as a threat of removing the family member, or “positive behaviour” may be seen as the family being viewed negatively. These “interpretations” may result in the family declining a service or having a relationship with the staff that is less than optimal.

The family information sheet should have an example of a family who uses the service from a similar cultural background. It should use very simple language to explain concepts.

15. Improving the level of community awareness/knowledge of Disability Services Commission business.

CaLD and Aboriginal workshop participants thought that the level of knowledge about the Commission in their communities was extremely low.

The Commission, and to a lesser extent the PBT, needed to participate more in cultural events in the community and run their own community awareness raising events for these specific communities.

Greater levels of contact with specific CaLD and Aboriginal agencies from the Commission and PBT are encouraged to provide specialist agency staff with information about disability in general, the Commission and PBT.

16. Simplify the referral requirements/process.

The current referral process appears quite complex and may pose a disincentive to engage with the PBT service to agency workers and families.

The referral requirements and processes appear to involve talking extensively with families about the service at a very early stage (either prematurely raising expectations or frightening people away from the service) and completing much paperwork. A suggestion from the CaLD agencies was that a pre-referral discussion or expression of interest could be introduced.

Themes common to Aboriginal and LAC workshops

17. Make access to services flexible and simple.

Both the Aboriginal and the LAC workshops identified access as a significant barrier to Aboriginal families.

Although meeting the access criteria may appear reasonable to an educated, middle class family, it was thought by the Aboriginal representatives to have a level of complexity and compliance that most Aboriginal families would not be able to navigate or meet.

Navigating a pathway to the PBT service requires families to have

- recognised the existence of a disability in the family member
- made a referral or been referred to the Commission for assessment
- developed a working relationship with the Local Area Coordinator
- discussed with an LAC their need/problem and
- for the LAC to have adequate knowledge of the PBT service and the ability to relate this to the family and then to be able to go through complex and lengthy referral paperwork.

Some of the access criteria that were considered to have a discriminatory effect were:

- The need to have had prior intervention: Aboriginal families have a very low uptake rate of mainstream government services.²¹ Poverty is also a reality that most families live with, so the use of any private user pays services would be out of reach. The “wait time” to receive Commission or other government funded psychology services has until recently been exceedingly long, and often the family’s situation has changed by the time the service was available.
- The need to be in a stable environment and to commit to a long-term involvement with the service: The home environments of many Aboriginal families are not stable and children may move from one caregiver to another, or a family may be living in temporary, crowded accommodation waiting for their own housing, and move several times over the course of a year.

“...Although the length of the service is an asset, it may be that some Aboriginal families require an intense service that is shorter in duration or flexible enough to be interrupted due to disruptive family circumstances such as funerals, housing, etc...”

18. The LAC to be one source of referrals but not the only one.

The LAC workshop participants generally felt that engaging with the Aboriginal community was a very complex and difficult task and that they often felt they lacked the knowledge, skills and time to do this effectively.

²¹ Access for Aboriginal and Torres Strait Islander People with Disabilities -Policy and Practice Plan April 2006

The LAC workshop illustrated the challenges LAC feel they face in relation to working effectively with families from Aboriginal backgrounds. LACs recognised the extra effort and cultural sensitivity required to engage effectively with Aboriginal families and expressed concern as to their capacity to commit this level of time (to families where there is often multiple systemic disadvantage) in the face of their other work demands. The LACs who had worked with Aboriginal families commented that the process of engaging successfully with Aboriginal families was very time-intensive and the issues that confronted these families were huge and complex.

Often disability was seen as a minor issue among the many problems confronting the family. Building a relationship with a family with multiple high order needs - such as poverty, lack of suitable housing, substance abuse, chronic health conditions, lack of transport - means spending time assisting the family to solve some of those issues before disability is even talked about. This may lead to the assumption that the LAC service is not relevant or needed by the family and so a relationship may not develop.

Specialist Aboriginal agencies are often supporting families with multiple issues which may include disability and challenging behaviour and they need to be considered as a possible referral source for the PBT.

“... Many Aboriginal families don’t have access to LACs and need to be able to access the service through networks that might be more relevant to their needs and who they trust...”

Themes common to CaLD and LAC workshops

19. Understanding how to use an interpreter.

The LAC group felt that they needed to have more awareness and information about the use of interpreter services.

The CaLD groups raised a number of issues that concerned families about the use of interpreter services. These include fears of loss of confidentiality and privacy, and having an interpreter who may have been on the other side in a civil conflict in their country of origin.

“...If a person (the interpreter) is from the same family clan or neighbourhood they may be seen as unsuitable as they potentially could spread gossip in the community about the family...”

Use of telephone interpreter services was seen as a positive option as it protected the identity of the family. The CaLD agency representatives recommended awareness-raising of the potential negative impacts of using interpreters and the need to consult with families and CaLD agencies prior to engagement of a service.

Suggestions made by each separate workshop group not listed in any of the groups above.

Themes raised by CaLD workshop

20. Having a better gender mix on the PBT team.

The lack of males on the PBT was seen as a possible barrier for men from Muslim backgrounds becoming involved in the service. The CaLD group stated that many Muslim men view the presence of another male as a sign of respect for their values, although their wives must only work with women.

21. Maintenance and follow-up essential.

The CaLD workshop identified this aspect as critical for their families. Many vulnerable families have poor family networks as often all extended family are overseas. Also, their community links with mainstream agencies, both non-government and Government, are minimal, with the exception of Centrelink and schools.

Developing a maintenance plan that is actually sustainable may take more time, effort, and work with specialist CaLD and Aboriginal agencies/contacts than the PBT model allows for. If the relationship with the LAC is weak or does not exist, then maintenance will not occur. The other part of this theme was the suggestion that PBT have some type of follow-up service after the family has achieved its goals and the PBT service has ended.

22. Modify the information/language in the family flyer.

The language in the flyer that is given to families needs to be simple and without jargon. Words that are everyday to people who work in the disability field, such as “psychology” and “partnership”, are not understood or have negative connotations and may frighten people away from the service.

”... The words psychology and mental mean that someone is mad or crazy and seen as very bad in the African community...”

“...The language used in the brochure around family breakdown might be very frightening ... these fears may put families off before they even start the service...”

“...Keep the whole flyer very simple with headings like, what we do; why we do it; how to contact us...”

Themes raised by the Aboriginal workshop

23. An informal and longer engagement period at the start of the service.

Aboriginal families find the formality of service systems difficult to deal with and will try to avoid contact with services that are overly formal in their approach

“...The referral and introduction to the service may be too formal for the Aboriginal community and yarning should be the way to start the process of possible referral and service ...”

The relationship is paramount to the acceptance of the service and without it there will be very little progress. Devoting more time to relationship-building at the start of the service through “yarning” (general conversations) should be considered as essential. Only when this level of engagement has occurred should there be an attempt, if any, to introduce the more formal aspects of the service such as written assessment tools, questionnaires etc.

“...Time needs to be long enough to give Aboriginal people time to feedback the information they want to feedback...this cannot be rushed...”

“...Families take information away and might come back to you later...Stay connected...make an effort to follow families up ...develop stick-at-it-ness...”

24. Having a holistic approach

The multiple complex problems facing many Aboriginal families require not just a systemic approach but a holistic approach to supporting them to manage challenging behaviours in a positive framework.

Issues of homelessness, chronic ill health, family violence, poverty, incarceration and unemployment of family members and caregivers impact greatly on a family’s capacity to care for and manage a family member with disability and challenging behaviour.

“...Be prepared to be flexible; part of this might be staying involved longer, being adaptable and working with families on issues other than the behaviour of the individual with a disability...”

Themes raised by the LAC workshop

25. Developing better working relationships between the PBT and LAC services.

The LAC workshop representatives believed this issue to be of great importance. They generally felt that they did not know enough about the PBT service to give families a good understanding of what it was and how PBT worked with families. The LACs stated the PBT referral paperwork was long and arduous. The combination of them feeling less than fully informed, trying to communicate with a family from a CaLD or Aboriginal background where clear, simple, and non professional language is essential, left them feeling that it was sometimes “just too difficult”.

In summary, in order to communicate effectively about a subject to a family where language and/or culture are a potential barrier, the LAC needs to have a very good understanding of the PBT service and processes. LACs would like to have closer working relationships with the PBT service from the start, at the point of consideration of a referral

“... A greater/better level of support from the PBT team in the referral process e.g. possible joint visits to the family home to discuss the service...”

26. Training for the LAC program to gain cultural knowledge/ competency skills.

The LAC workshop representatives believed that they could do a better job of the referrals for CaLD and Aboriginal families if their program had access to training which gave them skills and insight into how to better engage with and work with these families.

“... Some communities are closed to outsiders ...rarely do families come directly to LACs to tell them that they are experiencing difficulties...often families just adapt, learn to live with the problems ...until the problem reaches a new level ... (person commits offence and is imprisoned)...”

Very few referrals (two referrals) have been made to the PBT from the LACs for Aboriginal Families.

27. Greater clarity about what the service is for families, LACs and agencies.

There is a need to develop a range of strategies to improve the understanding of what the PBT service is and what it does.

This is especially important for families during the referral period. Suggestions included the use of stories about other families from similar backgrounds who have benefited from the service.

This would need to come from the PBT staff with consent from families who had received the service in either a written format (for the LAC and family), a verbal format where PBT worker talks directly with a family, or a DVD of a story.

Appendix 3

Positive Behaviour Team Substantive Equality Project Outline Statewide Specialist Services

Review of the Positive Behaviour Support Program from a Substantive Equality Perspective

Background:

It is proposed that the next Substantive Equality project be conducted within the Statewide Specialist Services Directorate. Statewide Specialist Services provides person/family-centred professional services and consultancy to people with disability, their families, carers, agencies and the community. Services are based on contemporary evidence based practice and aim to support each person's independence, inclusion and participation.

The project will review the Positive Behaviour Support Teams based in Myaree and Joondalup. The service has adopted a multi-disciplinary approach with team members drawn from a range of disciplines such as psychology, speech pathology and social work. The teams provide a range of specialist and intensive support using a Positive Behaviour Support model for people with disability who sometimes exhibit challenging behaviour, their family and carers.

Positive Behaviour Support is a model that is empirically-based, values driven and person centred. It aims to maintain/improve a person's behavioural repertoire, communication skills and to foster environmental conditions that promote choice, decision making and participation.

The review of the Positive Behaviour Teams from a substantive equality perspective has two stages. The first is to review procedures and practices to ensure they are culturally secure. The second stage is a review of the staff/client interface and aims to capture staff and client experiences. This will comprise a series of interviews with staff and clients.

Stage 1 Review of current procedures and practices

Stage one aims to review the current documents, policy, procedures and operations of the Positive Behaviour Teams to ensure that they are culturally secure and that they do not create any barriers to access for people from Aboriginal and culturally and linguistically diverse backgrounds. The Positive Behaviour Teams have recently undergone changes to the intake process which have emphasised the decision making role for LAC and potential clients in making a referral to the team. These changes will be examined to review the adequacy of the new process and to uncover any potential barriers or unintended consequences of this approach from a substantive equality perspective.

The project also proposes to explore the following areas from a Substantive Equality perspective:

Demographics

As part of background review, information on the population, sector and Positive Behaviour clients' demographics will provide a baseline to compare incidence of disability and PBT take up rates. The Sector Health Check (2007:75) stated that

“While the demographic and service usage statistics indicate that the proportion of Aboriginal disability service users is commensurate with the proportion of Aboriginal people in the Western Australian population, it would be misleading to conclude that Aboriginal people are accessing an equitable share of available disability services and funding. The demonstrated higher prevalence of disability in Aboriginal communities, backed up by significant anecdotal accounts of unmet need, clearly show that many Aboriginal people with disabilities are not having their needs met.”

Table below list the type of information required and the source of the information:
Table 1 Demographic information

Source	Type of information
Australia Bureau Statistics	Population distribution of CALD and Aboriginal and Torres Strait Islander background (Australia/ Western Australia/ metropolitan)
Annual Client Data Collection	Service users distribution of CALD and Aboriginal and Torres Strait Islander background (total service users (disability sector organisations and Commission)
Service Users Data Base	Positive Behaviour Clients' distribution of CALD and Aboriginal and Torres Strait Islander backgrounds (North and South)

This baseline can only be used as a broad indicator as there are no available statistics on the incidence of challenging behaviours in Aboriginal or CaLD families and any variation discrepancies in service take up will offer leads for further investigation rather than yielding definite conclusions.

Intake Process

As noted above, the intake process has recently changed. It is believed that the LAC program is in the best position to know local people and to work to improve access to professional services. It is proposed that the project examine this primary intake process in consultation with the Ethnic Disability Advocacy Centre (EDAC) and the Office of Multicultural Interests (OMI) as well as other organisations that are believed to be in a position to assist to provide relevant feedback. The aim is to ensure that the process for disseminating information to families, LAC and other services regarding the Positive Behaviour Teams is appropriately targeted and that the information is in a culturally appropriate form. It will also review the nature of information collected, how it is used to determine access and any cultural issues that may be involved such as cultural sensitivity in divulging information or cultural experience in dealing with government bodies. Actions include:

- Consult with EDAC and OMI in the development stage and in reviewing/exploring:
 - the information provided to LAC
 - the information LACs provide to families
 - the application/assessment forms
 - the prioritising or weighting system in referral management
 - alternative system for calling for referrals such as:
 - possibility of running forums with LAC and families
 - talking to Disability Service Organisations

- partnering with service contracting functions/forums to consumer and sector?
- o examine staff training and development needs.

Communication

Communication will involve a systematic examination of the current communication methods and materials provided to families by the Positive Behaviour Team. This will entail close involvement with the EDAC and other groups/organisations as appropriate in examining the family flyer to ensure that the materials and translations are culturally sensitive and appropriate.

Policy and procedures

Examine and review the policy and procedures relating to Positive Behaviour Teams to ensure they are culturally secure for CALD and Aboriginal families.

Service intensity

Service intensity for CALD and Aboriginal families can be captured by examining issues such as:

- Length of time the service is provided.
- Amount of time provided to the person/family.
- Provision of other services such as translation (materials and interviews) and equipment.

This data has the capacity to reflect any additional effort required to meet the needs of families with an Aboriginal or CALD background.

Staff skills

This stage will also involve a review of the current skills of team members and a review of cultural training that has been accessed with a view to making recommendations for future staff Performance Development Plans.

Stage 2: Review of experiences

This stage aims to capture current Commission and across government knowledge, trends and issues in culturally secure service delivery in order to build a culture of continuous learning.

This stage will examine approaches across government in terms of culturally secure practice as well as meet with individuals and families who have experienced support from the Positive Behaviour Team (North). This will involve:

- Consideration of publicly available material from other Departments.
- Discussion with identified officers from departments.
- Interviews with CALD and Aboriginal Families (self identified) regarding their experiences with DSC:
 - Families experience with the process
 - o Awareness of service
 - o Easy to find information
 - o Appropriate materials readily available
 - What did families think of the material provided
 - o Easy to understand
 - o Appropriate

- Accessible
- How was their experience with staff
 - Easy to understand
 - Sensitive to their needs
 - Approachable
 - Flexible
- Questions of interest such as what is working and how we can improve our services.
- Focus groups with Staff to discuss their experiences with working with families from CALD and Aboriginal background:
 - What happened
 - What worked
 - What didn't work
 - What to consider
 - What they would do differently.

Appendix 4

Interview questions for CaLD and Aboriginal families in the PBT service

1. How did you find out about the PBT service?
2. When information was provided to you by the PBT staff members about the service (written and verbal), how easy was it for you to understand? Can you comment on the language used, the questions asked by the staff, the paperwork provided to you (information and assessments)?
3. How well did you feel the staff understood your family's needs? Did they appear to be aware of your cultural and language needs?
4. What worked well for you and your family using this service?
5. Do you have any suggestions that you feel could improve the PBT service to better meet the needs of Aboriginal families/CaLD families?

Appendix 5

Interview Questions for PBT Staff.

In the context of working with families from a CaLD or Aboriginal background we are seeking staff experiences of the processes involved in delivering the PBT service (based on the document “Draft PBT Model of Service Delivery”).

Three over arching questions for all stages of the service model are:

- What is the current process?
- In your opinion, how well does the process work?
- In your opinion, could it work better to meet the needs of families from CaLD and Aboriginal backgrounds?

All other questions under the stages are prompting questions, if needed

1. **Referral** (question only for team leaders and managers) – what factors are taken into consideration when deciding on which families are given high priority?

Initial meeting with family

2. **Assessments** – how is information given to families? What information is given to families? What information do you need from families and how is it collected? Are the approaches currently being used working well? Do you have any suggestions that might work better?
3. **Systemic formulation** – How is this explained to families, appropriate agencies and the referral agency? How are the various systems brought together to develop the formulation? What role do they play in developing the formulation? What factors need to be considered in this process when working cross culturally – for example working with a Muslim school?
4. **Goals** –How well do you feel you understand the family’s “true” goals? Do you feel the process captures the “true” need of the family? What happens when the priority for the family is not the priority for the team?
5. **Development of the plan** - To what extent do the family’s cultural norms and practices influence or impact on the development of the strategies?
6. **Implementation of the plan** – What are the team’s expectations of the family’s roles in implementing the plan? What are the family’s expectations of the team members? To what extent does the family decide on its role and the role of the team? Is consideration given to what is culturally and professionally “OK”? How is this done?
7. **Review** - How is the review process explained to families? Who is involved in reviewing progress? Who decides? What factors are taken into consideration when reviewing progress?
8. **Maintenance** - Who reflects and why-how is this done? What benefits does it bring? How confident are the family/PBT staff/ other agencies that positive changes can be maintained?
9. **What further support/resources** may assist you to work more effectively with CaLD and Aboriginal families?

10. **Passing on your knowledge** - Do you have any suggestions for how the PBT could collect, maintain, hand on the specialist skills and knowledge that staff gain when working with CaLD and Aboriginal families?
11. **Is there anything else** you would like to comment on or say?

Appendix 6

CaLD Workshop - Substantive Equality Project -Tuesday 17th May 2011

List of CaLD agencies invited to SE workshop 17/05/11

- **Ishar Women's Multicultural Health Centre**
- **EDAC Ethnic Disability Advocacy Centre**
- **Mirrabooka Multicultural Resource Centre WA**
- **Centrecare Migrant Centre**
- **ASeTTS Association for Services to Torture and Trauma Survivors**
- **OMI Office of Multicultural Interests**
- **Multicultural Service Centre (North Perth Migrant Resource Centre)**

Agenda

1pm -1.10pm Working lunch

1.10pm-1.15pm -Welcome /introduction

1.15pm-1.35 pm- Introduction to Substantive Equality
(Equal Opportunity Commission)

1.35pm – 1.45pm Overview of Positive Behaviour Strategy

1.45pm- 2.15pm Positive Behaviour Team –background, model, evaluation and service access criteria

2.15pm -2.45pm Group work - Groups of no more than 5 people and 1 or 2 facilitators per group depending on numbers attending. Two questions to be addressed:

- How do you think this service model would work for the people you typically provide a service to?
- What suggestions/ideas do you have that could make this service more responsive to the cultural and linguistic needs of the people you typically see in your service?

Group Facilitators to take notes on butchers paper for the group and provide brief feedback to whole room after 25 minutes of discussion. Recorders and speakers can be participants if they wish to do this. Feedback to be only 2 main points for each question.

2.45pm – 3pm coffee break - afternoon tea provided -

3pm – 3.30 Positive Behaviour Team –Referral process and presentation of Statistics –

3.30-4pm - Group work (same format as 1st group) two questions:

- How well do you think this referral process would work for the people you see in your service /community?
- Do you have any other suggestions /ideas that could make this service more accessible to the people you typically see in your service/community

Reporting back after 25 minutes to whole room -2 main points for each question.

4pm -4.05 wrap up (including how we will feedback to participants) and thank you to participants

4.05pm close

Appendix 7

Aboriginal Workshop - Substantive Equality Project

Monday 23rd May 2011

Participants

Agency
Yorgum
Mid –West Metro Family Aboriginal Corporation
Kulunga Research Network
Royal Perth Hospital
DAFWA
Strong Families
Aboriginal Justice Program, Dept Attorney General
Uniting Care West
Dept of Education
Equal Opportunity Commission
DSC-Justice coordinator
DSC project officer
DSC

Agenda

Coffee/tea available on arrival

10am- 10.05am - Welcome /introduction -

10.05am -10.10am - Acknowledgement of Traditional Owners -

10.10am 10.30am - Introduction to Substantive Equality -
(Equal Opportunity Commission)

10.30am-10.45 -Overview of Positive Behaviour Strategy -

10.45am-11.15am - Positive Behaviour Team –background, model, evaluation and service access criteria -

11.15am-11.30am -

11.30am-12pm-Group work - Groups of no more than 5 people and 1 or 2 facilitators per group depending on numbers attending. Two questions to be addressed:

- How do you think this service model would work for the Aboriginal families you typically see in your service/community?
- What suggestions/ideas do you have that could make this service more responsive to the cultural needs of Aboriginal families in the metro area?

Group Facilitators to take notes on butchers paper for the group and provide brief feedback to whole room after 25 minutes of discussion. Recorders and speakers can be participants if they wish to do this. Feedback to be only 2 main points for each question -

12pm – 12.30pm - Positive Behaviour Team –Referral process and presentation of Statistics –

12.30-1pm - Group work (same format as 1st group) two questions:

- How well do you think this referral process would work for the Aboriginal families you see in your service /community?
- Do you have any other suggestions /ideas that could make this service more accessible to Aboriginal families living in the metro area?

Reporting back after 25 minutes to whole room -2 main points for each question-

1pm -1.05 wrap up (including how we will feedback to participants) and thank you to participants -

1.05pm -1.35pm

Appendix 8

LAC Workshop - Substantive Equality Project -Monday 30th May 2011

Coffee/tea available on arrival

10am- 10.05am - Welcome /introduction -

10.05am 10.25am - Introduction to Substantive Equality -
(Equal Opportunity Commission)

10.25am-10.35 -Overview of Positive Behaviour Strategy -

10.35am-11.00am - Positive Behaviour Team –background, model, evaluation and service access criteria -

11.00am-11.15am -

11.15am-11.45pm-Group work - Groups of no more than 5 people and 1 or 2 facilitators per group depending on numbers attending. Two questions to be addressed:

- How do you think this service model works /would work for the Aboriginal families in your district accessing the LAC service? CaLD families?
- What suggestions/ideas do you have that could make this service more responsive to the cultural needs of Aboriginal families in the metro area? CaLD families?

Group Facilitators to take notes on butchers paper for the group and provide brief feedback to whole room after 25 minutes of discussion. Recorders and speakers can be participants if they wish to do this. Feedback to be only 2 main points for each question -

11.45pm – 12.05pm - Positive Behaviour Team –Referral process and presentation of Statistics –

12.05-12.35pm - Group work (same format as 1st group) two questions:

- LAC has been the primary (and only) source of referrals to the PBT for the last 2 rounds. How well do you consider this referral process has worked or would work for you and the families in your district from Aboriginal and CaLD backgrounds?
- How do you think we could improve the out-reach of this service to urban Aboriginal families? Do you have any other suggestions /ideas that could make this service more accessible to Aboriginal families living in the metro area?

Reporting back after 25 minutes to whole room -2 main points for each question-

12.35pm -12.40.pm wrap up (including how we will feedback to participants) and thank you to participants –