GOVERNMENT OF WESTERN AUSTRALIA

Disability Services Commission

National Disability Services
WESTERN AUSTRALIA

Toward Responsive Services for All!

Understanding the WA disability service sector capacity to meet the needs of people whose behaviour can be challenging

Final Report

Project Team
Monique Williamson - National Disability Services WA (Project Manager)
Charlotte Howell - Hills Community Support Group
Leanne Pearman - My Place
David Rogers - National Disability Services WA

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Acknowledgments

This report represents collaboration between members of the project team, the project reference group, the Disability Services Commission and various project respondents.

Thank you to all project respondents, especially to the families and people with disability who were willing to share their experiences (particularly those whose experience has been difficult). This project has given us the opportunity to stop and reflect on what we are doing well and what is not working in relation to supporting people who are seen as having challenging behaviour. It has provided an opportunity to open up discussion, share experiences, highlight areas of concern and consider solutions.

We hope we have accurately captured your views and that this report will inform improvements in the disability service sector, so that there are 'responsive services for all'.

Project Reference Group

Tracey Delamere	Rocky Bay
Gerry Gibson	Activ Foundation
Jacki Hollick	Disability Services Commission
Ed Mayvis	i.d.entity.wa
Angela Moran	Therapy Focus
Cheryl Rogers	Valued Independent People
Adam Sullivan	Lady Lawley
Michele Thomas	Autism Association

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Executive Summary

In Western Australia, as with other states of Australia, some people with disability require particularly individualised (and at times intensive) disability support services due to behaviour that is challenging. Many examples can be given of improved quality of life for such individuals when we get service responses right. Some people require extreme diligence in relation to service strategies and may require short periods of more intensive supports throughout their life.

This project sought to investigate the current state of play in the Western Australian disability service sector in relation to providing services to people with disability whose behaviour is seen as challenging. The report was commissioned by the Disability Services Commission (Commission) as part of the Positive Behaviour Framework (PBF) initiative. The PBF was launched at a forum in the Boulevard Centre, Floreat, on Thursday 30 April 2009. The PBF was developed in response to Recommendation 51 of the Western Australian Sector Health Check on Disability Services in 2007. The PBF aims to 'develop a sector-wide strategy to respond to the needs of people with disability who sometimes exhibit challenging behaviour and their families and carers.[1]'

This project was undertaken by a small team of people led by National Disability Services WA. Information was collected from a range of stakeholders including people with disability, families and carers, service providers, peak bodies and government departments. A consultation paper was circulated electronically to key stakeholders. Respondents could complete the consultation paper and return it or attend a focus group meeting. Some stakeholders were directly approached and interviewed. The information collected was analysed to identify key trends and common themes. These themes were collated and validated through the project team and reference group. An interim report was circulated to provide stakeholders with a final opportunity to comment.

This report also includes a summary of past capacity building initiatives. The main strategy in recent years was the Commission's Challenging Behaviour Consortium.

It is clear that there is work to be done to improve the disability service sector's capacity to meet the needs of people with disability whose behaviour can be challenging. Service provider respondents provided insight into their own struggle (and guilt) when having to refuse or discontinue services for individuals. There was a view that better matching of individuals to appropriately equipped service providers, particularly in relation to accommodation services, could reduce the number of support service arrangements that fail. In some cases, urgency was believed to be driving inappropriate matching of individuals to services.

[1] Disability Service Commission (March 2009) Positive Behaviour Framework p3.

Prevention was raised as a primary issue requiring greater attention. Two key questions were identified for further deliberation.

What early investments could reduce the likelihood of poor outcomes later?

What family support services could be put in place to ensure people can remain with their family as long as possible?

The major project findings included:

- **Impact on individuals**
  This report is about people. Understanding people including how they communicate, their general health and wellbeing, and what is important to them, is at the heart of good support services.
- **Issues for families**
  Of concern throughout the consultation was the experience of some families who could not get family support services including respite, because of their child's behaviour. Services that were willing to develop individualised respite support services for children experiencing particularly difficult periods of behaviour, felt under resourced and under supported to do so. The way services are provided must respect the wisdom and experience of families.
- **Complexity related to multiple diagnosis**
  Disability services reported significant challenges in getting additional support for people through the mental health, justice or drug and alcohol systems. Issues identified included a critical shortage of timely and effective psychiatric services, people getting caught up in the justice system with poor outcomes due to limited sensitivity and understanding of issues related to disability, and limited support for people with disability and drug and/or alcohol addictions.
- **Disability service infrastructure**
  Problems exist within current disability services infrastructure particularly non government services. These included a lack of creative service design, recruitment and retention of staff with a resilient and positive attitude, supervision and support to staff, developing an optimal service culture, appropriate service environments, managing industrial relations and risk, providing structured environments, ineffective funding allocation tool and access to profession staff.
- **Interdisciplinary professional behaviour teams**
  These teams play an important role in supporting service capacity. Current access to these services is not timely.
- **Restrictive practices**
  There are differing levels of understanding and use of policies in relation to restrictive practices across the sector.
- **Issues for regional and remote services**
  Regional and remote disability services reported challenges in accessing timely and effective behaviour support. Access to professional development and training opportunities is limited. All of the issues related to shortages of effective psychiatric services are intensified in regional and remote areas.

- **Lack of Collaboration and Coordination**
  Service providers and families spoke of frustration when certain important information was not shared amongst stakeholders. There were also examples cited of a lack of collaboration and /or case management across government departments.

Finally, this report suggests a way forward by making main proposals, and several suggested sector capacity building initiatives, against each of the findings. These proposed solutions are presented in tables throughout the report.

This report provides insight into the current capacity of the disability services sector. It suggests many services require significant support including information, resources, access to professional support staff and professional development to improve their capacity in this area. It highlights a group of services who have developed their own capacity in this area. Yet surprisingly, these services report that they struggle to sustain their capacity and require ongoing support and resources to maintain and improve positive outcomes.

Behaviours that are challenging are likely to create distress for the person, family and/or carers, support staff and organisations. This is not an area that lends itself to quick fix solutions. The development of service capacity is not likely to involve one-off short-term strategies; rather an ongoing targeted investment and attention to the issues will be required. Some of the solutions to issues raised will be across sector and policy driven, whilst other strategies should be targeted and applied on a case by case basis. Any strategies applied should be well considered and evaluated to ensure that the best outcome is achieved for the disability service sector and particularly for people with disability and their families.

Proposals

1. Family support services
It is proposed that the sector's future direction should involve consideration and development of proposals for responsive and tailored family support options for people with disability who may have episodes of intensive behaviour and cannot obtain services in existing organisations. Families under particular stress ought to be able to access a service that does not refuse or shorten the service period.

2. Improve mental health outcomes
It is proposed that future directions for relevant agencies and the disability sector should involve investigation and development of appropriate strategies to improve the mental health outcomes for people with disability in the following three areas:

- access to timely and responsive treatment for people with disability and mental illness
- access to support in acute crisis situations that promote intensive intervention models whereby the person is able to remain in the least restrictive environment

- promote research, expertise and information in relation to the impact and treatment of mental illness in people with disability.

3. Development of best practice service principles
It is proposed that future directions for the Commission in partnership with disability sector organisations involve development of best practice service principles in Positive Behaviour Support including a list of service attributes in relation to supporting people whose behaviour is seen as challenging. These underpinning principles and attributes can be used to evaluate individual service capacity and targeted service development strategies.

4. Flexible and timely funding strategy
It is proposed that the Commission in consultation with the sector continue to review and develop funding streams that acknowledges that support levels can fluctuate significantly for some individuals over time. A person centred approach, whereby the resources can taper off over time as the person's situation is stabilised, should be considered.

5. Targeted sector development
It is proposed that future directions for the Commission and the sector involve working together to develop strategies, which may include the prioritisation of targeted resource allocation, to support services to develop and maintain the infrastructure required to provide responsive services to people whose behaviour can be challenging. This infrastructure would include:

- ongoing investments in workforce
- development of service culture
- staff stability and consistency
- staff supervision
- professional advice
- individualised service design
- training and professional development.

6. Interdisciplinary teams
It is proposed that support to disability sector organisations through interdisciplinary behaviour support teams is expanded by

- extension of the available hours of the current behaviour support helpdesk
- expansion of the positive behaviour team model into disability sector organisations to ensure optimal outcomes are achieved, based on ongoing evaluation and evidence based practice.

7. Disability sector policy and guidelines
It is proposed that future directions for the Commission in partnership with disability sector organisations involve development and promotion

of guidelines to facilitate better standards and consistent practice in such areas as restrictive practices, medications policies, organisation's behaviour policy and positive behaviour support practices.

8. Regional and remote services
It is proposed that partnerships with regional and remote disability sector organisations and the Behaviour Support Consultation Team be considered to explore targeted cost effective solutions to improve capacity in rural and remote areas on a case by case, region by region basis and that pilot projects are encouraged.

9. Across-government Collaborative Responses
It is proposed that key stakeholders investigate, apply and evaluate strategies to improve outcomes for people with disability who are in complex situations that require across government responses (eg the People with Exceptionally Complex Needs (PECN) project).

1. Introduction

Challenging behaviour is a concept that is often used in the discourse of disability. It is a broad concept and can be used to describe a range of behaviour. The terminology can also be used to label individuals. At times the label can pervade a person's reputation. It is a concept that is relative, determined by the interpretation of the person using the label. Clearly, experience tells us that there is a correlation between disability and maladaptive behaviour. This can be expected as disability may impact on a person's functioning and capacity to communicate, therefore resulting in frustration and use of behaviour to get a message across. It is important to be clear about what we mean by challenging behaviour. In this report, it tended to be used to describe behaviour such as violence towards self and or others, anti social and/or illegal behaviour. However, in terms of this scoping project, defining the behaviour matters less than understanding the ability of services to provide effective support to the people with the behaviour. When provided with adequate resources, such as professional advice, health and mental health services, the disability service system should be able to adequately provide support to any individual with disability.

This project seeks to understand the current capacity of the Western Australian disability service sector to adequately support people with disability whose behaviour, at times, is identified as challenging particularly in providing quality, responsive individualised services for these people. It is part of a broader initiative, the 'Positive Behaviour Framework', and aims to inform the development of future strategy to improve the capacity of the disability sector to provide services to people whose behaviour can be seen as challenging. Disability services for the purpose of this project, refers to Commission funded and provided services in Western Australia. This could include accommodation, social participation, respite services, therapy services and/or intensive family support.

Implicit in the rationale for this project, is an assumption that the disability service system does not have sufficient capacity to support some people whose behaviour can be seen as challenging. This was validated during the consultations. For example, in some cases:

- people with disability are refused continuation of services because the organisation is not adequately prepared, resourced or structured to provide support to the person during times of intensive and frequent behaviour
- individuals and families are refused access to family support services such as respite, due to a person's behaviour
- people are in service arrangements that are considered by project respondents as restrictive environments and not conducive to good outcomes
- medication may be over relied on as a means to control behaviour rather than other strategies to improve a person's situation and reduce behaviour.

This report provides insight into the current capacity of the disability services sector. Project findings are reported in themes and are supported by potential capacity building strategies. It gives an overview of efforts to improve capacity over recent years, particularly the challenging behaviour consortium. Finally the report makes comment on potential priority areas and a way forward for improving the disability sectors capacity to support people with disability who have behaviour described as challenging.

2. Project Methodology

The project methodology included:

1. Defining evaluation criteria
The first stage of the project was to define the elements and practices that give services capacity to support people with challenging behaviour. The notion of 'disability service sector capacity' is underpinned by a set of beliefs about what constitutes best practice in supporting people who are seen as having challenging behaviour. These elements were arranged into a set of criteria against which data and information collected could be evaluated. The elements were validated by the project reference group.

The elements of best practice include:

- Authentic focus on the individual – understanding who they are, what matters to them, how they communicate, their health and wellbeing, what their aspirations are and what areas they want and/or need support in.
- Flexible and creative individualised service design – service strategies are creative and flexible and respond to the individual and focus on:
    - Engagement and developmental opportunities – services provide opportunities for a person to be active, engaged and learning.
    - Provision of choice and control – structuring the service in a way that maximises opportunities for choice and control.
    - Maximises involvement of family and friends.
    - Focus on communication – strategies are used to facilitate and promote the persons communication.
    - Good matching of person with housemates and/or support staff.
- Service culture that is positive, promotes optimism and resilience.
- Support staff, particularly a positive attitude and person centred practices.
- Team consistency – there is consistency and strong sense of team work.
- Support for staff – including adequate supervision and access to professional support, where required.
- Physical environment – promotes comfort and safety.
- Organisations policy and practices – promote positive behaviour practices.
- Professional support is available as required.

2. Data collection
Information was gathered, including a summary of current practices, comment on gaps against the evaluation criteria and examples of stories where services have worked (or not worked) well for people with challenging behaviour.

Data collection methods included:

- A general call for submissions/comment circulated widely through email networks including Commission funded agencies, peak bodies and reference group networks.
- Several focus groups and interviews with key stakeholders (see Appendix 1). Key stakeholders included:
    i. People able to comment on overarching sector wide trends – such as Commission service contracting and development officers, peak bodies, standard monitors and policy staff.
    ii. Disability Services Commission – executives and managers, staff working with people with challenging behaviour and training coordinator.
    iii. Families and people with disability.

- Review of Past Program Initiatives – specific strategies tried to date, outcomes achieved.

3. Analysing data

The data collected was integrated and analysed to identify key trends and common themes. The themes were those issues that were raised by more than one stakeholder group. The themes were collated and validated through the project reference group. The reference group met for several hours to consider each of the themes and the descriptions applied to the themes by the project team.

4. Stakeholder review

An interim report was circulated widely through email networks including Commission funded agencies, peak bodies and the networks of the reference group. Feedback and comment received was incorporated into the final report.

5. Development of proposals

The project team developed proposals and suggested capacity building strategies. These were circulated to the reference group for comment and refinement.

3. Key findings

There is a need for multi layered and comprehensive strategies to improve our current capacity to effectively support people with disability particularly those with intensive and frequent periods of difficult behaviours. As one respondent suggested 'there is no silver bullet, solutions require an ongoing commitment to get things right and keep things right, for each individual'. For these individuals, support services need to be particularly proactive, responsive, consistent and individually tailored. People need to be known and understood on a deep level to find out what purpose a particular behaviour serves. Similarly strategies to improve the person's situation need to be creative, focussing on both short term strategies and long term approaches.

1. Impact on individuals

People with disability, that sometimes (or often) have behaviour that is considered challenging, are significantly impacted on when our disability service system is unable to establish effective responses to their support needs. Some people end up with particularly poor outcomes that further impinge on their quality of life. Misunderstood, not understood, labelled, physically and/or emotionally harmed and marginalised are words that aptly describe the experience of some individuals.

In some cases, project respondents spoke of a focus on containing the behaviour rather than trying to understand the reason for the behaviour or a deeper understanding of the person. Refreshingly, the project team heard many success stories, where individuals after years of significant turmoil, including being shuffled between prison, mental health facilities and disability services, were able to get support services structured in a way that worked for them and therefore stabilised their life. Similarly while many disability services struggle to get services right for some of these individuals, there were a few service providers who were still willing to work around the real and perceived challenges, and to stick by people even when situations become difficult and resource intensive.

While this project is about understanding the disability service sector's capacity to support people who may have challenging behaviour, (with a focus on both systemic and service issues), the essence of this report is about people. Any gaps in the disability service system have a cost to individuals, many of whom may already be extremely vulnerable. Throughout the consultation, the project team was reminded that people need to be seen and respected as individuals, rather than a primary focus on their disability or their behaviour. Services, and particularly support staff, that focus on the strengths of the person and genuinely see their potential, were seen as more likely to achieve better outcomes.

Suggested strategies from project respondents that could improve outcomes for individuals include:

- Relationships: the importance of intentionally building a natural support network for people who are seen as challenging should be a primary

focus. We heard cases of people who were quite isolated and relied on only paid staff and sometimes due to staff turnover were supported by staff who did not know them well.
'People with good freely given relationships stick around when formal services cannot cope and offer support to family members in a way which formal services can't.' Project Respondent

- Communication: there are many examples where behaviour can be traced back to a means of communication. In many cases improving communication for a person who has limited functional communication can improve what is seen as challenging behaviour. Accessing good professional support such as speech pathology can be costly for people with disability and/or families where they are left to pay for this out of their own resources.

- Health and Wellbeing: it is important that medical ailments are ruled out. The reason a person may be exhibiting a seemingly challenging behaviour may be linked to an unrecognised medical condition such as an earache, tooth ache or urinary tract infection. There are acknowledged short falls in the current generic health system including General Practitioners' inexperience with people with disability, as well as limited time for thorough consultations or a lack of an individual's or support staff's ability to communicate symptoms[2]. Ongoing strategies to ensure a person's general health and wellbeing are optimised will be an important strategy to improve and minimise incidents of challenging behaviour.

Suggested capacity building strategies

1. Disability service leadership and culture development - such as training, professional development and mentoring to ensure services focus on the strengths of the person and genuinely see their potential, especially when supporting people seen as having behaviour that is challenging.

2. Sharing of success stories – across sector sharing of success stories so that people can learn from what works. This may also keep people focussed and build resilience when things get difficult.

3. Enhancing services capacity to intentionally build a natural support

[2] Melville, CA, Cooper, SA, Morrison, J, Finlayson, J, Allan, L, Robinson, N, Burns, E, & Martin, G (2006), 'The outcomes of an intervention study to reduce the barriers experienced by people with intellectual disabilities accessing primary health care services', Journal of Intellectual Disability Research, Vol. 50 (1) pp 11-17
Lennox, N & Edwards, N (2001), Lessons from the Labyrinth Views of Residential Care Officers on Barriers to Comprehensive Health Care for Adults with an Intellectual Disability. Developmental Disability Unit, School of Population Health, The University of Queensland. Report to Disability Services Queensland

network – strategies and skills in the promotion and development of natural support networks and relationships building particularly where people with disability have limited unpaid relationships. In some cases, broader use of strategies such as citizen advocacy and public guardianship could also be promoted.

4. Improving communication – better investment in strategies that promote the improvement of communication for people with disability that have limited functional communication. This could include better access to speech pathologists, access to assistive technology, training and professional development for staff and families in regard to facilitating communication.

5. Enhancing general health outcomes – advocacy, training for support staff, and strategies such as annual health assessment, development of good relationship with General Practitioners and pharmacist and other strategies should be promoted and applied to improve health outcomes for people with disability.

2. Issues for Families

2.1 Lack of Family Support Services

It became apparent throughout the consultations that there are some families who are unable to get family support services, particularly a break from the caring role through services such as respite. Existing disability services within their current infrastructure, in some cases, feel unprepared and are unable to provide a service because of the person's behaviour. For some families this was compounded by children being regularly sent home and/or suspended from school. Due to the limited scope of this project we were unable to determine the extent of this situation. However anecdotal evidence suggests that this is the reality for more than just one or two isolated cases. These issues tended to involve young adolescents with autism, who also had frequent periods of intensive behaviours. Some of the shortfalls in the education system, as perceived by project respondents included inexperience of teachers, school psychologists and other staff in teaching/supporting people with challenging behaviour.

Some reported children being regularly sent home and/or suspended from school. This was the case in both metropolitan and regional Western Australia. The education department policy is that all children will have access to schooling. In practice, on a school by school basis, this appears not to be the case. Protection of staff and other children, industrial relations and lack of access to effective interdisciplinary teams were cited as reasons for the current situation.

It was suggested by some respondents that in some cases restrictive practices are relied on to control behaviour in some educational environments.

The reasons why disability services, particularly respite services, are unable to provide support services to some individuals with challenging behaviour are varied. They include:

- the lack of competent support staff
- lack of resources to meet the individualised service strategies required by the person/family
- risks to staff and other people who use the service
- limited access to, or guidance from, professional staff or professional behaviour services
- general inexperience in designing specific services during periods when the person's behaviour is problematic or at its worst.

It does not tend to matter to families why services refuse support or call early for them to retrieve their child, as this is less important than the rejection and frustration the family and the child may experience. One family member stated that whilst they don't blame the services for not being able to provide a service to their family member who was challenging, they did feel abandoned by them. This can have a subsequent effect on the extended family, where sibling relationships may break down due to the main carer being unable to 'have a break' and nurture other family relationships. The Disability Services Commission is considered to be the 'provider of last resort' for accommodation; however it appears that no such service provider exists for family support services such as respite.

In cases where respite is block funded, some respondents suggested that it fails to account for the extra resources that may be required to support people who are seen to have challenging behaviour. For example, respite services are expected to meet a level of output[3] hours for money received. The extra resources and infrastructure required to provide effective support services to families and children, where the child may have periods of challenging behaviour is not funded through the current block funding methodology.

Would output hours that acknowledge the additional resources required by services, (when respite is provided to people seen as having challenging behaviour), lead to an incentive for service providers to develop skills in this area?

One respondent suggests the development (or extension of) expert support staff with the capacity to work with families at short notice in times of crisis, similar to the crisis care service that exists through Perth Home Care Services.

'The Crisis Care Support Service offers short-term emergency support for the main carers of people who are frail aged or have a disability in the event of critical illness, carer's stress or any other urgent incident.

[3] Output hours in this case means a service gets an amount of funding to provide so many hours of respite service over a year.

> This service is specifically for those incidents that occur without warning and result in the main carer being unable to continue to care for their family member.
>
> Crisis carers can provide support in the home for up to three consecutive days. Often, less than 24 hours support is required, and sometimes morning and evening services over a few days are able to meet the clients needs.'
> Source: www.phcs.org.au/page/Services

Families and other stakeholders suggested that there is a need for new models of support services, rather than a reliance on out of home respite, for some people with challenging behaviour, as it does not work for some individuals who can return home particularly distressed by the change in routine and environment. There may be a strong case for an individualised approach for some people who are very sensitive to change. For example, some people may rely on a small number of people they trust to provide support. Therefore some respondents suggested there may be a case for allowing family members such as an aunty to provide paid support in some situations.

2.1.1 Access to professional staff for respite services – there appears to be a strong case for funding professional services for some respite services, particularly larger services willing to work with children/adolescents at times where challenging behaviour is an issue. One provider is currently investing in the skills of a psychologist who is available to support staff and is on call if significant crises arise. This was seen by this provider as a critical component of making their services work for people that other services may have refused. The willingness of this service to work with children and adolescents when other services could or would not was acknowledged by many throughout consultations. However, it is an ongoing issue, internally, finding resources to maintain such positions even though they are seen as fundamental to the services' capacity.

It is critical that service capacity is increased through creative, individualised analysis and targeted investment particularly in the area of specialist services. Service capacity solutions could be considered on a case by case basis rather than a blanket policy across the sector such as 'not funding professional services in the area of respite'.

2.2 Respect for Families

The role of families and carers, as one of the primary stakeholder in many situations, needs to be acknowledged and validated. Where families require support, information and guidance to understand and improve their child's quality of life and behaviour, this should be provided in a way that respects their wisdom and promotes the independence and power of families to own such support, information and guidance. Families need to be supported in a way that sees them as the solution not the problem.

Strategies that build family confidence, resilience and tolerance should be a primary focus. The diversity of parenting styles and family functioning, as well as the cultural family context, should be acknowledged and respected. While there may be isolated cases where a child is at risk because parenting or family function is of significant concern, most families and parents are likely to be the best judge of what support they require.

One parent in responding to the interim report validates this issue as follows: 'The report outlines many issues that parents, not unlike ourselves, face on a daily basis. I congratulate those involved in documenting so accurately the issues faced by people with disability and their families and friends.

Family leadership in this area is crucial in designing a response for each individual involved. Service providers and the sector will not have all the answers to such complex issues. Families and the people facing these challenges must be at the centre of any decision made in relation to support provided. Authentic partnerships between those that have all the control (the sector) and those who typically have the answers (people with disability, their families and friends) need to be established. The principles related to co-production could play a significant role in designing an outcome for these complex issues.'

Where the person is no longer living with the family and/or is an adult, in most cases the family is still likely to be an important stakeholder. They will require ongoing information and may want to be able to influence service design and the health and wellbeing of their family member. It was suggested through the consultations that more work needs to be done to ensure the Carers Recognition Act 2004 is fully promoted and honoured in service models and practices.

2.3 Out of Family Care

There were issues raised in the consultation process regarding children who have periods of intense challenging behaviour where families believe the risks to other family members, particularly other young children are too great. This can result in families no longer being prepared to have the child in the family home. These decisions can be devastating for families and complicated by a system that is not sympathetic to such cases. It was suggested that the current Disability Services Commission policy position is not sufficiently responsive to children who for a variety of reasons cannot remain in the family home.

The Disability Services Commission has developed an emergency accommodation program for young people. This stops children being co-located with adults if they require emergency accommodation. More preventative work needs to occur, such as pilot family support services to avoid a reliance on emergency accommodation care. Other factors such as children's access to regular schooling and family's access to family support services such as respite should be improved to ensure that the need for permanent accommodation services is avoided, where possible.

Some project respondents suggested a need for more collaborative family and person centred practice from both the Department of Child Protection and the Commission, in some cases. Where families are under significant pressure and turmoil and are struggling to maintain the family unit as a result of a child's behaviour, some respondents suggested that the family can be treated as if they are neglecting or abusing their child rather than not coping.

Commission Local Area Coordinators (LAC) can play a critical role in supporting families and people with disability. It was suggested by some respondents that LAC, in general, need better access to information on contemporary strategies and services to support families who have a child whose behaviour can be challenging. The LAC is often the first contact for families who require assistance. LAC may benefit from more targeted information regarding positive behaviour support strategies and how to assist families in this area. There may also be benefit in developing a generalised resource that provides information on the services and supports available to families.

There are obviously some families who require ongoing and additional support to continue to care for their child, due to episodes of significant behaviour that are challenging. In these cases models such as access to 24/7 specialised LAC or professional staff may be of benefit. For example, one family member spoke of her frustration in wanting real help, yet all she got offered was a cup of coffee – not 'real' support.

Proposal 1. Family support services
It is proposed that the sector's future direction should involve consideration and development of proposals for responsive and tailored family support options for people with disability who may have episodes of intensive behaviour and cannot obtain services in existing organisations. Families under particular stress ought to be able to access a service that does not refuse or shorten the service period.

Suggested capacity building strategies

1. Family support service Innovations – develop and pilot innovative models of family support services, with a focus on services that reduce the distress on some individuals by the change in routine and environment.

2. Professional services for some respite services – where there is a case and proven outcomes, fund professional services such as psychologists to enhance the capacity of respite services.

3. Improving education outcomes for children – the education system needs to explore ways to improve education outcomes and consistent schooling for children with disability who at times have behaviour that is seen as challenging.

4. Family/carer centred services – sector development through professional development, advocacy, and quality assurance to ensure family centred practice and culture.

5. Carers Recognition Act 2004 – the Carers Recognition Act should be promoted and compliance monitored.

6. Specialised support for some families – pilot models such as access to 24/7 specialised LAC or professional staff for families who require ongoing and additional support to continue to care for their child, due to episodes of significant behaviour that is challenging.

7. Family leadership – strategies such as information, advocacy and mutual support networks to foster and promote family leadership.

3. Complexity related to multiple issues/diagnosis

3.1 Lack of timely and effective psychiatric services

It is important to note that many people with disability, whose behaviour can be challenging, do not require psychiatric services[4]. Challenging behaviour may be a result of a number of factors, one of which may be an underlying mental health condition. Where this is the case, there are a number of acknowledged shortfalls in the mental health system including:

- Lack of expertise in diagnosing and managing dual diagnosis such as developmental disability and mental health problems[5].
- Lack of evidence on preventative strategies in people with intellectual disability[6].
- Inadequate screening and early detection and monitoring of mental health status in people with intellectual disability[2].

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[4] Allen, D. and Davies, D (2007). 'Challenging behaviour and psychiatric disorder in intellectual disability' Current Opinion in Psychiatry. Philadelphia: Vol 20 (5); p450

[5] White, P, Chant, D, Edwards, N., Townsend, C, and Waghorn, G (2005). 'Prevalence *of* intellectual disability and comorbid mental illness in an Australian community sample.' Australian & New Zealand Journal of Psychiatry. Vol 39 (5), p395-400.

[6] Yen, C-F, Loh, C-H and Lin J-D (2009). 'Prevention of mental health problems in people with intellectual disability.' Current Opinion in Psychiatry. Philadelphia: Vol 22 (5); p 447.

- Lack of an evidence base on use of medication used to treat mental illness in people with intellectual disability[2].

These shortfalls are resulting in particularly poor outcomes for many people with disability who seek psychiatric services.

3.1.1 Lack of specialised psychiatric professionals

There is a problem for many people who may benefit from (or desperately require) effective psychiatric services, in accessing these services in a timely manner. There appears to be both problems with a shortage of psychiatric professionals who have expertise in supporting people with an existing developmental disability or acquired brain injury, and in some cases the costs associated with this support. It was suggested that in more complex cases, such as where a person has no or limited English language, the outcomes of the public mental health system can be particularly poor.

Problems with getting timely psychiatric services were raised relatively consistently throughout the consultation period by a number of stakeholders. This issue is significantly compounded in regional and particularly remote areas.

It was reported that one disability service provider in WA holds a clinic with a consulting psychiatrist one and a half days a week. While this strategy supports the development of expertise and improves access, they reported that one and a half days is insufficient to meet demand.

During the consultations, an example was given of a multi disciplinary approach to supporting people with disability who also have mental health problems that were employed in another state in Australia. One element of this approach that was regarded as successful was the inclusion of specialised psychiatric nurses with high-quality skills in developmental disability and mental illness and pharmacology. These nurses can be an important part of a multi-disciplinary team for some individuals.

It was reported that the Commission's Accommodation Support Directorate was appointing a psychiatric nurse to improve the outcomes for people requiring psychiatric support in this service. The nurse can provide a consistent view and provide a conduit between disability and psychiatric systems. This type of strategy may be of benefit more broadly.

It is important that disability support staff are provided with information and training regarding mental health. This could include such training as 'Mental Health First Aid'.

3.1.2 Over-reliance on medication

Some people clearly require medication to stabilise or improve a psychiatric or neurological condition. However, medication should be a part of a comprehensive strategy to improve a person's quality of life rather than the primary instrument to control behaviour. This scoping project did not undertake an analysis of medication usage by individuals, yet concerns were

expressed throughout the consultation project on the primary use of medication as a means to control behaviour. This in part is a reflection of the lack of a systematic evidence base and the expertise to guide general practitioners and other professionals in this area. Recent research regarding the use of psychotropic medication to decrease aggressive or challenging behaviour in people with intellectual disabilities recommends limiting these medicines to severe or emergency situations[7].

Where medication is prescribed, interviewees gave examples of the reactions to some prescriptions or the problematic interaction of medication for some individuals. Some examples were described of people suspected of being on the wrong mix of medications; however safe environments to reduce and cease medication, whereby the person's wellbeing could be adequately monitored by health professionals, are not easily accessible. For one service provider the solution was a public hospital with the disability service provider providing around the clock care.

Where strong medication is prescribed on a PRN (as needed) basis some respondents suggested that support staff can rely on this, in some cases, without looking at other strategies to prevent behaviour and improve the person's situation. The development of policies, practices and support staff supervision was described as a strategy to improve this situation.

It was suggested that some organisations need to have better practices in place to ensure people with disability are adequately supported to provide full information to ensure general practitioners, psychiatrists and neurologists are fully informed and have reliable information on which to base their recommendation for medication. In accommodation services this could include senior staff or supervisors always attending appointments or using information recording strategies to improve consistency. There were concerns raised with the lack of communication between the GP and other specialists such as psychiatrist, in some cases.

3.1.3 Psychiatric emergency situations

The consultation revealed several examples of acute situations, such as high levels of distress and/or violence against self, property or others, where disability services and support staff felt unprepared and under supported in community based services. In these cases police, ambulance and/or the Psychiatric Emergency Team (PET) (now replaced by the Mental Health Emergency Response Line and the Community Emergency Response Teams) are usually called to assist support staff.

It is worth noting that a preventative or early intervention approach, whereby designing and resourcing services that are supplemented by effective and timely psychiatric support for each individual, could be provided to avoid major critical incidence for these individuals.

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[7] Walling, AD (2008). 'Do Antipsychotics Improve Behavior in Patients Who Are Disabled?' American Family Physician. Leawood: Vol 78 (9); p 1090.

There was a view that removing people from their home and providing treatment in secure psychiatric facilities is not working. People tended to regress when put back into their home environment. Yet respondents suggest no other solutions exist when people are in crisis. The experience of many respondents is that generic mental health services rarely have experience working with people who have a dual condition such as developmental disability and mental illness.

There is a view amongst some prominent researchers in the area that mainstream mental health services do not meet the needs of people with intellectual disabilities. They suggest improved specialist clinical services and more clinical training opportunities are required[8].

Other stakeholders suggested more flexible use of funding to allow specialist services to be purchased through, for example, accommodation funding, in some circumstances.

There are intensive intervention models that have been piloted and evaluated internationally[9]. These approaches provide specialist teams to support individuals in their own environment, where possible.

Two important questions require further deliberation.
How can we strengthen the generic mental health service system to better respond to the needs of people with dual diagnosis?
Is there a place for specialist psychiatric professionals in the disability service sector?

3.2 Justice system

People with disability, whose behaviour can result in a criminal offence, such as assault and/or sexual offences etc, provide particular challenges for our service system. Developing services that support people to stay out of the prison system or transition people already incarcerated out of the prison system requires thoughtful approaches tailored to each individual's circumstances. Issues such as housing and employment as well as recruiting competent support staff can limit successful outcomes.

Where people do commit offences, the consultation process included stories where local police worked well with disability services, mostly due to the relationship built by individuals in the local station. On the other hand, stories were also told of very difficult situations where police were at a loss to know how to approach or respond to the person with disability.

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[8] Torr, J, Lennox, N, Cooper, S, Rey-Conde, T, Ware, R, Galea, J and Taylor, M (2008). ' Psychiatric care of adults with intellectual disabilities: changing perceptions over a decade.' Australian & New Zealand Journal of Psychiatry; Vol 42 (10), pp 890-897.

[9] See Donnellan, AM, LaVigna, GW, Zambito, J, & Thvedt, J (1985). 'A Time-Limited Intensive Program Model to Support Community Placement for Persons with Severe Behavior Problems.' The Journal of the Association for Persons with Severe Handicaps. Vol 10 (3) pp 123-131.

One respondent provided insight into the prison system for people with an intellectual disability. While prisons provide confinement they also provide rigid routines and consistency and people can become reliant on this structure. It is critical that this is acknowledged and compensated for, when planning release programs for these individuals to reduce recidivism.

The recent review of the Disability Services Act 2003 included the discussion regarding custodial powers for the Commission[10].
'It should be noted that the Ministerial Review of the Disability Services Act Report (June 1998) cautioned strongly against the Commission taking on custodial duties and suggested the Act may need to be modified to safeguard against such an eventuality…'

There is also a danger of such a power leading to a loss of rights and due process for people with disability, as it may become convenient for all police and judicial systems to divert all manner of cases to the Commission.

Follow-up submissions to the Interim Report have been largely supportive of the status quo; however submissions from the WA Police, Department of Corrective Services and the Office of the Public Advocate supported further consideration of the provision of custodial powers. It was noted that this issue had only been canvassed in the Discussion Paper as a result of it being a matter considered in another jurisdictions' legislative reviews. There has been no advocacy from people with disability, carers or disability advocacy agencies for such powers.

This is, however, a complex matter that has been the subject of much consideration over recent years. It is not appropriate given the time-frame of this review and the terms of reference and composition of this Steering Committee to further this discussion within this report. The Commission enjoys a good working relationship with the WA Police, Department of Corrective Services and the Office of the Public Advocate and shares many opportunities for cooperative policy and program development. These include the current drafting of the new Criminal Law (Mentally Impaired Accused) Bill 2008.

Some respondents suggested that this debate should be continued.

While some programs have resulted in improved outcomes for people with disability in the justice system, issues remain.

3.3 Drug and alcohol services

In cases where a person has a disability and drug and alcohol problems or addiction, service providers report challenges accessing support with these

[10] Disability Services Commission (2009) Review of the Disability Services Act 1993. Ministerial Report to Parliament in accordance with Section 57(5) of the Act. Available at:
http://www.disability.wa.gov.au/DSC WR/_assets/main/Guidelines/Documents/Doc/FINALREPORTDSA.DOC

issues. Similarly to the lack of evidence, expertise and knowledge on dual diagnosis such as developmental disability and mental illness, there are also issues for people with a developmental or acquired disability and drug and/or alcohol addiction. Project respondents reported a lack of drug and alcohol support services for people with disability.

It can be challenging for disability services that may only provide short periods of support to individuals during the week, to influence addictive behaviours. These service providers reported frustration in only being funded to provide a few hours of support during periods where the person was having a difficult time with drug and/or alcohol and more intensive support was thought to be required.

Proposal 2. Improve mental health outcomes
It is proposed that future directions for relevant agencies and the disability sector should involve investigation and development of appropriate strategies to improve the mental health outcomes for people with disability in the following three areas:

- **access to timely and responsive treatment for people with disability and mental illness**
- **access to support in acute crisis situations that promote intensive intervention models whereby the person is able to remain in the least restrictive environment**
- **promote research, expertise and information in relation to the impact and treatment of mental illness in people with disability.**

Suggested capacity building strategies

1. Research - development of university based research and practice such as the University of Queensland - Queensland Centre for Intellectual and Developmental Disability which provides clinical services at no cost to Queensland adults with intellectual or developmental disability who are 17 years and older including comprehensive health assessments, a psychiatric assessment service and a telephone/email consultation service, including behaviour support consultancy.

2. Minimising perceived over reliance on medication – strategies such as improvement in access to psychiatric services and better understanding and expertise in dual diagnosis should improve the appropriate use of medication.

   Organisations could have practices in place to ensure people with disability are adequately supported to provide full information to ensure general practitioners, psychiatrists and neurologists are fully informed and have reliable information on which decisions for medication are made. Some disability services could be supported to improve standards, practices, policies and guidelines in relation to medication. Service providers, patients and families could advocate for improved

communication between psychiatrists, neurologists, general practitioners and pharmacists and/or use of technologies to support this such as recoding systems.

3. Psychiatric emergency situations – consider, identify, develop and pilot innovative solutions to support families and services in crisis/emergency situations.

4. Mental health training for support staff – develop and provide information and training regarding mental health to disability support staff. This could include such training as 'Mental Health First Aid'.

5. Justice system – more work at a strategic and practice level is required to improve the interface between the justice system and disability service system. Information and education strategies regarding disability issues could be provided to police and other areas of the justice system. Pilot initiatives could be trialled to promote the successful transition from prison for people with disability.

6. Drug and alcohol services – a broader range of drug and alcohol services with a specialist focus on people with disability should be available.

4. Disability Service Infrastructure

Many services acknowledge their limitations in regard to getting services right for people with challenging behaviour. These services are at least willing to admit that, in their current infrastructure, designing and implementing an effective support strategy for some people is not possible. Some are working to extend their capacity and trial new pilot initiatives to build their capability and improve services.

On the other hand, there are some services that have a focus on providing support to people with challenging behaviour. They are willing to work with the people that other services refuse, and have approached service design with a 'can do and will do' attitude. These services need to be invested in, supported and their knowledge shared to ensure we have a sound system to respond to the needs of people whose behaviour can be seen as challenging.

There is a rich diversity in services across the Western Australian service system, with each service having its own culture and style of service provision. This diversity allows for more choice for people with disability and families when selecting services. Each service has its own approach to recruiting and managing staff and designing services. A consistent approach across the sector, to practices such as recruitment, training, service design and policy is neither seen as productive nor necessary. However, there is a need for a broad framework that outlines general standards and acceptable practice in behaviour support that can provide services with some direction and guidelines. General guiding principles or agreed best practice and policy frameworks such as the Behaviour Support Policy and Practice Manual

produced by the New South Wales Department of Ageing, Disability and Homecare[11] developed with the sector, could be of benefit.

Project respondents described the factors below as impacting on services' capacity to support people who are seen to have challenging behaviour.

4.1 Creative individualised service design

People, who at times, have challenging behaviour and particularly those with frequent and intense behaviour, require creative individualised[12] service responses designed with and for them. While the language of individualisation is common, the skill of individualised service design is usually much richer and more complex than most people comprehend. Genuinely knowing and understanding the person (or including those who do) is a critical component, as is a comprehensive analysis of the person's broader life and functioning. It is about grappling with the question of 'why'.

- Why is the person behaving in this way?
- What are they communicating?
- What's not working for the person?

It is about understanding what the world looks like through the eyes of the person. This aspect of individual service design is difficult enough in itself, yet we are also required to take our understanding of the person and match it with creative service responses likely to improve the person's quality of life.

Some respondents suggested further investment in this approach, especially the skills required to understand people and design effective holistic strategies to meet their support needs.

This reinforces the view expressed in 2003 in the Commission's Accommodation Blueprint Report:
'There is also a strong recommendation that services are individually designed, questioning the assumption that people with challenging behaviours are best accommodated together.'

Researchers suggest that the best practice with challenging behaviours is to secure 'highly desirable living arrangements' then add on whatever supports are necessary to make the situation successful. Stability is the key and "the logic is to withdraw supports as progress is made, rather than continuously uproot the person to new locations" (Kendrick 2000)[13].

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11 http://www.dadhc.nsw.gov.au/dadhc/Publications+and+policies/People+with+a+disability/Behaviour_Support_Manual.htm

12 This does not necessarily mean people receive services alone, rather that even when people share support services with others, they are tailored to an individuals needs and aspirations.

13 Disability Service DSC (2003) Accommodation Blueprint Steering Committee Final Report and Recommendations March 2003 p.35

Thirty people in March 2009 attended the Optimal Individualised Service Design course facilitated by Michael Kendrick. This course was aimed at increasing skills and capacity of people to design individualised service responses. In mid 2009 Queensland Government hosted a similar course and involved 10 people with disability who were considered to have some of the most challenging behaviours (and costly services) in that jurisdiction. It is too early to understand the impact of this approach however outcomes should be monitored.

During the consultation there was a view that, in most cases, people whose behaviour could be particularly challenging, did better when services were smaller and tailored. If people required accommodation support it was suggested that it is important for most people that these arrangements are small (living alone or only sharing with one or two people at the most). This, in practice will be influenced by the available resources such as housing, funding and support staff etc. Where people do need to share services then compatibility is an important element to consider.

Some service providers suggest that when incomplete information about the person was disclosed prior to accepting the person and designing a service, arrangements failed. One respondent recommended that better investment in analysing the needs of individuals and better matching of individuals to services was required. They suggested that the Commission's Options Explorations Team needed to give more consideration in cases where the person may be seen as having particularly frequent and intense challenging behaviour.

One respondent suggested intense resourcing may be required to establish people whose behaviour can be challenging in certain service types. This would include resources to ensure effective service design, effective staff training and additional support throughout the settling in period.

4.2 Support staff

Getting, focussing and backing up good disability support workers was seen as central to effective services particularly for people with intensive and frequent episodes of challenging behaviour. Selecting the right people, particularly people who are resilient, have positive values and an optimistic attitude was critical. Training of support staff is seen as important, as is orientating them to the positive aspects of the person, as well as strategies to prevent and work through the difficult behaviour. Where support staff are working in particularly challenging situations, access to frequent and timely supervision and guidance by professional staff may be required. This could include 24/7 on call advice, particularly where staff are working in isolation.

In some cases services gave examples of high staff turn over rates and a refusal by staff, permanent and casual, to work in some situations with people whose behaviour can be of particularly high intensity. Other service providers spoke about targeted staff selection and support strategies to lower levels of staff turnover. This included being upfront, yet positive, about the skills and attitude required.

In one case a support worker spoke of being placed in a situation in an accommodation arrangement with a person with disability she did not know well. The person was new to the service and placed with limited information and in significant distress. The support worker was injured and called the police to resolve an incident. This support worker spoke of the need for better preparation, transition and support for workers in these community based situations.

In another case a support worker spoke about being placed in a situation in an individual support arrangement with a person with disability she also did not know well. In this situation the support worker recalls watching the person with the disability sign over and over again using Makaton. The support staff had no knowledge of sign language and while they frantically tried to check the person's profile information they were injured and in significant distress. This was the first shift ever for this support worker in the disability field.

The values, attitude and skill of direct support workers are seen as critical to successful services. However challenges remain in attracting and retaining people in this area. One respondent suggested that there 'needs to be an increase in the number of people trained and confident in working with people with challenging behaviour in their own homes as there seem to be lots of 'chiefs' in the area of challenging behaviour but not many 'Indians'.

There was an example given of staff being paid a higher salary as a recognition and incentive to work in situations with people who are seen as challenging. There were conflicting views about whether this was an effective strategy. The financial recognition was deemed to reflect the extra skills and training required of these staff to provide a holistic service to the individual.

'As service providers we are not in a position to recruit appropriately well trained and experienced staff due to low wage conditions and ongoing staff shortages. Human services in general needs to be taken more seriously and given a higher priority by the wider community, especially when those services are provided for individuals with challenging behaviour.' Project Respondent

Other strategies described to retain and back up staff included:
- providing access to on call staff
- having shorter working shifts
- counselling for staff
- having genuine empathy for how staff are finding things
- providing clear routines
- regular meetings
- rewards such as special lunches etc.

4.2.1. Staff stability - intentional strategy

In recent years, as the mining boom attracted workers from all across WA, there have been significant staff shortages in the disability sector. It was reported that this period had an adverse impact on some services for people seen as having challenging behaviour. In some cases agency and relief staff

refused to work in some situations, high staff turnover increased episodes of challenging behaviour etc. Some service providers reported using deliberate strategies to encourage those they saw as good staff to work with people who were most sensitive to staff turnover. They also used strategies to ensure that where new staff were required, the introduction of these staff had as minimal impact as possible.

Another service provider is establishing an internal team of staff who have experience supporting people who are seen as challenging. This approach is also being used with the Disability Services Commission with new Level 3 positions.

4.3 Communication

The consultations highlighted several examples of the importance of better communication with and between stakeholders particularly with people with disability who have behaviours that are seen as challenging. One of the primary drivers of challenging behaviour is believed to be limitations with functional communication. As one project respondent suggests:
'….The difference between doing a plan 'to' someone or 'with' them is their understanding of why a strategy is being employed during an occurrence of behaviour. If you operate on a principle of behaviour as communication, then an improvement in communication between staff and the people we support will minimise the occurrence of the behaviour.

Recently I was asked to help support a gentleman with low expressive communication who had been lashing out at staff. It was just at the stage when people were starting to question the need for medication. I spent three afternoons observing the gentleman's interactions with me, other staff and residents. It became clear fairly quickly that there was little if no effective communication between him and staff. Over the next week we revised his communication needs, worked with staff and within 10 days had eliminated the aggressive behaviour. The emphasis was purely communication and not behaviour support in the traditional sense.

When crafting behaviour support plans I always start with developing an understanding of the person's communication. The most effective strategies are the ones that the person can understand. I know this is something that we all do, but when looking at responsive services, access to communication technologies and resources is essential. In my experience the better the communication the lower the risk of a behavioural occurrence and the more effective support strategies become.' Project Respondent

4.4 Supervision, support and management of staff

Many project respondents identified more investment in practices that can improve the supervision, support and management of direct care staff. A first line management structure is required to guide, educate and mentor support staff and to identify creative solutions to experiences staff find challenging. First line supervisors are also in a position to guide consistency, structure and culture of support staff teams.

'There is a need for on-the-job coaching and mentoring to educate staff around an individual's communication styles, supporting staff to understand people better through a hands-on supervision approach. Teaching staff to make the link between the written support plan and the support plan in practice. Picking up when a consumer appears confused and highlighting this to staff. In so many of our various models the need for confident, skilled supervisors is paramount and makes such a difference to the quality of life outcomes for the individual and being able to communicate with the individual about their support plan should be the first thing staff attempt when carrying out any Behaviour Support Plan.' Project Respondent.

4.5 Service culture

Service 'culture' refers to the tone, values and beliefs that influence the way services are provided to people within service environments. Schein (2004)[14] describes culture as:
'a pattern of shared basic assumptions that a group learns as it solves its problems of external adaption and internal integration, that has worked well enough to be considered valid and, therefore, to be taught to new members as the correct way to perceive, think and feel in relation to those problems.'

The culture of disability services, and particularly individual service sites, impacts on the outcomes achieved for people with disability. The tone of the service staff team and their beliefs about people with disability who are seen as challenging, influence the behaviour and resilience of staff. During the consultation many respondents provided insight into the pride and positive expectations about getting services right for individuals who can be very challenging. The decision of whether a service maintains support for people through difficult periods will be influenced by service culture.

One respondent spoke about focusing on the positive aspects and qualities of people who can have challenging behaviour and to build a culture of respect. Through the consultations it was clear that some disability services had invested in developing a service culture that promoted positive behaviour support and a respectful approach to people with disability whose behaviour at times can be seen as challenging. Development of a disability services culture was seen as an important factor in building the sector's capacity to provide responsive services to all.

4.6 Service environments

People's behaviour will be influenced by their environment. As such, creating an environment that suits the person is important. Designing an environment for the individual will often require a comprehensive assessment to look at what environment is best for the individual before matching service programs and service locations. Several service providers expressed challenges in

[14] Schein, E, (2004). Organizational culture and leadership, 3rd ed, Jossey-Bass, San Francisco.

adequately matching the service program to the best environment for that individual during the initial referral stage.

Some service providers expressed challenges in supporting some people safely due to the environment, for example, in vehicles and/or in public places. This then limited the options for supporting this individual particularly for social participation services. Similarly limitation in accessing suitable housing through Department of Housing current guidelines (such as where perspex windows and solid doors might be required) was expressed as a challenge for some service providers.

Furthermore, for piece of mind, people at certain times may require a familiar and structured environment to support them through a difficult period. Social participation services, in particular, suggest this can be very difficult if they are community based rather than centre based. Some services spoke about moving back to at least having a safe quiet centre based environment when a person is having a particularly difficult time and requires a safe and structured environment.

One respondent suggested further work needs to be done on various aspects of the environment such as lighting and its effect on individuals with disability such as autism.

Another respondent suggested that further work needs to be done on understanding and exploring the interpersonal environments and programmatic environments for the individual.

One service provider reported they are building new housing designed to cater for people who at the moment are not suited to living with other people. It is hoped that this model has a flow through model and allows people to gain skills and move on to other accommodation or community living options.

4.7 Industrial relations

Services reported being faced with unions and workers compensation claims in some situations, for example where a person has challenging behaviour that involves some level of violence toward others. The safety of support workers and the creation of a safe working environment are both regulatory obligations for service providers, as is a duty of care toward the person/people with disability who use the service. Service provider respondents suggest balancing these requirements and shaping services in the best interest of all stakeholders can be challenging.

4.8 Risk assessment and analysis

Central to support services for people with disability whose behaviour can be challenging is effective risk identification and management. There was evidence in consultations that some service providers need more opportunity to understand risk assessment and risk reduction strategies. It appeared that there are still high risk situations (such as people who can be violent in isolated environments with ill prepared support staff) that could have risks reduced through better analysis and risk management strategies.

Some respondents suggested there may also be cases where people are too restrictive because they lack skills and experience in risk analysis.

4.9 Staff training

There is a variety of staff training available and used by disability services. Training is seen as a critical component to preparing and retaining staff. There are associated costs that can be difficult for some services to meet. Training is also seen as important for staff teams, whereby a team of staff are supported to work together to ensure consistency and shared understanding of behaviour issues.

Positive behaviour techniques and training were cited as particularly important. Training and skill development that occurred in-situ was seen as important. It was also suggested that training should include strategies to improve staff communication skills. Some staff have poor general communication skills and can exasperate challenging behaviour.

Support workers could benefit from more training that supports better understanding of people who have a dual diagnosis such as developmental disability, mental health problem, drug and alcohol abuse, acquired brain injury and/or autism.

There is a variety of training used by the disability services sector. Organisations tend to favour certain training courses for staff. Some disability service providers indicated that they have developed their own 'in house' training for new staff on this topic.

The disability sector in WA has had access to a variety of local, national and international training programs in relation to challenging behaviour. Many respondents emphasised the need for ongoing training and development opportunities to maintain and promote effective support services.

The following training programs/packages have been used by the sector in recent years.

- PART - PART™ is a proactive response approach to the prevention and management of aggression in the workplace consistent with a positive support framework resulting in positive outcomes for all. Formerly known as Professional Assault Response Training, PART 'Predict, Assess & Respond to Aggressive/Challenging Behaviour', uses a train the trainer approach. A number of disability service organizations have used this training.

- Institute for Applied Behaviour Analysis **(**IABA) - the Institute provides training seminars and institutes that are appropriate for anyone who is interested in learning to support people with challenging behaviour using person-centred, no aversive approaches. These workshops are provided from time to time across Australia including recently in Perth. www.iaba.com/

- SMARThinking 2006 - the SMARThinking self-paced learning module format consists of a series of four workbooks. Modules 1, 2, and 3 are designed for entry level direct care staff. Module 4 provides information and support for other staff members who have responsibility for monitoring the practical work of other staff.
  www.ideaswa.net/Training/Training_Material/Smarthinking.php

- The Nonviolent Crisis Intervention® program, developed by the Crisis Prevention Institute (CPI)**,** teaches staff to respond effectively to the warning signs that someone is beginning to lose control, but also addresses how staff can deal with their own stress, anxieties, and emotions when confronted with these challenging situations. This program has been presented in Perth.

- Managing Threatening Confrontations
  Understand and manage escalating behaviours – this is a five-stage framework for managing escalating behaviours. Training also has a DVD, using situational re-enactments that include actors with developmental disability.

Other training used by the disability service sector includes private training providers, service providers, Registered Training Providers Certificate III and IV in Disability Work and Commission Behaviour Management training including Passive Self Defence.

There can be real and ongoing costs associated with training and maintaining support team focus on positive behaviour strategies and effective individualised support. This can be an ongoing cost and investment when a person has particularly extreme behavioural episodes.

4.10 Routine, structure and predictability

Establishing clear routines and consistent practices was seen as particularly important in support services for people who can have challenging behaviour. Several respondents spoke of accommodation services in the 90s where they thought staff had clear expectations and supported one another to achieve clear routines and consistency and this then resulted in reduced behaviour and a better quality of life for individuals in accommodation services. Regular meetings attended by a psychologist, who also worked alongside support workers to guide them, made a big difference. Support staff were committed to getting things right for the individuals in the service.

The cognitive impact of some developmental disabilities can lead to a reliance on structure. The routine and structure needs to be governed by the person with disability. One service provider spoke about the significant outcomes that have been achieved through establishing support services in a way that maximises consistency. For example by having staff live in over several days to reduce disruptions of a daily rotating roster.

Comprehensive training which teaches the staff to look at all areas of the person's life, skills, communication, history etc is seen as critical. This training allows the person the ability to describe and understand all possible relating elements and how these can impact the person and suggested ways to best support the individual.

4.11 Service funding allocation tools

The Estimate of Requirement for Staff Support Instrument (ERSSI) is an instrument used by the Disability Services Commission to allocate funding to individuals with disability. This instrument determines the support needs of individuals. Several service providers interviewed as part of this project suggested that the ERSSI does not adequately identify the support requirements of people whose behaviour is seen as challenging. This can result in service funding that may not adequately match the best service design option. Similarly respondents described the fluctuating nature of some people's behaviour which means they may have long periods of stability with services working well and times of instability where increased resources are required.

It was reported that there have been cases where young people with disability who have a high level of skills and require limited support with their daily living skills have been extremely vulnerable due to limited funding allocation. In some cases through the ERSSI people received very limited funded support hours. However, when they moved to their accommodation it was apparent that they had limited awareness of, and skills to ensure, their personal safety. This has resulted in them being extremely vulnerable to abuse and exploitation including sexual abuse.

It is important to note that funding is only a part of the problem. We were given examples during the consultation of people with relatively high levels of funding who still could not receive a service. It is more than an issue of money. It is about investments in the right areas and the infrastructure to tailor services as required. In many cases finding staff willing to work in difficult situations with people at times of crisis, was seen as challenging.

It is also suggested by some that very high cost service strategies can be ineffective and result in containment and limits to an individual's quality of life. Some respondents called for a funding strategy that better responded to people's fluctuations in behaviour particularly those who find themselves in crisis situations.

There are additional costs for some services who are working with people who have challenging behaviour. These additional costs can include higher workers compensation, recruitment and training costs, and costs of professional services and on call requirements.

In the case of Alternative to Employment Services first line supervision is not included in the funding formula through The Commission's Business Rules. Many service provider respondents suggested there is a strong case for

funding effective first line supervision particularly where service users can have challenging behaviour.

One respondent commented on the need for funding to support comprehensive assessments whilst the person is selecting which service they would like to use. This assessment would provide a clear understanding of the meaning of that person's behaviour and suggested proactive and reactive strategies to support the person. The detailed information would give service providers the opportunity to best match the service they are seeking. It is often the case that people are refused continuation of services while they attempt to work out what the person is communicating through their behaviour and how to best support the person. Ideally we need to place an emphasis on getting services right for the individual from the beginning and the only way we can do that is to understand the person before matching service programs.

4.12 Access to Professional Staff

Professional staff, such as speech pathologists, occupational therapists or psychologists, can provide an important resource to some disability services. There are challenges in recruiting and retaining good professionals with experience in disability as well as their discipline. Salary disparity across both government and private sectors, when compared to not-for-profit organisations, was reported by some as a significant issue.

In terms of psychologists, attracting people with experience and expertise in working with people with disability remains tough. In some cases having professional staff internal to an organisation was seen as a cost effective way to provide timely and responsive support. It was suggested that disability professional staff, in all disciplines, need more opportunities for further education in the area of Positive Behaviour Support.

Proposal 3. Best practice service principles
It is proposed that future directions for the Commission in partnership with disability sector organisations involve development of best practice service principles in Positive Behaviour Support including a list of service attributes in relation to supporting people whose behaviour is seen as challenging. These underpinning principles and attributes can be used to evaluate individual service capacity and targeted service development strategies.

Proposal 4. Flexible and timely funding strategy
It is proposed that the Disability Services Commission in consultation with the sector continue to review and develop funding streams that acknowledges that support levels can fluctuate significantly for some individuals over time. A person centred approach, whereby the resources can taper off over time as the person's situation is stabilised, should be considered.

Proposal 5. Targeted sector development
It is proposed that future directions for the Disability Services

Commission and the sector involve working together to develop strategies, which may include the prioritisation of targeted resource allocation, to support services to develop and maintain the infrastructure required to provide responsive services to people whose behaviour can be challenging. This infrastructure would include:

- **ongoing investments in workforce**
- **development of service culture**
- **staff stability and consistency**
- **staff supervision**
- **professional advice**
- **individualised service design**
- **training and professional development.**

Suggested capacity building strategies

1. Individualised service design – sector development in individualised service design. Better allocation and use of resources in some cases for people with extreme behavioural episodes. Better matching of people to services by the Commission's Options Exploration Team.

2. Agreed positive behaviour practices and standards – develop general guiding principles or agreed best practice and policy frameworks such as the Behaviour Support Policy and Practice Manual produced by the New South Wales Department of Ageing, Disability and Homecare[15] with the sector.
3. Support staff – disability services should be supported to undertake workforce development initiatives and strategies to recruit and retain high quality support staff particularly in the area of supporting people whose behaviour can be seen as challenging. This may mean increased investment and funding by the Disability Services Commission to ensure the capacity of the sectors workforce. This could include piloting and evaluating funding for counselling services, staff training, on- call 24/7 support, regular meetings for staff where staff are paid to attend and higher salaries in some cases.

4. Service culture – the disability service sector could benefit from greater knowledge, strategies and practical investment into how to influence and develop a positive service culture. There may also be a case for particular investment in the service culture of particular service sites that focus on services for people seen as having behaviour that is challenging. Professional development opportunities to promote skills and understanding in relation to culture development.

5. Facilitating communication – more professional development and staff

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http://www.dadhc.nsw.gov.au/dadhc/Publications+and+policies/People+with+a+disability/Behaviour_Support_Manual.htm

training opportunities in facilitating communication could be made available to service staff.

6. First line supervision – investment in professional development and mentoring opportunities for first line supervisors.

7. Environment – more opportunities to understand the impact of environment on those people sensitive to environment. The Disability Services Commission and other stakeholders influence the guidelines from Department of Housing to ensure the needs of people with disability and challenging behaviour are reflected in housing policy.

8. Industrial relations – service sector development with strategies to manage industrial relations and support to people with disability and behaviour that can be challenging.

9. Risk assessment and management – sector development in risk assessment and management.

10. Training – ongoing resources and opportunities should be available to support training and professional development for individual and teams of staff in positive behaviour support and other behaviour support strategies.

11. Routines, structure and predictability – services should be supported to achieve consistent, predictable and structured service environments tailored to the needs and preferences of people with disability. Ongoing resources and investment may be required to focus teams of staff on this aspect of service practice.

12. Professional staff – workforce planning and development strategies should be considered to promote and develop the sectors pool of professional staff. Salary parity with other sectors should be improved.

5. Interdisciplinary professional behaviour teams

Interdisciplinary professional behaviour support teams, such as the Disability Services Commission's Behaviour Support and Therapy team play an important role in supporting services to develop effective responses to people with disability who can have challenging behaviour. It was suggested throughout the consultation that these services need to be:

- timely
- provided in a way that empowers family, carers and support workers
- thorough and available as long as is required
- responsive and therefore available 24/7 when required.

Some respondents suggested that the current team has a long waiting list and is therefore not timely. They also suggest that in some cases a focus on recording of information is frustrating to support staff that may have been

waiting for more practical advice and may have already undertaken a process of recording data.

There was a view from some respondents that reliance on professional support can be distracting and counter productive and in some cases distract from achieving real issues for the person. This view was countered by respondents who suggested the service was valuable.

One psychologist had a view that both families and/or staff need to be empowered to find and own solutions and the role of professionals is to support this and build confidence in stakeholders by guiding them rather than prescribing behaviour support plans. One respondent suggested there was an over reliance on behaviour support plans and sometimes these plans in themselves may cause people to pay attention to the plan rather than 'listening' or paying attention to the person. Another respondent validated the use of these plans, as they underpin a consistent approach by staff.

There were differing views about the most effective placement of behaviour support multi-disciplinary teams. Some service providers preferred their own specialised teams and infrastructure rather than intermittent support through the Commission.

During the consultation process the project team had the opportunity to meet with Gary Lavigna who is considered an expert in the field of applied behaviour analysis.

He suggested the critical element of a successful multi-disciplinary team is to broadly understand the person's whole situation. There is a risk that interdisciplinary teams can undertake assessment of a person's situation by considering each of their disciplines. He used the analogy of an elephant, each member of the team can get caught up in describing their part of the problem eg communication for the speech therapist, lifestyle of the social worker etc therefore describing and understanding just a piece of the picture. In the case of an elephant, it is like describing the trunk, tail or legs and together you may have all the pieces of an elephant's body but no one understands how it all fits together. Somewhere in the process a team needs to step back and take an overarching view.

The Disability Services Commission's Positive Behaviour Team, which is working with families, to support them to understand and influence their family member's behaviour appears to be having good outcomes for many families, using the approach described above. This team is applying a service model that incorporates the strengths of different discipline areas yet remains focused on the big picture. The approach is not for everyone as its focus is on understanding the family system, the functional context of the behaviour and applied behaviour analysis. It is time limited and requires a process of intensive observation and interview. The approach is being evaluated and early signs suggest it is a valuable approach for many families. This strategy could be analysed and developed to consider ongoing support to some

families. Similarly the aspects of the approach that are working well could be applied to other and future interdisciplinary teams.

Gary Lavigna also described an approach whereby a team of professionals with training and experience in applied behaviour analysis is able to attend crisis situations and support individuals, services staff and/or families to move through the situation. Many respondents suggest this type of crisis support is required in WA, particularly for those individuals who are currently reliant on police and ambulance in an emergency situation.

Proposal 6. Interdisciplinary teams
It is proposed that support to disability sector organisations through interdisciplinary behaviour support teams is expanded by

- **extension of the available hours of the current behaviour support helpdesk**
- **expansion of the positive behaviour team model into disability sector organisations to ensure optimal outcomes are achieved, based on ongoing evaluation and evidence based practice.**

Suggested capacity building strategies

1. Interdisciplinary teams – where required, review, evaluate and improve multi disciplinary team approaches to ensure they are timely, provided in a way that empowers stakeholders, available as long as is required and consider 24/7 approaches.

2. Intensive interdisciplinary support – consider and pilot an option to provide timely and responsive support in critical situations.

3. Composition – consider the benefits of specialised psychiatric nursing professional as part of existing or future multi disciplinary teams.

6. Restrictive practices

The practices that are accepted to be used to improve or manage incidences of challenging behaviour are underpinned by a set of beliefs about the human rights of individuals. There are practices that are generally prohibited such as violence and punishment. There are other practices that are only recommended in very extreme situations and are known as restrictive practices. These practices such as restraint generally would only be used under extreme and isolated circumstances, for short periods and under strict external supervision and guidance.

The recent review of the Disability Service Act 1993 raised the limitations of the Act to ‘specifically address the rights of those whose behaviour is

described as challenging or extreme[16]'. It also acknowledges the Victorian and Queensland Governments have recently introduced strategies to improve the monitoring and use of restrictive practices. During the consultations some respondents suggested that the extent of legislative response such as that imposed in Queensland is too cumbersome for service provides, however many people suggested better practices and policy is required in this area.

What safeguards are in place to ensure that people who are seen as having challenging behaviour are free from neglect and abuse? How are support staff supervised and supported in this area?

There was information provided during the consultation process that suggests restrictive practices are still relied on (and overused in some cases). There appears to be a lack of consistent policy and practice in this area. For example in some cases respondents from services reported they did not have policy or practice guidelines in regard to restrictive or prohibited practices. Where there is the use of restrictive practices, it was recommended by one respondent that they are regularly reviewed by impartial external persons rather than service providers' own professionals.

Proposal 7. Disability sector policy and guidelines
It is proposed that future directions for the Commission in partnership with disability sector organisations involve development and promotion of guidelines to facilitate better standards and consistent practice in such areas as restrictive practices, medications policies, organisation's behaviour policy and positive behaviour support practices.

Suggested capacity building strategies

1. Restrictive practices – develop clear standards and promote better policy and practice in regard to restrictive practices.

7. Issues for regional and remote services

People living in regional and remote Western Australia reported having both benefits and challenges associated with living away from the metropolitan area. The benefits included an increased likelihood of relationship based strategies that are able to achieve outcomes across departments such as mental health, justice etc and an increased use of generic services and

[16] Disability Services DSC (2009). Review of the Disability Services Act 1993. Ministerial Report to Parliament in accordance with Section 57(5) of the Act. Available at:
http://www.disability.wa.gov.au/DSC WR/_assets/main/Guidelines/Documents/Doc/FINALREPORTDSA.DOC

community based solutions because specialist services are not always available.

Regional and remote disability services reported challenges in accessing timely and effective professional behaviour support. There was an acknowledgement that the two half days per week that the Commission's Behaviour Support and Therapy Team are available via phone consultation can be helpful, however more assistance is required outside these times. Where the team had visited regional centres, the support was seen as effective however ongoing support and local capacity was seen as more important for ongoing situations.

Access to regular education through schooling was reported as extremely difficult for some children whose behaviour is seen as challenging. Some children were registered at school yet regularly excluded. The infrastructure in schools including school psychologists and teachers are often inexperienced in working with people with disability who have periods of extreme behaviour.

Some regional areas tend to experience high transient populations therefore need to continually renew and rebuild local skills and expertise in a number of areas. This can be costly.

Access to professional development and training opportunities is limited. All of the issues related to shortages of effective psychiatric services are intensified in regional and remote areas. Some service providers in regional areas spoke about the lack of experience and infrastructure in supporting people whose behaviour can be challenging and being totally unprepared when faced with designing supports for a person who can have intense and frequent challenging behaviour.

Proposal 8. Regional and remote services
It is proposed that partnerships with regional and remote disability sector organisations and the Behaviour Support Consultation Team be considered to explore targeted cost effective solutions to improve capacity in rural and remote areas on a case by case, region by region basis and that pilot projects are encouraged.

Suggested capacity building strategies

1. Monitor outcomes and issues in regional and remote areas – with a view to develop further responsive approaches to local need.

2. Regional and remote service providers – particular investment in regional and remote service providers access to training and development opportunities in relation to challenging behaviour.

8. Lack of collaboration and coordination
In some cases there was a problem with the lack of collaborative and/or coordinated approaches between stakeholders.

8.1 Service providers and families
A consistent approach facilitated at home may not be followed through when the person returns to a service provider. Service providers and families spoke of frustration when certain important information was not shared by other stakeholders. For example, where a person may be attending medical appointments related to their overall wellbeing or specifically related to behaviour, the information may not be passed on to the service provider. One respondent suggested 'often families and carers are not involved or informed of changes in service provision in an effective or timely manner'.

8.2 Government departments
There were also examples cited of a lack of collaboration and /or case management across government departments and agencies.
'The report highlights all of the areas that we as service providers struggle with on a daily basis. In particular the issue of dual diagnosis and the difficulty getting all stakeholders to co-operate and take some responsibility for the ongoing support of individuals with challenging behaviours.' Project Respondent

One respondent raised examples of problems experienced by some young people due to the interface between the Department of Child Protection and the Disability Services Commission.

'Some of the young people in the child protection system have a number of challenging behaviours and a decision-making disability, and may or may not qualify for funding through the Disability Services Commission. Quite often there is no immediate family to advocate for or support these young people in their transition to independent living when they turn 18 years of age and no longer come under a Care and Protection Order. A particular concern is the lack of accommodation and support services once they exit the system. Frequently, these young people have an intellectual disability as well as challenging behaviours and lack insight. Support to maintain a stable environment in the community is required. As these young people may have been in the care of the Department for Child Protection, they may be eligible to receive limited funding for some support services until they reach 25 years of age. However, the planning for such young people leaving care needs to occur well in advance of the expiry of the order and identify if a guardian or administrator is required, and establish eligibility for funding from the Disability Services Commission. Such action will avoid the young person being in 'limbo' until the supports are put in place. Quite often, the young person's behaviour deteriorates at this time due to the uncertainty the young person faces. This in turn causes more problems in trying to access services because of the challenging behaviours.

The leaving care service providers funded by the Department for Child Protection to provide independent living skills development for young people

transitioning to independent living may not have the necessary skills to manage this particular cohort of young people with decision-making disabilities and challenging behaviours, particularly those who do not qualify for funding by the Disability Services Commission. Many of these service providers are established to manage mainstream young people and are not set up to manage those outside the 'norm' who require a more intensive support network.' Project Respondent

The WA State Government initiative People with Exceptionally Complex Needs Project (PECN) is an attempt to address this issue however it is in its early stages and involves only a small number of individuals.

The PECN project is a partnership of key government agencies working together to provide a coordinated, whole-of-government service delivery response to improve the wellbeing of a small group of people with extremely complex needs who are known to multiple agencies. The PECN cohort is made up of adults with disability or a combination of disabilities (including mental illness, intellectual disability and/or acquired brain injury). They may be high users of health, disability, alcohol and drug, housing, police and corrective services.

It is expected the PECN initiative will significantly improve interagency collaboration and coordination of services and encourage agencies to use existing resources in innovative and creative ways to respond to individual needs. There were examples provided of services developing a Memorandum of Understanding with other services and departments, as one way to improve collaboration.

Proposal 9. Across government responses
It is proposed that key stakeholders investigate, apply and evaluate strategies to improve outcomes for people with disability who are in complex situations that require across government responses (eg the People with Exceptionally Complex Needs (PECN) project).

Suggested capacity building strategies

1. Stakeholder communication – strategies that promote collaboration between stakeholders should be profiled and applied across the sector.

2. Interagency agreements – may assist in promoting collaboration both at a government level and between service providers.

3. Collaboration between the Commission and Department for Child Protection – a coordinated and constructive relationship should be developed between the Commission and DCP in relation to planning for leaving care and transitioning to independent living for young people in care. This should include the relevant government and non government

services providers and the young person and should commence in sufficient time to ensure a smooth transition for the young person.

4. What people said works

- Recognition of families and carers.
- Establishing predictability and stability in routines, staff and environment.
- Support staff modifying their approach when it is not working.
- Committed staff.
- Acknowledging staff are facing real challenges and providing support.
- Ordinary people – optimistic and resilient.
- Asking 'what would it take to get support services right?'…'what does a good life look like for this person?'
- Listening to what isn't said…understanding what is said.
- Identify with the focal person what matters most. This is not an assessment of need. This is a conversation with him/her.
- Most people's needs are unexciting and ordinary. Swimming with dolphins is great but it is unlikely to address day to day boredom and or friendlessness.
- Really listen. Empathy.
- Accept his/her values. Do not impose service or workers' standards.
- Accept the persons pace.
- Individualise. Recognise his/her uniqueness.
- Don't buy into the person's reputation or label. Recognise the person. Behaviour is just that. Everyone has the capacity to change.
- Build team around the skills, attitudes and personality required to assist the person to move towards their goals and aspirations. No trust = no chance.
- Help family and other stakeholders (that focal person wants involved) to understand the support services values and methodology. They have an important role. They need to know what matters most.
- Build service around person's interests and motivators.
- Maximise disposable income. Maximise personal ownership.
- Flexible Action Planning.
- Set routines can be helpful. This is not the same as an inflexible approach.
- Providing opportunities is one thing, insisting people take them is another.
- Agree support limitations e.g. I cannot support you to commit an illegal act.
- Be open and don't impose your low expectations. If the focal person wants to learn to drive, for example, support him to be assessed by a driving instructor. He's the expert on a person's driving potential.
- Duty of care does not justify wholesale risk aversion.
- Risk – over professionalising an ordinary life.
- Inclusion – listen to the Focal Person. We are going to share in his/her journey.
- Remove barriers to success.
- Don't get caught up in the 'in your best interests' agenda eg most people

may prefer to be slimmer but few want to eat a strictly healthy diet. People know that.
- Multi Agency approach may be required. Multi agency power struggle isn't.
- Successful outcomes are measured on the happiness scale.
- Understand the person – and how their disability impacts on them i.e. a genuine understanding of autism specifically assists families/service providers to understand the person and their 'view' of the world Flexible approaches to support.
- Getting the model of support 'right' for the person in the first instance.

5. Past capacity building initiatives

Developing ways to provide better services to people with disability whose behaviour we find challenging is not a new initiative. For many years, as a disability service sector, strategies such as training, professional development and committee development have been established to improve our capacity in this area. Any future capacity building initiatives should consider analysis and/or evaluation of past efforts.

The Challenging Behaviour Consortium – 2003 to 2005
The Challenging Behaviour Consortium was a joint initiative between the Commission's Accommodation and Service Purchasing Directorates and self nominated non-government organisations. The consortium consisted of representation from the Commission and seven other non-government organisations.

The initiative had three broad aims:
1. To work collaboratively to strengthen the capacity of participating organisations to support individuals who present with severe challenging behaviours.
2. To provide greater choice of residential placement for people who present with severe challenging behaviours.
3. To decrease the numbers of people being referred to the Commission for either:
    a) permanent residential accommodation or,
    b) emergency short term accommodation at the Commission's Boulton Street service.

The consortium used an action learning approach and was resourced with a Commission funded project team. The consortium members met regularly. Themes were researched and presented at each third week interval and members were given the opportunity to review, discuss and seek advice on individual case studies.

Researched themes included:
- engagement

- structure
- active support
- skills training
- routines
- problems with punishment
- crisis management
- functional communication.

During 2004 - 2005 the Commission provided a specialist team (coordinator, project officer, 2 x clinical psychologists and speech pathologist) to work with these self identified consortium organisations. The Commission also assisted in documenting the 'Action Learning' points and identified recommended resources between each meeting and circulating this to the consortium.

Outcomes of the initiative include:

- Revision of SMARThinking 2006 Module.
- Development of Challenging Behaviour tip sheets (available at http://www.disability.wa.gov.au/publication/behaviourtipsheets.html).
- List of identified resources (eg Proactive Behavioural Support: Structuring and Assessing Environments, The Cultural Cameo's Resource Manual etc).
- Report from the Commission's project team on the current factors affecting service provision in participating organisations including:
    - role of first line managers/supervisors
    - communication
    - transfer of Learning
    - staff training
    - organisational procedures
- Presentation by a project team member (Morag Budiselik) at the 41st Annual ASSID Conference in Canberra 2006. 'Hitting the Ground Running – the account of an intensive behaviour support project for people with disability and challenging behaviours'.
- Presentation by a project team member (Morag Budiselik) at the 41st Annual ASSID Conference in Canberra 2006. 'Learning to Care: Addressing training challenges in disability services'.

6. Current disability service sector resources

6.1 Disability Services Commission

The following strategies are in place to support people with disability, families and/or service providers to improve outcomes for people whose behaviour is seen as challenging.

6.1.1. Positive Behaviour Team

The Positive Behaviour Team (PBT) includes Behaviour Support Specialists with backgrounds in clinical psychology, social work and speech pathology.

The aim of the service is to encourage lasting, positive behaviour change and improved quality of life of the person with disability and their family by increasing the capacity of the person, their environment and support systems. Specifically, the service 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 disability, along with their family/carers.
- Prevent family breakdown or premature placement of the person with disability out of the family home.

The PBT service is based on the positive behaviour support model with emphasis on a flexible, creative and strengths based approach to service delivery in partnerships with families/carers. The approach is systemic with intervention being based on a thorough functional assessment which attempts to identify the barriers to previous interventions and positive change.

6.1.2. Behaviour Support and Therapy Team (BSTT)

The Behaviour Support Team, as part of the BSTT, includes clinical psychology, behaviour consultants and social work. This program is a consultancy service for funded accommodation providers supporting individuals described as displaying challenging behaviour. This includes consultation, intensive behavioural interventions for individuals, advice regarding staff education and training and advice with the development of management structures and practices.

The primary focus of this service is the establishment of positive behaviour support strategies that will optimise the implementation of interventions for challenging behaviours in the long term.

6.1.3. Behaviour support helpdesk

A clinical psychologist or behaviour consultant is available to non-government organisations, Commission Local Area Coordinators, Commission Local Area Managers, and practice leaders on:
Tuesday mornings 9.00am – 12.30pm and
Thursday afternoons 1.00pm – 4.30pm
The contact number is 9486 2955.

6.1.4. Psychology Consultancy, Country Western Australia

Psychology consultancy within Country Western Australia is a service provided to families and individuals who are registered with the Commission living in rural and remote areas. Being linked to a consultant psychologist allows local service providers and families to access information from behaviour management professionals to address areas of specific concern. The consultant psychologist is not the primary service provider but rather a resource to be used by professionals from within the local community to support the individual or families. The psychologist works with the family, individual and LAC over an agreed period of time (to a maximum of four months) via phone/videoconference consultations and/or face-to-face visits. The team presents regular workshops via videoconference throughout the year to enhance people's ability to understand and develop behavioural management plans where necessary. The consultant psychologist conduct assessments using an appropriate combination of methods (eg interview, observation, collection of data from participants). The psychologist will advise the family and their Local Support Network on a plan for addressing the issues after completion of the assessment.

The overall aim is to build on existing supports within the community and strengthen relationships between individuals, families and local service providers.

6.2 Existing Disability Service Sector Committees

6.2.1. Positive Behaviour Support in Action Interest Group

The Positive Behaviour Support in Action Interest Group is an open group to professionals working across the disability field who are zealous about supporting people whose behaviour can be challenging. The interest group was formed in September 2007 and currently the group meets every six weeks with the location and role of chair hosted by a different organisation at each meeting.

The aims of the 'PBS in Action Interest Group' include to:

- Develop quality services for people with disability who exhibit behaviours of concern.
- Develop best practice in positive behaviour support.
- Explore models of positive behaviour support.
- Provide a forum for problem solving, networking and information exchange across the sector.

Strategies include:

- Case study presentations by participating organisations.
- Resource sharing.
- Presentation of different models of positive behaviour support used in Western Australia: MTC, IABA, PART, Breakaway.

The interest group consists of representation from a number of non-government organisations, the Commission's Learning and Development,

Positive Behaviour Support and Therapy Team, Service Purchasing, and Local Area Management.

The Commission's Service Purchasing assists in letting other organisations know about when the group is meeting and how they can participate.

Through the establishment of this group several training initiatives have been pursued and shared. Several partnerships/networks have been developed and several organisations have presented on services they provide and ways they can assist others.

The interest group members suggest that to be more effective in increasing the sectors capacity to meet the needs of people whose behaviour can be challenging, an independent consistent chair and project team would be valuable. This would assist the organisations involved learning in between meeting dates when individual cases are extremely vulnerable, keep organisations on track with strategies they can generalise across services and keep the momentum of the group going.

7. Conclusion

This project provided a unique opportunity to explore the disability service sector in relation to its capacity to support people with disability whose behaviour can be challenging. While concerns with the sectors capacity have been raised in several reports[17] over the last decade, until now there has not been a broad environmental scan of the sector to identify gaps and to direct improvements. One weakness of the report is that it has not included the many stories of successful service strategies, where people whose behaviour has been considered challenging have been supported in a way that ensures they experience good outcomes.

The report affirms the need for more work to be done and provides a direction for sector improvements. While there are more questions to be considered, more deliberation required regarding some solutions, there are many priority areas and practical improvements that can be made now. It is important that efforts to improve the sector capacity take account of stakeholder views. This project has demonstrated that there is existing wisdom amongst stakeholders regarding where improvements efforts can be targeted.

There are improvements required across government and the private sector so that disability services operate in an environment where the people they provide services to can get adequate access to generic services such as housing, education, emergency and health.

Finally, many of the capacity building efforts identified in this report should be implemented and sustained over time. This is not an area that aligns itself to time-limited short sharp efforts. Ongoing diligence is required.

[17] Disability Services Commission (2003). Accommodation Blueprint Steering Committee Final Report and Recommendations p35.
Disability Services Commission (2005). Disability Services Commission Annual Report 2004-2005 p28.
Disability Services Commission (2007). Western Australian Sector Health Check on Disability Services.

Appendix 1: Project Respondents

Individual Respondents

Anita Ghose	Activ Foundation
Jamie Smith	Activ Foundation
Gerry Gibson	Activ Foundation
Jean Taylor	Autism Association
Michele Thomas	Autism Association
Janet Wagland	Brightwater Care Group
Tanja Bernardini	Carers WA
Tara Ludlow	Carers WA
Gaby Slade	Community Vision
Tammy Budridge	Disability Services Commission
Sue Coltrona	Disability Services Commission
Tracy Foulds	Disability Services Commission
Andrea Gibellini	Disability Services Commission
David Gornall	Disability Services Commission
Fran Gresely	Disability Services Commission
Jacki Hollick	Disability Services Commission
Bronia Holyoak	Disability Services Commission
Nola Kenny	Disability Services Commission
Anne Lawson	Disability Services Commission
Marc Lema	Disability Services Commission
Jill Mackenzie	Disability Services Commission
Craig McIver	Disability Services Commission
Steven Mountford	Disability Services Commission
Sarah Beveridge Pearce	Disability Services Commission
Janet Wynne	Disability Services Commission
Steve Robinson	Enable Southwest
Paul Armishaw	Hills Community Support Group (Inc)
Cheryl Gallaher	Hills Community Support Group (Inc)
Gail Palmer	Hills Community Support Group (Inc)
Ed Mayvis	i.d.entitywa
Sue Hart	Red Cross - Lady Lawley
Adam Sullivan	Red Cross - Lady Lawley
Tracy McNichol	Mosaic Community Care
Rod Davies	My Place
Darren Ginnelly	My Place
Andrew Jefferson	People with Disabilities
Gordon Trewern	Nulsen Haven Association Inc
Stephen Van Vlijmen	Nulsen Haven Association Inc
Linda Craig	Peel Community Living
Frances Buchanan	Rocky Bay
Linda Chiu	Rocky Bay
Tracey Delamere	Rocky Bay
Richard Long	Senses Foundation
Angela Moran	Therapy Focus
Jillian Pearsall Jones	The Centre for Cerebral Palsy
Gary Taylor	The Centre for Cerebral Palsy
John Treasure	Teem Treasure

Fran Tilley	Uniting Care West
Cheryl Rogers	Valued Independent People
Margaret Walsh	Valued Independent People

Committees/Groups Interviewed
Council of Regional Disability Services – 14 December 09
Disability Services Commission LAC Metro Managers Meeting 2 October 2009
Disability Services Commission LAC Country Managers Meeting 20 October 2009
Disability Services Commission Accommodation Directorate Local Area Managers Meeting 7 October 2009
Disability Services Commission Positive Behaviour Team 13 October 2009
Disability Services Commission Service Contract and Development Staff 15 October, 2009
Independent Standards Monitors Meeting10 September 2009
NDS WA Accommodation Subcommittee 14 September 2009
NDS WA Social Participation Subcommittee 10 September 2009
Industry Advisory Group Community Service, Health and Education Training Council 24 September 2009

Families and People with disability
The consultation process also included interviews with people with disability whose behaviour has been considered challenging.

Similarly, several families were interviewed or contributed through written comment. Some host families were also interviewed.

Peak Bodies
Carers WA
People with Disabilities
National Disability Services WA

Government Departments
Office of the Public Advocate

Project Team also met with Gary Lavigna, Institute for Applied Behaviour Analysis (IABA)

Appendix 2: Consultation Paper

Toward Responsive Services for All!

Understanding the WA Disability Services' Sectors Capacity to meet the Needs of People who's Behaviour can be Challenging.

Consultation Paper

A component of the Positive Behaviour Framework Initiative September - November 2009

Closing Date for Responses Friday 25th September 09

Project Aim
This scoping project seeks to understand the current capacity of disability services in Western Australia to adequately support people with disability whose behaviour, at times, is identified as challenging. It is part of a broader initiative, the Disability Services Commission's 'Positive Behaviour Framework', and aims to inform the development of strategy to improve disability services to make sure people whose behaviour can be challenging can get the services that they require.

Project scope
This project is concerned with the current state of play in disability services. Disability services, for the purpose of this project, refer to Disability Services Commission funded and provided services in Western Australia. This could include accommodation, social participation and respite services or intensive family support. Specific information is sought on the current capacity of services to support people with challenging behaviour, identification of strategies that work well, stories of best practice and gaps in current service capacity.

Methodology
Data will be collected from key stakeholders through:

- Call for responses - circulation of this survey (or download from www.ideaswa.net/Projects/PBF.php)
- Focus groups with stakeholders including the following open consultations:
    - **Wednesday 16th September 2009 10.00 am – 11.30am** at NDS Units 1, 59 Walters Drive Osborne Park.
    - **Monday 21st September 2009 10.00 am – 11.30am** at NDS Units 1, 59 Walters Drive Osborne Park.
      To register for either of these events email monique.williamson@nds.org.au or call 9208 9802.
- Interviews with key project respondents

We welcome contributions from all interested parties including people with disability, families, support service providers and support staff.

What we mean by challenging behaviour?
Emerson[18] (1995) defines challenging behaviour as "behaviour 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 or deny access to the use of ordinary community facilities" (p.4).

This consultation is concerned with people whose behaviour is sometimes difficult for services (and services staff) to respond to and manage. The intensity of the behaviour and the frequency of the behaviour are both factors that influence the ability of services to support people.

[18] Emerson, ER. (1995). Challenging behaviour: Analysis and intervention in people with learning difficulties. Cambridge: Cambridge University Press.

Instructions

Please complete as many of the questions as you would like from the list below. Thank you for your time and contribution.

Name:

Organisation, if applicable:

Contact email:
By providing an email address we are able to forward you a copy of the draft report for comment. Individual responses will be kept confidential. However a list of people and/or organisations that have responded will be included in the project report.

Completed surveys can be forwarded (before 25th September 2010) to:
Monique Williamson National Disability Service, WA
Post: PO Box 1428, Osborne Park, WA 6916
Fax: 08 9242 5044
Email: mmonique.williamson@nds.org.au

General Consultation Questions

1. Thinking about disability services in Western Australia, what are the things we should keep, toss, change or add to improve their ability to support people whose behaviour can be challenging?

Keep	**Toss**
Change	**Add**

If completing electronically the box will expand as you enter information. If completing in hard copy please use back of page for additional space.
2. Which elements of the diagram (page 5) do you think disability services are good at, and which elements do they need to improve on? Are there elements missing?

3. Can you think of an example where a disability service has responded well to a person who sometimes has challenging behaviour? What were the things that made this work?

4. Can you think of an example where a disability service has responded poorly to a person who has had challenging behaviour? What were the things that did not work well or were missing?

5. Why do services stop (or refuse to start) supporting certain people with challenging behaviours?

Additional Questions for Service Providers
Background Information

1. How many people in your service would you consider as having challenging behaviour that is significant enough to restrict the person's life or disrupt the usual service delivery?

2. What aspects of your service do you consider are 'prepared' or 'good at' supporting people whose behaviour can be challenging?

3. What factors impact on your organisations decision to refuse or discontinue providing services to a person because of challenging behaviour?

Restrictive Practices

4. In your organisation, what are the practices that staff are not allowed to use to manage challenging behaviour?

5. How do staff find out about these?

6. How are these monitored?

7. Where medication is prescribed to manage people's behaviour how is it monitored?

8. How do you make decisions about whether certain strategies used to manage behaviour are ethical?

Staff Training and Supervision

9. What strategies do you use to prepare and train staff to work with people whose behaviour can be challenging?

10. How are staff supported and supervised when working with people whose behaviour can be challenging?

11. What strategies have you found that work to recruit staff with the right attitude and skills to support people who sometimes have challenging behaviour?

12. How do you keep your support staff teams focussed and motivated to support people who sometimes have challenging behaviour?

Service Culture

13. How would you describe your services 'culture' in relation to people who have challenging behaviour?

14. What do you think are the service structures and models that tend to work better for people with challenging behaviour?

Professional Support

15. What are your thoughts about the helpfulness and availability of professional support such as therapists and psychologists?

16. What do you think is the role and value of 'behaviour support plans?