

**SPLIT RIDGE ASSOCIATES LTD**

**REPORT ON THE  
PROVISION AND FUNDING OF SPECIALIST  
BEHAVIOUR SUPPORT SERVICES**

**31 July 2011**

# SPECIALIST BEHAVIOUR SUPPORT SERVICES

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## Glossary of Terms

Term	Definition
<b>ASD Guideline</b>	The NZ Autism Spectrum Disorder Guideline is based on overseas and New Zealand evidence, experience and practice. It has information for people with ASD, their families, health professionals, support service providers and those involved in education. It covers diagnosis and treatment of Autism Spectrum Disorder (ASD), supporting and teaching children and adults with ASD, employing people with ASD and living with ASD.
<b>Behaviour Support Alliance (BSA)</b>	<p>The Behaviour Support Alliance is made up of some providers of Behaviour Support Services contracted by Ministry of Health. The Alliance meets every 3 months to discuss the services they are delivering. The Alliance came together with the following aspirations:</p> <ul style="list-style-type: none"> <li>• Establishment of common ground</li> <li>• Sharing ideas</li> <li>• Mutual support</li> <li>• Providing leadership and direction to the future of behaviour support</li> </ul> <p>The Ministry of Health does not fund this group.</p>
<b>Challenging behaviour</b>	<p><b>Challenging behaviour</b> – can be defined as either:</p> <p>“Severely challenging refers to behaviour of such 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 delay access to and use of ordinary community facilities.” (Emerson et al. 1987) or,</p> <p>“On an everyday basis the negotiation of the label ‘challenging behaviour’ is a social process. Although there will undoubtedly be some people about whom there will be a wide measure of agreement, there will be others about whom opinions differ across the range of people involved in their care. The person him/herself may also have a view on the matter.” (Qureshi 1994)</p>
<b>Child Development Services (CDS)</b>	Child Development Services are non-medical, multidisciplinary allied health and community based services. They focus children who have disabilities or who are not achieving developmental milestones. They also encourage and help each child to achieve their potential. They work with other agencies involved in providing services to children to ensure that the Child Development Service is integrated, easily accessible and that service links and boundaries are clear. The service provides specialist assessment, intervention and management services to ensure good rehabilitation/habilitation results for children who have an intellectual, sensory or physical disability.

<b>Community Liaison Teams (CLT)</b>	Teams attached to the Regional Intellectual Disability Secure Services but with a community focus. The role of the Community Liaison Teams is primarily to maintain and improve service delivery and thereby prevent regression of clients into more intensive levels of service provision. The role is defined primarily by consultation and liaison with support agencies but may also include some direct clinical care provision.
<b>Disability</b>	“A person with a disability is someone who has been assessed as having a physical, psychiatric, intellectual, sensory or age related disability (or a combination of these) which is likely to continue for a minimum of six months and result in a reduction of independent function to the extent that ongoing support is required”.
<b>Dual Diagnosis</b>	The presence of intellectual disability and a concurrent mental health disorder.
<b>Forensic mental health services</b>	Forensic services within New Zealand assess, treat and rehabilitate people with a mental illness who had, or were alleged to have, committed a crime and those who are likely to offend.
<b>High and Complex Strategy</b>	<p>This strategy was developed to meet the needs of those people with intellectual disability and who have significantly challenging behaviours. The criteria for access to these services are:</p> <ol style="list-style-type: none"> <li>1. Show behaviour which poses a serious risk of physical harm to themselves or others</li> </ol> <p><b>AND</b></p> <ol style="list-style-type: none"> <li>2. Any of a - c below</li> </ol> <ol style="list-style-type: none"> <li>a) Access is limited or prevented not only to ordinary opportunities and facilities, but also to mainstream disability support services</li> </ol> <p><b>Or</b></p> <ol style="list-style-type: none"> <li>b) Appears to manifest a psychiatric disorder, requiring mental health professional assistance for assessment, treatment or management</li> </ol> <p><b>Or</b></p> <ol style="list-style-type: none"> <li>c) Behaviour results in a breach of law, requiring involvement of criminal justice personnel (including Police, Correction or the Courts)</li> </ol>
<b>Intellectual Disability</b>	<p><b>Definition of Intellectual Disability</b></p> <p>The Ministry of Health’s Disability Support Services is only mandated to use the definition of intellectual disability as stated in The New Deal:</p> <p>“Intellectual Disability – Permanently impaired learning ability (usually from birth) which prevents or inhibits people from developing the range of physical and social skills usually found in a person of that age.”</p> <p>Disability Support Services also recognises the <u>American Association on Intellectual and Developmental Disabilities (AAIDD)</u> definition of intellectual disability:</p> <p>“Intellectual disability is a disability characterized by significant limitations</p>

	<p>both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.</p> <p><b>Intellectual functioning</b>—also called intelligence—refers to general mental capacity, such as learning, reasoning, problem solving, and so on.</p> <p>One criterion to measure intellectual functioning is an IQ test. Generally, an IQ test score of around 70 or as high as 75 indicates a limitation in intellectual functioning.</p> <p>Standardized tests can also determine limitations in <b>adaptive behavior</b>, which comprises three skill types:</p> <ul style="list-style-type: none"> <li>• Conceptual skills—language and literacy; money, time, and number concepts; and self-direction.</li> <li>• Social skills—interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.</li> <li>• Practical skills—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.”<sup>iii</sup></li> </ul>
<p><b>Needs assessment</b></p>	<p>A needs assessment for a person with a disability is undertaken by a needs assessor working for a NASC. The needs assessor meets with the person, and other key people such as family, caregivers, and other significant people, to work out and then prioritise the person’s needs. This may take several, or ongoing, meetings. The purpose of the process is to decide what a person needs to achieve and maintain independence in accordance with their abilities, resources, culture and goals.</p> <p>A persons needs may also include the needs of their family/whanau and carers; their recreational, social and personal development needs; their training and education needs; and their vocational and employment needs.</p>
<p><b>Needs Assessment and Service Coordination Organisation (NASC)</b></p>	<p>The Ministry of Health funds these organisations. Their roles are first to assess people’s needs, and then to coordinate services to meet those needs.</p>
<p><b>Regional Intellectual Disability Care Agencies (RIDCA)</b></p>	<p>Provide a function similar to the NASC agencies, but is specifically providing assessment and coordination services for those people who meet the criteria for eligibility for high and complex behavioural needs service provision.</p>

<b>Regional Intellectual Disability Supported Accommodation Services (RIDSAS)</b>	<p>Services provided for those people who meet the criteria for eligibility for high and complex behavioural needs service provision. Services provided are:</p> <ol style="list-style-type: none"> <li>1. Residential care (secure and supervised)</li> <li>2. Supported living</li> <li>3. Emergency short term care</li> <li>4. Respite care</li> <li>5. Vocational services</li> </ol>
<b>Regional Intellectual Disability Secure Services (RIDSS)</b>	<p>Services provided for those people who pose such a risk as to require secure hospital based services, or who are required to receive services with this level of security through direction of the courts. Services are provided by District Health Board contracted services.</p>
<b>Strengthening Families</b>	<p>Strengthening Families is a programme that provides a way for families to get coordinated access to services. It is run in a way that meets the unique needs of each family and whānau. This builds on the strengths and dreams of families, with support from health, social service, education and other services working together.</p> <p>Eleven government departments have committed to being part of Strengthening Families and staff are expected to be involved as a core part of their work.</p>

## 1. Executive Summary

In November 2010 Split Ridge Associates Ltd was contracted by the Ministry of Health to undertake a project to develop a:

- Behaviour Support Services strategy to be submitted to and approved by the Senior Management Team within three weeks of the contract commencement
- Funding impact assessment to inform implementation of the Behaviour Support Service delivery model
- New Behaviour Support Service delivery model.

This report provides a comprehensive overview of this project. It builds on the Ministry of Health's previous reviews of Behaviour Support Services (BSS), which occurred in 2005, 2007 and 2008.

Previous reviews highlighted concerns regarding the purchase and delivery of BSS and led, among other outcomes, to a common service specification regardless of service provider. Those reviews did not consider different models but looked more at the quality of existing services.

The project methodology involved structured interviews with identified stakeholders and providers, analysis of current funding mechanisms, and the development of a service model for Regional Specialist BSS with options for the organisation and governance arrangements.

The conclusions reached from the analysis of interviews clearly confirmed many of the observations from earlier reviews and projects. In summary, these were:

- variability around how people gain access to BSS and variable access in terms of waiting times
- inconsistent approach to BSS delivery
- clients and their families have little influence on the structures and service being provided
- reporting to Needs Assessment and Service Coordination (NASC) by providers is variable
- variable maturity of relationships among providers and also between providers and specialist clinical services within District Health Boards (DHBs)
- some beginning evidence of working together and joint work but not across all providers
- range of skills and qualifications, a number of which are not in line with the service specification
- little evidence of clinical leadership
- need for greater national quality approach, including action research.

These reaffirmed earlier observations which concluded the following.

- "We don't know who is getting Behaviour Support
- We don't know how long people are getting Behaviour Support
- We don't know how many "Eligibility Assessments" we are buying

- We don't have confidence that the providers are prioritising referrals in a way that the NASC/Ministry of Health would want them to (they may just go on the end of the waitlist)
- We don't have confidence that the right people are getting Behaviour Support (ie, people in residential care may be getting Behaviour Support over people in the community.<sup>iii</sup>)

In initiating and conducting the project the following six principles were developed and adopted by the project team to underpin the findings, conclusion and recommendations of the project:

- nationally consistent access – equity for eligible referrals
- responsive but flexible – meeting client needs
- integrated across the service continuum – no gaps or delays
- evidence-based practice – best practice and outcomes orientated
- clinical leadership and engagement – clinician lead
- sustainable over the longer term – affordable and value for money.

Brief monthly updates were prepared and posted on the Ministry's website to report progress and summarise the issues that arose during the project. Regular monthly status reports were provided to the Ministry, as well as monthly teleconferences. There have also been a number of meetings with Ministry staff to report on progress, issues arising and provisional options being considered.

In summary the project has established (and in some cases reaffirmed) that with respect to BSS there is considerable variation in:

- how people gain access to and wait for specialist BSS
- the way providers deliver BSS
- reporting to NASCs and the Ministry
- relationships among providers and also between providers and specialist clinical services within DHBs
- expectations and recognition of the workforce
- the present and potential contribution of clinical leadership
- the disability philosophy of some NGOs and DHBs.

The project did establish some evidence of providers beginning to work together but not to the extent that it engaged all providers. However, this is not consistent around the country and is not aligned to the required philosophy of behaviour support in relation to the Disability Strategy or evidence-based practice.

The project team is of the firm view that well-organised and structured Regional Specialist BSS, equivalent to other specialist disability and health services, with strong clinical leadership and support should now be established. Such a service would be responsible for ensuring compliance with a nationally consistent service pathway for specialist BSS.

The proposed service model for specialist BSS acknowledges earlier work as well as findings on the present practice and service arrangements. The project has developed a pathway which it considers should be adopted in order to ensure consistency of access to BSS. The four decision points are as follows:

1. Does the referral meet the criteria for eligibility and if so what is the urgency?
2. If criteria are met, the referral is allocated for either an emergency intervention or a planned intervention to include discharge and outcome expectations, training and support, any direct services needs and proposed therapeutic interventions.
3. Regular review of the planned intervention to determine how it is to be continued or modified to reflect the contribution of significant others, such as family, partner, school, and other residents.
4. Discharge, which is a joint decision including the family, significant others and/or the residential provider.

The existing specification has been revised to support this pathway. It is referred to in more detail in section 9.

Further, the project team believes that in order to manage a number of ongoing service limitations the development of clinical leadership needs to have an early priority as part of the service development process. Consistent with this theme the project team proposes that specialist BSS be more aligned with related DHB services.

Discussions with both Ministry and provider personnel indicate that regardless of the funding and service arrangements that are adopted, it must be underpinned and supported by a entity described in earlier projects as the 'Centre for Excellence'. Whether this continues to be the description or not, its role would be to foster and innovate for best practice within the New Zealand context. Such an entity could consist of the Regional Clinical Leaders with a presence from academia, education and clinical specialties. Its functions would be to:

- create education, training and clinical internship opportunities
- develop relevant research to support New Zealand-specific evidence-based practice
- provide a forum for clinical leadership by hosting the establishment of a formal behaviour support network with a focus on shaping processes and interventions that give value to service users, rather than a focus on structures.

The project team considers that the Ministry needs to carefully and explicitly assess its requirements for such an entity and that proposals be sought from credible academic and research organisations. This consideration could look at opportunities for some form of collaboration with the Queensland Centre of Excellence.

## 2. Recommendations

The project team's recommendations are as follows.

1. That Regional Specialist Behaviour Support Services be established and distributed regionally (Northern, Midland, Central and Southern) across the country. Each team to be lead by clinicians and underpinned by joint governance arrangements between DHBs and Non-Government Organisations (NGOs) with a focus on building consistent clinical and service capacity across the service continuum.
2. That a nationally consistent service pathway and revised service specifications be adopted and applied by the Regional Specialist BSS, in order to deal with the present variability of access and service provision. The development of relevant quality and outcome KPIs should be part of any such revision. A prioritisation tool should be developed to assist in the management of referrals to Regional Specialist BSS.
3. That a separate service specification for Autism Spectrum Disorder (ASD) clients be developed in accordance with the ASD guidelines.
4. That as part of the implementation of Regional Specialist BSS, consumer advisory groups (which must include Māori and Pacific people) be established and resources allocated so consumers, families and significant others can contribute to and participate in the service.
5. That a consistent data-gathering and reporting system that reports on actual utilisation and outcomes be established.
6. That the Ministry consider and detail the proposed role of a Centre for Excellence in the New Zealand context, with a focus on:
  - creating training and clinical internship opportunities
  - developing relevant research to support New Zealand-specific evidence-based practice
  - providing a forum for clinical leadership and perhaps being a vehicle to host the establishment of a formal national behaviour support network with a focus on shaping processes and interventions that give value to clients, providers and funders.
7. That the Ministry initiate an approach and engage with Health Workforce NZ, the various professional and regulatory bodies and training providers to:
  - review the current programmes being provided to establish a benchmark for disability support workers and those employed in all BSS
  - better target disability workforce funding to the staff of all BSS, by encouraging and enabling disability support workers to access training specifically relating to intellectual disability
  - to develop a process to work closely with regulatory bodies of occupational therapy, nursing, psychology, social work and medicine to recognise the need of their disciplines to incorporate behavioural support into undergraduate and postgraduate programmes and ensure a career pathway relevant to behaviour support.

8. That the Ministry considers, for the longer term, some form of clinical integration between the Community Liaison Team service and the proposed Regional Specialist BSS.
9. That relevant changes are made to other specifications in contracts that relate to behaviour support such as:
  - needs assessment coordination
  - residential services
  - Community Liaison Teams.

### **3. Introduction**

The Ministry of Health plans and funds long-term disability support services for people with physical, intellectual and/or sensory disabilities. Most clients are under 65 years of age. Presently the Ministry contracts with a wide range of organisations to provide behaviour support services (BSS). The Ministry is undertaking a project to examine the provision and funding of BSS for people with disabilities. Split Ridge Associates Ltd has been contracted by the Ministry to assist in this project and report on how BSS are funded and provided.

The core activity of BSS is to develop, implement, monitor and review a plan that successfully minimises the impact of challenging behaviours exhibited by a person, enabling them to develop maximum levels of independence and positive participation in the community. In undertaking this project the project team adopted the definition of 'challenging behaviours' proposed by the Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language (College Report CR144 June 2007):

'Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.'<sup>iv</sup>

### **4. Limitations**

The following limitations have been identified.

1. The project team was reliant on the documents supplied by the Ministry of Health and various providers, as well as information gathered during the meetings with providers and stakeholders.
2. The project is primarily a snapshot of the service and does not attempt to evaluate the BSS processes or effectiveness over time.
3. This project does not constitute an audit of the financial performance of the BSS reviewed.
4. The project team had considerable difficulty in obtaining, for purposes of analysis, valid and reliable measures of BSS utilisation. For example, one dataset that was provided for analysis by the Ministry reported that for the quarter ended 30 June 2010 only one provider had completed any assessments. Further, only one provider (not the same) had a waiting list as at 30 June 2010. Another (different) provider (and the only one) reported no new

referrals as at 30 September 2010. This highly variable reporting of activity is at odds with the feedback received at the various meetings with providers.

Thus the project has been unable to obtain any reliable measure of the current activity and patterns on which to base predictions of future patterns of utilisation.

5. While the project team obtained solid information about the current value of contracts, the lack of reliable utilisation data has compromised any credible analysis of current costs against activity and has also limited the capacity to predict the likely costs associated with present rates of referral and intervention. As an example, an earlier project estimated that there was considerable variability by provider of the average dollar amount per client supported, ranging from approximately \$250 to \$1,400.
6. The ability to meet with all of the stakeholders was affected by timing and circumstances. The scheduled meeting with People First was unable to go ahead due to the Christchurch earthquake. The timing of Māori and Pacific peoples' hui did not align with the time constraints of the project. However, the project team considers that the interests of these groups should be taken into account as part of the transition and implementation phase.

Having noted these points, it should also be noted that all parties involved in the project provided considerable assistance to the project team.

## 5. Background

In conducting this project the project team was mindful of earlier work done on BSS. Each of these projects highlighted concerns about the purchase and delivery of this service. In 2005 the Ministry adopted advice to put in place a standard service specification for BSS. The Ministry noted in a discussion paper (December 2008)<sup>v</sup> that earlier projects had established key issues of:

- pressure on services
- waiting times
- managing access.

That same paper also noted that none of the earlier projects had 'provided information to allow consideration of new models or purchasing frameworks'.<sup>vi</sup>

During 2007 and 2008 DSS undertook a range of activities which sought to find a better way of providing specialist BSS for people with disabilities. The work was informed in part by the outcomes of two previous projects on BSS, one completed internally by DSS and one by Enhancing Quality Services Ltd. Both projects highlighted concerns regarding the purchase and delivery of BSS and led, among other outcomes, to a common service specification regardless of service provider. The projects did not consider different models but looked more at the quality of existing services.

In early 2007, DSS decided that a BSS project in three stages was required, which would include the following activities:

- **Stage 1** – Consultation with the disability sector to establish a view on what they require from BSS, and a literature review on the international experience of purchasing BSS for people with intellectual disability.
- **Stage 2** – Provide recommendations to the senior management team of DSS on preferred future BSS models.
- **Stage 3** – The development of options for delivery of BSS with the purpose of establishing a consistent and effective service with a well-understood continuum of service for the client group which is underpinned by equity of access and value for money.

The Ministry subsequently issued a request for quotation to progress the predicted work and as a result of this, the present project was scoped and Split Ridge Associates Ltd was contracted to undertake the work.

With respect to funding, the Ministry, through a mix of revenue streams, funds providers through 23 contracts generally designated as Behaviour Support. There are 10 mainstream behaviour providers who provide the majority of services. For the 2010/11 year a total of \$12,835,087 was allocated to fund these contracts. In addition another \$3,269,894 is allocated to fund High and Complex Community Liaison Teams. Further the Ministry advises that a further \$200,000 of discretionary funding is available to NASC for BSS. These totalled \$16,304,981 for the 2011/12 year.

Autistic Spectrum Disorders (ASD) has a ring fenced allocation of \$5m, out of which \$950,000 is allocated for BSS.

For the purposes of this project no new or additional funding is anticipated for BSS for the 2011/12 and future years.

In summary the present (2010/11) funding for BSS is:

- |  |                            |
|--|----------------------------|
| • BSS contract funding plus discretionary provisions | \$16,304,981               |
| • ASD BSS  | <u>950,000</u>             |
|  | <b><u>\$17,254,981</u></b> |

## 6. Method, findings and discussion

In undertaking this project a project management approach was adopted consisting of the following components:

- clarification of deliverables and outputs, including a briefing by the Ministry of Health on 19 January 2011 which signalled commencement of the project
- development of six principles by the project team which were applied to the approach, analysis and proposed solution and recommendations:
  - nationally consistent access – **equity** for eligible referrals
  - responsive but flexible – meeting client **needs**
  - integrated across the service continuum – no **gaps** or **delays**
  - evidence-based practice – **best practice** and outcomes orientated
  - clinical leadership and engagement – **clinician led**
  - sustainable over the longer term – affordable and **value for money**
- development of a sector communication plan, including monthly updates posted on the Ministry's website
- data gathering and analysis which revealed solid information about the financial value of the contracts but variable quality material on utilisation and outcomes
- consultation process and stakeholder visits, carried out according to a template
- model development and literature review, which relied on comparing the current practice against the contracted specification, revisiting earlier work and researching arrangements in other jurisdictions – principally Australia and the UK
- development of a procurement plan to support the proposed service arrangements
- risk analysis and mitigation as assessed by the project team.

The project team comprising Ms Suzanne Win, Dr Frances Hughes and Mr John Ayling commenced the project on 19 January 2011. The project was completed by the planned completion date of 30 June 2011.

### Method

Qualitative and quantitative information have been used in the project, including a desk review, interviews with staff involved with the service, interviews with clients of the service and a review of material retained by the service, including client files.

The project team considered a range of documentation, including:

- service specifications
- previous project materials
- documents relating to organisational management and service structure
- documents relating to models of care, case management, referral processes and outcomes and any other relevant papers.

A list of the documents reviewed is in Appendix II.

## Findings

As noted earlier the project team met with a wide range of providers, NASCs and consumers. Each meeting followed a structured agenda. The conclusions reached from these meetings clearly confirmed many of the observations from earlier projects:

- variability of access to BSS and associated waiting times
- inconsistent approach to BSS delivery
- clients and their families have little influence on the structures and service being provided
- reporting to NASCs by providers is variable
- variable maturity of relationships among providers and also between providers and specialist clinical services within DHBs
- some beginning evidence of working together and joint work but not across all providers
- range of skills and qualifications, including some that are not in line with the service specification
- little evidence of clinical leadership
- need for greater national quality approach, including action research.

These reaffirmed earlier observations which concluded the following.

- 'We don't know who is getting Behaviour Support.
- We don't know how long people are getting Behaviour Support.
- We don't know how many 'Eligibility Assessments' we are buying.
- We don't have confidence that the providers are prioritising referrals in a way that the NASC/Ministry of Health would want them to (they may just go on the end of the waitlist).
- We don't have confidence that the right people are getting Behaviour Support (ie, people in residential care may be getting Behaviour Support over people in the community.<sup>vii</sup>

### *Variability of access to Behaviour Support Services and associated waiting times*

This project again confirmed that there are a number of entry points into BSS. Some are referred via the local NASC, some are self-referred and a number of residential care providers assess clients as needing BSS and refer them directly to their own BSS. Such variable arrangements raise issues of equity of access and questions over eligibility. Equally the capacity to monitor outcomes and service efficacy becomes problematical.

The project established that there is significant and unacceptable variation in waiting times for access to BSS. It ranges from some services who claimed a 'nil' wait time to another where there was a wait time in excess of 18 months. From the data available it is difficult to establish the reasons for such a variation. Given the unreliability of the waiting times data, the project team places little confidence on this marker of 'need'.

### *Inconsistent approach to Behaviour Support Services delivery*

The project team visited and interviewed over 120 individuals from a variety of organisations and interests and teleconferenced with five. One aspect of the findings was again the inconsistent approach to the provision of BSS. This ranged from how referrals were received and dealt with, eligibility assessment, development of a care plan, monitoring and discharge. In some instances people on a behaviour support programme have never been discharged. Further there is variability on training and discipline background, how the practitioners providing BSS are supervised, how

they maintain their professional standards and ongoing maintenance of this aspect of professional practice.

As noted earlier the project team came across a number of examples where residential care providers who also hold contracts for BSS refer clients directly into their own service without necessarily going through the local NASC. Further there is a provider of neuro-behavioural services whose clients do not meet the intellectual disability criteria but are accessing BSS. The project team is troubled by these arrangements and while we don't believe it warrants a recommendation (because what is proposed excludes such arrangements); it is an example that compromises the principle of equity of eligibility and consistency of access.

*Clients and their families have little influence on the structures and service being provided*

The project team met with the Consumer Consortium on 19 April. That was a very useful session in that a number of consumers and delegates indicated some issues with the current arrangements. The project team also heard from Parent to Parent and Autism New Zealand, whose concerns related to:

- waiting times
- geographic differences in access to and the location of services
- services that better meet people with autistic needs
- ASD without an intellectual disability diagnosis is not covered in the current national BSS specification.

*Reporting to NASCs by providers is variable*

As has been noted earlier the reporting arrangements across all NASCs are variable, which raises doubts over the quality of the data upon which to assess service utilisation. While some analysis has been undertaken the project team is not confident that it reflects or presents a true picture of BSS utilisation.

*Variable maturity of relationships among providers and also between providers and specialist clinical services within DHBs*

Again, and consistent with earlier observations, there is considerable variability among the provider community in their relationships with the clinical services of DHBs. While some services have informal professional relationships (some of long standing), in others no such relationships exist. The project team became aware that in some cases there was a view that DHBs are not interested or indeed philosophically aligned with respect to disability, to the extent that any clinical collaboration with DHB colleagues could be difficult. In the context of the principles adopted for this project this is a matter that is clearly inconsistent with evidence-based best practice and clinical leadership and engagement, which needs to be remedied with some urgency.

*Some beginning evidence of working together and joint work but not across all providers*

The project team did come across examples of some providers in recent times looking to develop the capacity of BSS by researching opportunities for collaboration. These are to be encouraged. Consideration should be given to some form of integration of clinical capacity with the proposed Regional Specialist BSS on the grounds of:

- professional support
- strengthening of clinical leadership
- efficiency in the utilisation of support functions
- improved integration of team skills and competencies
- better capacity to transition back into mainstream disability services.

*Range of skills and qualifications, including some that are not in line with the BSS specification*

The project team came across situations where the qualifications of staff providing BSS were not consistent with the requirements of the service specification.

*Little evidence of clinical leadership and clinical governance*

Apart from some small pockets of optimism, there is little evidence of the principles of clinical leadership being currently applied to BSS. Clinical leadership is a relatively new aspect of health and disability services management. It involves clinician and other health practitioners having an active role in how a service is planned, organised and managed.

‘I often refer to clinical leadership as “the sword in the stone”; a powerful force for good if you can just get it out of the stone and wield it!!

Doctors love taking authority and are seldom prepared to take responsibility for performance and almost never for productivity and metrics which bring together performance and cost.

When they do it is magic! Couple it with innovation and change management and you have everything your heart desires.’<sup>viii</sup>

‘Clinical governance is the system through which health and disability services are accountable and responsible for continuously improving the quality of their services and safeguarding high standards of care, by creating an environment in which clinical excellence will flourish.’<sup>ix</sup>

‘Clinical governance is the system. Leadership, by clinicians and others, is a component of that system.’<sup>x</sup>

The Ministerial Review Group’s report to the Minister, *Meeting the Challenge* (July 2009) devoted considerable attention to ‘clinical leadership’<sup>xi</sup>.

The project team came across a few examples of clinical leadership either embedded or beginning to be embedded. But generally there was little evidence of practitioners within BSS having a formal role in the management of the service. It is noted, however, that there is clinical leadership within the provisions of the Intellectual Disability Compulsory Care Act (through the workings of the Community Liaison Teams) which could be relevant to the proposed service and in doing so provide a good interface between forensic services and mainstream intellectual disability services.

For behaviour support services to be recognised and operate as a specialist service, clinical leadership from all of the various professional interests needs to be developed and embedded in this service. As might be expected, current services linked or associated with DHBs exhibit greater evidence of this.

#### *Need for greater national quality approach, including action research*

Conversations with both Ministry and provider personnel indicate that, regardless of what funding and service arrangement is adopted, it must be underpinned and supported by a entity described in earlier projects as the Centre for Excellence. Whether this continues to be the description or not, the project team supports the need for such a body. Its role would be to foster and innovate for best practice within the New Zealand context. Such an entity could comprise service leadership (both management and clinical) with a presence from academia, education and clinical specialties. Its functions would be to:

- create training and clinical internship opportunities
- develop relevant research to support New Zealand-specific evidence-based practice
- provide a forum for clinical leadership and perhaps be a vehicle to host the establishment of a formal national BSS network with a focus on shaping processes and interventions that give value to a service user rather than focus on structures.

#### *Workforce*

Staff working with clients in disability services should have access to appropriate behavioural support education and training. Those who work in BSS should also have access to more specialised initial and ongoing training – through their undergraduate and postgraduate discipline education and once in the BSS field. It is of concern that no consistent form of behavioural support training based on evidence-based practice has been identified for staff in disability services. This is further compounded for those BSS workers who are not from a regulated professional discipline. Too many providers have had to develop their own training initiatives, resulting in wide variation. This results in large investments of training which is not aligned to an NZQA pathway, not professionally recognised and not transferable.

There is also a need for strategies and systems that enable staff to access appropriate training and ongoing development. Such processes could involve:

- an evaluation of current programmes to establish a benchmark for disability support workers and those employed in BSS
- Ministry disability workforce funding being better targeted to BSS staff
- encouraging and enabling disability support workers to access training specifically relating to intellectual disability
- the Ministry working more closely with regulatory bodies of occupational therapy, nursing, psychology, social work and medicine to recognise the need of their disciplines to incorporate behavioural support into undergraduate and postgraduate programmes that they have responsibility for approving.

## Discussion

In summary it is clear that there are systemic issues, (some of long standing) associated with the present arrangements by which BSS are funded, accessed, provided and monitored.

The project team is not confident that a 'general tidy up' of the present arrangements will address the issues identified in this and earlier projects. The present focus on contract compliance and its concomitant impact on the relationships among providers and between them and the Ministry (and DHBs), confirm that a new approach towards BSS is necessary for service development, building capacity and investing in best practice.

A recent joint report from the Royal College of Psychiatrists, the British Psychological Society and the Royal College of Speech Therapists (June 2007) noted that:

'The service community (the people commissioning and planning services, providing them, working in them and using them) needs to recognise that challenging behaviour is relatively common in services for people with learning disabilities and that it is unlikely to disappear as the result of shortterm treatment. The implication is that the present model, in which support is almost entirely provided by unqualified and unskilled staff, relying on a small amount of specialist services to help them or deal directly with the most challenging individuals, needs to be replaced.'<sup>xii</sup>

Appendix III provides a précis of the interviews and discussions with contracted behaviour support providers during March and April 2011.

Appendix IV summarises responses from the survey of NASCs conducted by the project team in April and May 2011.

## 7. Demographics

In light of the earlier limitations on utilisation of BSS, the project team reviewed (by NASC) the number of people assessed and registered as having a primary intellectual disability diagnosis. On average across the country, 24% of those registered are 17 years or under.

**Table 1:** Summary by NASC of the distribution of the registered intellectually disabled population

NASC	Clients				
	0–17 yrs	18 yrs +	Total	0–17 yrs as %	18 yrs + as %
AccessAbility – Otago/Southland	218	797	1,015	21.5%	78.5%
AccessAbility – Taranaki	104	325	429	24.2%	75.8%
AccessAbility – Whanganui	31	124	155	20.0%	80.0%
Capital Support – Wellington	69	128	197	35.0%	65.0%
Disability Support Link – Waikato	365	1120	1,485	24.6%	75.4%
Focus – Wairarapa	36	136	172	20.9%	79.1%
LIFE Unlimited – Hutt Valley	124	345	469	26.4%	73.6%
LIFE Unlimited – Tairāwhiti	38	118	156	24.4%	75.6%
LifeLinks – Canterbury/West Coast	325	1334	1,659	19.6%	80.4%
NorthAble – Northland	112	374	486	23.0%	77.0%
Options – Hawke’s Bay	110	388	498	22.1%	77.9%
SupportLinks – Manawatu	54	95	149	36.2%	63.8%
SupportNet – Bay of Plenty/Lakes	207	736	943	22.0%	78.0%
Supportworks – Nelson Marlborough	93	533	626	14.9%	85.1%
Taikura – Auckland	987	2549	3,536	27.9%	72.1%
AccessAbility – Auckland RIDCA*	3	68	71	4.2%	95.8%
Capital Support – RIDCA	40	40	80	50.0%	50.0%
Disability Support Link – RIDCA		27	27	0.0%	100.0%
LifeLinks – RIDCA	1	97	98	1.0%	99.0%
<b>Totals</b>	<b>2,917</b>	<b>9,334</b>	<b>12,251</b>	<b>23.8%</b>	<b>76.2%</b>

\* Regional Intellectual Disability Care Agency

**Table 2:** Summary by region of client distribution.

REGION	NASC	Clients			
		0–17 yrs	18 yrs +	Total	% of Total
<b>Southern</b>	AccessAbility – Otago/Southland	218	797	1,015	
	LifeLinks – Canterbury/West Coast	325	1,334	1,659	
	Supportworks – Nelson Marlborough	93	533	626	
	LifeLinks – Southern RIDCA	1	97	98	
	<b>Region totals</b>	<b>637</b>	<b>2,761</b>	<b>3,398</b>	27.7%
<b>Central</b>	AccessAbility – Whanganui	31	124	155	
	Capital Support – Wellington	69	128	197	
	Focus – Wairarapa	36	136	172	
	LIFE Unlimited – Hutt Valley	124	345	469	
	Options – Hawke’s Bay	110	388	498	
	SupportLinks – Manawatu	54	95	149	
	Capital Support – Central RIDCA	40	40	80	
	<b>Region totals</b>	<b>464</b>	<b>1,256</b>	<b>1,720</b>	14.0%
<b>Midland</b>	AccessAbility – Taranaki	104	325	429	
	Disability Support Link – Waikato	365	1,120	1,485	
	LIFE Unlimited – Tairāwhiti	38	118	156	
	SupportNet – Bay of Plenty/Lakes	207	736	943	
	Disability Support Link – Midland RIDCA		27	27	
	<b>Region totals</b>	<b>714</b>	<b>2,326</b>	<b>3,040</b>	24.8%
<b>Northern</b>	NorthAble – Northland	112	374	486	
	Taikura – Auckland	987	2,549	3,536	
	AccessAbility – Auckland RIDCA	3	68	71	
	<b>Region totals</b>	<b>1,102</b>	<b>2,991</b>	<b>4,093</b>	33.4%
	<b>Totals</b>	<b>2,917</b>	<b>9,334</b>	<b>12,251</b>	

There appears to be no New Zealand data to confidently calculate the incidence of behaviours that would warrant referral to a specialist BSS.

A UK survey found that approximately one in six people with learning disabilities engage in behaviours which represent a significant challenge to their carers (Kiernan and Qureshi 1993). These challenging behaviours include aggression, self-harm, over-activity, damage to the environment, persistent screaming or shouting, and a range of odd, unusual or socially unacceptable mannerisms and acts.<sup>xiii</sup> Applying this measure to the NZ population suggests that nationwide approximately 2040 people may require access to specialist BSS.

That same UK survey showed that the average caseload per community support team was 34 (range 2–230) and the average practitioner caseload was between 1 and 25 based on the model of

service delivery. For sizing purposes within the New Zealand context this would be equivalent to approximately 60 teams if the average of 34 was applied. Clearly this is unachievable, unaffordable and unsustainable. It confirms the need for reliable case mix measures to be an early aspect of the implementation plan in order to better assess current caseload (volumes and intensity) before any definitive position on resourcing can be established.

## **8. Service model**

Anticipated service models need to encompass a number of streams, such as intellectual disability behaviour support, wider disability behaviour support (including sensory and physical), eligibility, high and complex, and ASD. Given that ASD falls outside the eligibility policy for mainstream Disability Support Services, the project team considers that a separate service specification for this component should be developed in accordance with the ASD guidelines.

The consultation with providers and consumers suggests (with some confidence) a two-tier approach to the model design for BSS. The first, or primary tier, falls within the expected competencies of an experienced disability support worker. The competencies for low level intervention are those required to manage individuals who express themselves through difficulties in managing their own behaviour, including training which focuses on understanding of behaviour, strategies that encourage holistic understanding of the individual, and de-escalation. Generally it would be expected that an experienced Disability Support Worker would have training in calming and de-escalation (Institute of Behavioural Analysis) and Non-Violent Crisis Intervention (accredited by the Crisis Prevention Institute). There is no recognised competency training based on the NZQA framework. The project team considers that behavioural support should be a unit standard for level 3 which can be incorporated into national certificates and diplomas – such as human services and the like.

Supporting the day-to-day practice of disability support workers would be the specialist tier 2 services, described for the purposes of this project as a Regional Specialist BSS team. This team would assess and manage more complex referrals of clients who present with challenging behaviours – the management of which is outside the competencies of a Disability Support Worker.

This tier 2 service is the focus of this project in terms of ensuring compliance with the principles developed by the project team that BSS be:

- nationally consistent access – equity for eligible referrals
- responsive but flexible – meeting client needs
- integrated across the service continuum – no gaps or delays
- evidence-based practice – best practice and outcomes orientated
- clinical leadership and engagement – clinician lead
- sustainable over the longer term – affordable and value for money.

The premise of this separation is based on the following:

- All those who work with disability clients need to have training and education in understanding behaviour in a holistic context
- All disability support workers in residential services should provide an environment and support for the individual's health and normal self-expression

- Service issues such as incompatibility and physical health problems should be managed by the residential services provider.

The proposed service model for specialist BSS acknowledges earlier work as well as findings on the present practice and service arrangements. The project has developed a pathway which it considers should be adopted in order to ensure consistency of access to BSS. The four decision points are as follows.

1. Does the referral meet the criteria for eligibility and if so what is the urgency?
2. If criteria are met, the referral is allocated for either an emergency intervention or a planned intervention to include discharge and outcome expectations, training and support, any direct services needs and proposed therapeutic interventions.
3. Regular review of the planned intervention to determine how it is to be continued or modified to reflect the contribution of significant others, such as family, partner, school, and other residents.
4. Discharge, which is a joint decision including the family, significant others and/or the residential provider.

Diagrammatically it is represented in the form of a flow chart (or pathway) at Appendix V. The project team proposes that the service model as described be applied as a nationally applied service pathway that underpins a robust service specification for people presenting more complex referrals involving challenging behaviours.

Within the pathway the project has considered the various components and competencies associated with the decision points by the Regional Specialist BSS Team. These will need to be further developed (and validated) as part of the service development process. Three categories of intensity are proposed, as follows.

- **One-off** interventions – if it is assessed that the service user should need only a single intervention. This would include referrals for behaviours associated with incompatibility, environment and responses to changes in life.
- **Moderate** interventions – for referrals requiring a mix of interventions at a range of professional competencies. Typically these referrals would be exhibiting a number of challenging behaviours of some duration and present some risk on account of their severity, and require a mix of interventions over a period of time. The expected end result would be to reduce the frequency and intensity of the challenging behaviour so that the service user can be managed within the tier 1 competencies outlined earlier.
- **High and complex** interventions – are those requiring a more active mix of clinical skills in order to manage all aspects of the behaviour. It would be anticipated that these referrals and plans may require active clinical management and project over a sustained period of time in order to minimise the 'intensity, frequency or duration of behaviour that threatens the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.'<sup>xiv</sup>

Appendix VI summarises the proposed approach for managing referrals to the Regional Specialist BSS.

A key element of our proposed approach to the establishment of Regional Specialist BSS is the presence of multidisciplinary teams, which would operate through two mechanisms. Firstly, to apply

the collective knowledge and skills of the various clinicians, and secondly to use various processes and tools to assess, guide, plan, review and discuss individual cases. Regional Specialist BSS would include, as a minimum:

- psychiatrists with a special interest in intellectual disability
- psychologists
- speech language therapists
- mental health nurses, with a focus on education, psychological and physical health
- associated health workers, such as occupational therapists and social workers
- behaviour support workers.

These teams would each have formal negotiated access arrangements with a designated DHB allowing regular access to clinical services such as psychiatry, child and adolescent services and paediatrics. Further, to ensure physical health implications are covered, a GP (preferably the service user's own) would need to be actively involved.

An important and fundamental aspect of the Multi Disciplinary Team (MDT) role, (besides managing assessments and interventions) is to provide support and education to families and significant others. In the case of residential care providers, the ongoing availability of the BSS team will build the staff's confidence in the understanding of behaviour and de-escalation strategies. A recent joint report from the Royal College of Psychiatrists, the British Psychological Society and the Royal College of Speech Therapists (June 2007) noted that: 'behaviour [support] services need to use their specialist skills to help managers in the provider network lead their staff in the provision of local services'..<sup>xv</sup>

Intuitively the project team considers that active and focused interventions (as opposed to maintenance programmes), will reduce the need for some of the high-cost packages. However, in the light of limited financial information and unreliable utilisation data, it has not been possible to validate this. It confirms the view that this is a gap that needs to be filled by relevant research in the New Zealand context.

### **Proposed service arrangements and governance options**

There are a number of options by which BSS could be organised and structured. While form is an important part of the project, the core function and purpose of specialist BSS has to prevail. The project team has identified the following service configurations that it considers could offer a well-performing Regional Specialist BSS:

- a. Present contracting arrangements for BSS continue but work is done to improve consistency and rigour in access and service arrangements and achieve greater cooperation among providers.
- b. Transfer the present funding and service obligations in their entirety to DHBs to negotiate suitable local contracts for BSS.
- c. National funding and service obligations for BSS continue with the Ministry but it negotiates regional service arrangements with preferred providers.

- d. The Ministry facilitates the establishment of regional service arrangements for BSS between providers and DHBs.
- e. Individuals requiring BSS have individual funding packages by which they fund and organise access to BSS as required.

Appendix VII provides a brief summary of the key features, benefits and risks of options (b), (c) and (d).

Options (a) and (e) have been discarded at this time. The project team considers that (a) would carry a number of risks particularly with respect to sustainability and value for money, and for which the only a viable long-term solution providing reasonable mitigation is a revised service model. Option (e) is not considered to provide sufficient remedy to the issues of inconsistency and variability that presently characterises BSS. It may remain an option when there is more confidence in the capability of BSS providers, although any developments of this option would need to carefully assess the implications for maintaining cohorts of competency and also possibly a suitable monitoring framework.

Option (b) is also not proposed on the grounds that to do so would transfer the present service risks directly to DHBs, which could further compromise the earlier described service principles and capacity to achieve a consistent national arrangement.

Option (c) leaves open a possible future migration to option (d) on the grounds that there would then be an opportunity for a partnership approach involving the Ministry, NGO providers and designated regional DHBs to establish BSS as a respected specialist service.

The project team considers that the establishment of Regional Specialist BSS along the lines proposed provides an exciting opportunity for innovative partnerships between existing NGO providers and DHBs to assume responsibility for providing this service in a manner consistent with the principles (as described on page 9) that have underpinned this project.

It is inevitable that when structures are proposed they are often considered to be the only lever to enhancing responsiveness and improving outcomes. The project has established that there are a number of informal networks (such as the Behaviour Support Alliance) currently involved in BSS. These informal networks are voluntary and loosely connected, often forming around specific issues such as the recent project on staff competencies. This is appropriate if the objective is sharing good practice or coming together for specific projects. However, it is our observation that they are predominantly vehicles by which interests are represented. The lack of formal recognition has implications for service development, particularly when there is no mandate or presence of the Ministry.

Whatever arrangement is adopted should be underpinned by a more formal network arrangement where relationships are continuous and where there are agreed (but definitive) rules, standards and behaviours and where members of the network surrender sovereignty to achieve shared objectives. These types of networks can be defined as a set of relationships between individuals and organisations working together to achieve a common goal.<sup>xvi</sup> It is an aspect of service leadership that appears to be relatively underdeveloped for BSS. The project team is of the view that the establishment of a clinical network for BSS would allow issues of access, variability in wait times and outcomes to be addressed.

## Leadership

The project team is proposing that the development of the earlier mentioned tier 2 Regional Specialist BSS be underpinned by the establishment of a clinical network with both regional and national responsibilities for service development and quality outcomes.

The NHS Scotland plan, Our National Health, defined managed clinical networks as:

‘...linked groups of health professionals and organisations from primary, secondary and tertiary care working in a co-ordinated manner, unconstrained by existing professional and existing organisational boundaries to ensure equitable provision of high quality effective services.’

The plan contrasted these with loose networks, which it describes as ‘woolly constructs’.<sup>xvii</sup>

Organisations have traditionally solved problems of coordination by using either markets – to commission services from external suppliers, or hierarchies – to provide the service themselves in-house. Which approach is chosen is, in theory, determined by the relative costs of the different solutions and the importance of direct control for managing risk. Networks offer a new option which is particularly suited to situations with high levels of uncertainty and a need to coordinate multiprofessional and multisite teams, and where simple solutions of outsourcing or vertical integration fail to address the problem of how to coordinate complex activities.<sup>xviii</sup>

The project team considers that some of the transition risks associated with a new approach to the provision of specialist BSS can be mitigated by the network approach outlined above.

It is in this context that the project team believes that a New Zealand version of the Queensland Centre of Excellence can play a role by supporting both clinical practice and clinical leadership through internship and research opportunities.

## 9. Transitioning for the future

To set up the new Regional Specialist BSS, a managed transition will be necessary. This includes:

- moving to greater consistency of access and eligibility, along with the development of a transparent access and urgency (prioritisation) tool
- formalising training and education for behaviour support staff
- building relationships, particularly with DHBs, and establishing clinical leadership and regional networks for BSS
- establishing a reliable data collection and reporting system
- aligning with other special needs providers
- building confidence between providers, clients and families.

## Managed transition

### *Consistency of access and eligibility*

The findings clearly demonstrated considerable variability about how people in need of specialist BSS accessed those services. Not only does this compromise the principle of equity, but it also raises questions of costs and value for money in that people unable to get access may then require urgent and intensive care which an earlier intervention may have prevented. The project team proposes that in conjunction with sector interests, (the Ministry, NASCs, DHBs and selected providers) a tool be developed to transparently determine criteria for access and urgency.

#### *Formalising training and education for behaviour support staff*

All BSS are reliant on the expertise and experience of their staff to deliver specialist services required in the contract. As noted earlier those staff who are not employed as a regulated health professional need to have access to NZQA certificates and training programmes which incorporate units in behavioural support. Regulated health professionals employed in BSS should have had specialised BSS integrated into their specific discipline training. All behaviour support workers should have access to ongoing clinical supervision and professional development activities. Clear and focused engagement with the regulatory bodies in relation to their disciplines is needed to create a clear pathway for regulated disciplines to work in this area.

#### *Building relationships*

The project team recognises that there is considerable risk associated with transforming the present service arrangements into those proposed. It proposes that the implementation needs to invest in formalising a clinical network as outlined above. A network that engages clinicians involved in the provision of specialist BSS has the potential to: 'Provide configurations that may be more closely aligned to the patient's pathway and experience of care rather than to institutions or traditional professional fault lines.'<sup>xix</sup> Aligning with DHBs and their capacity will provide more certainty and confidence.

#### *Establishing a reliable data collection and reporting system*

The present reporting arrangements (with 74 reporting elements) are clearly unsatisfactory and give little confidence in terms of reporting integrity and predictive capability. Implementation of the proposed Regional Specialist BSS approach will require the development of a data collection and reporting system. Further discussion and agreement with key stakeholders is needed as to whether this becomes a stand-alone system or can be added to an existing system. Nevertheless, as a bare minimum such a system will need to reliably record (over time) the numbers:

- referred (new and returns/follow ups) for assessment
- of assessments undertaken
- waiting for assessment
- for which active intervention plans are in place
- being monitored.
- of cases closed/discharged with some agreed measures of outcomes.

Clearly whatever dataset emerges will also need to reflect ethnicity and domicile elements.

### *Aligning with other special needs providers*

The project team noted variability in the extent of and maturity of relationships with other special needs providers, such as Special Education, Child, Youth and Family and High and Complex providers, some of which prepare plans specific to their area of responsibility. Part of the implementation will be to ensure greater consistency, particularly in the detailed components of behaviour support intervention plans.

### *Building confidence between providers, clients and families*

There is a call from clients and families to have input into the design and governance of BSS. While this is a specialist service it is important to ensure that advice is sought on a formal basis to ensure that it is appropriate and responsive. It is proposed that for each regional service a consumer advisory group (including Māori and Pacific peoples) be established so service users, families and significant others can contribute and participate in the development of the services.

In summary these aspects of transitioning represent a mix of systems and tools, sector capacity and development and a new way of operating and relating. Some can be readily put in place with the necessary investments, such as prioritisation tools and reporting systems, while others are more evolutionary and require ongoing leadership, including training, relationships with other services and building confidence. The approach of the Ministry and the overall sector to this project will dictate the take up of the recommendations and the pace of improvement in the service.

## **Specifications**

The project team reviewed the following service specifications:

- Purchase Unit Code DSS220 – Behaviour Support Services for People with Intellectual Disability Presenting Behaviours that Challenge
- Purchase Unit Code DSSCLT – Community Liaison Team (CLT)
- Forensic Mental Health Services – Mental Health and Addiction Services – Tier Level Two Service Specification.

The review of DSS220 and DSSCLT concluded that although they are highly prescriptive, they are essentially relevant in terms of the access, referral, intervention and exit from the service.

However the absence of relevant quality of service and the outcome measures as key performance indicators does compromise their effectiveness. The Ministry should consider, as part of the implementation, working with providers and other interests to develop relevant indicators of utilisation and outcomes.

Our conclusions from this review of the specifications suggest that variable compliance with the specifications has contributed to our overall findings rather than any limitations in the specifications. Nevertheless DSS220 has been modified to reflect the proposed specialist service model and it is proposed that these be the basis by which the Ministry progresses its development of this service. There is a copy of DSS220 with suggested changes at Appendix VIII.

The Forensic Service Specification is far less prescriptive and has an outcomes focus, and it could be a model that is adopted by the proposed Regional Specialist BSS once set up.

The project team considers that there could be some integration benefits if a way could be found to integrate the clinical capacity of Community Liaison Teams into the proposed Regional Specialist BSS. Clearly this would need to be a longer-term consideration as the transition to Regional Specialist BSS will require careful management of the changes to the existing service arrangements. Nevertheless for the longer term it may provide benefits for the at-risk intellectually disabled population.

## **Training**

The findings of the project team with respect to training mirror observations from the literature in that attention needs to be given to behaviour support. The project team proposes that the Ministry initiate focused engagement with:

- the regulatory and professional bodies with respect to recognised competencies required to underpin a well-performing behaviour support service
- education and training providers with respect to development of relevant curricula
- Workforce New Zealand to put in place longer-term requirements for the behaviour support workforce.

The project team has not provided a specific training plan as it would need to include the results of the above discussions.

## **Procurement**

People with challenging behaviours need to be well-supported through timely access to responsive and competent services. The organisation of services has not provided the opportunity (or incentives) for cooperation between providers and access to ongoing professional peer support for staff. Separate and small-scale services (unless they are part of a well-supported network, of which there is presently very little evidence) are not sustainable. Thus the Ministry as part of managing the transition may wish to consider undertaking a formal review of present provider capacity to be considered to undertake the proposed service. Further, the project team considers that while the Regional Specialist BSS will have the necessary skills to undertake assessments and develop intervention plans that manage the risks of challenging behaviour, they will also have an important requirement to support residential care providers, other special needs providers and families. This expectation has been factored into the proposed specification and estimate of costs.

Clearly the proposal to establish Regional Specialist BSS with closer links to the specialist capacity of DHBs has a number of significant implications, not only for the way the service is presently contracted and provided, but also for the existing providers.

Subject to the Ministry consideration of the recommendations, the following key elements need to be taken into account as part of the procurement plan.

### *Receipt of the project report and consideration of recommendations*

The Ministry of Health considers the findings and recommendations, seeks clarification (if necessary) and undertakes the necessary briefing within the Ministry and possibly Minister(s). The Ministry will need to consider how it intends to manage the roll-out and the resources required. This is conservatively estimated as taking up to six weeks.

### *Briefings to the sector*

The Ministry convenes four regional forums which existing providers and the designated regional DHB attend. The Ministry would lead the briefings on the proposal to establish Regional Specialist BSS and the components of the transition plan. Part of that briefing would include the Ministry's intention to seek a Request for Proposal from each region – such proposals would clearly reflect a DHB and NGO governance and service partnership to establish and maintain a Regional Specialist BSS. The Ministry may consider giving providers and DHBs the opportunity to comment on this report and its recommendations but not in such a way as to constitute formal consultation. This, depending on the option for comment, is estimated to take another six to eight weeks.

### *Request for proposal*

The Ministry prepares the Request for Proposal (RFP) documentation and formally advises all existing contracted providers and designated DHBs of its intention to invite an RFP from each region – with the very clear expectation that the RFPs are to reflect a DHB and NGO partnership to establish and maintain a Regional Specialist BSS. The time for providing responses is estimated at 45 days.

### *Assessment of RFPs and finalisation of implementation plan*

The Ministry will assess the RFPs and make decisions applicable to each region, for which 30 days has been allowed. Concurrently the Ministry will finalise its proposed implementation approach and plan, taking into account the detail of each regional response. At this stage the Ministry confirms how it will undertake (or engage) relevant expertise to implement the Regional Specialist BSS in each region, and develop a specific implementation plan for each region. Those plans will need to cover:

- development and agreement of a service pathway whereby criteria and rules for access will be applied across all service teams, NASCs and providers using the pathways and its components as set out in this report
- development and implementation, in conjunction with NASCs and providers, of a common prioritisation tool to be used in all assessments to determine eligibility and urgency
- working in conjunction with contracted NGOs and designated DHBs to establish regional clinical networks (of which it is proposed that there be four across the country), that foster clinical leadership of multidisciplinary teams and take responsibility for service outcomes
- specifying a reliable data collection and reporting system for specialist behaviour support services
- formalising, in conjunction with professional bodies, training and education for their members who work as behaviour support staff in multidisciplinary teams
- achieving alignment and consistency with other special needs providers
- establishing a Centre of Excellence (or equivalent) to advance relevant New Zealand research, provide evidence-based guidelines and facilitate and support the maintenance of the clinical networks.

*Contractual matters*

The Ministry in accordance with its contractual obligations and having made decisions regarding the proposal for new Regional Specialist BSS, advises existing providers of its intention to cancel the existing contracts. It is understood that the present contracts require six months' notice. Contemporaneously the Ministry announces each of the successful regional providers and sets out the intention to migrate the present service arrangements to the establishment of Regional Specialist BSS.

*Commence implementation*

Implementation of the plans to establish the Regional Specialist BSS begins.

*Communication*

It is proposed that the present communication processes that applied during the project continue throughout the procurement process.

**Table 3:** Summary of steps and estimated timeframes

Table 3. Procurement - Provisional Timeline	2011/12											
	07/11	08/11	09/11	10/11	11/11	12/11	01/12	02/12	03/12	04/12	05/12	06/12
<b>Phase</b>												
Receipt of the project report and consideration of recommendations		█										
Briefings to the sector			█									
Request for Proposal (RFP)			█	█								
Assessment of responses and finalisation of implementation plan				█	█							
Contractual matters						█	█	█	█	█	█	█
Commence implementation						█	█	█	█	█	█	█
Communication		█	█	█	█	█	█	█	█	█	█	█

As part of the procurement plan the project team proposes that consideration be given to alliance contracting, which offers a different approach to contracting and sharing the complex risks of both service provision and funding. Appendix IX describes this approach in more detail. The underlying principle of alliance contracting is one of cooperative intent between the funders and the providers in managing the service accountabilities.

Again this is a matter for consideration as part of the implementation plan.

## **Indicative costs**

The project team was able to quantify the value of the contracts that fund the present arrangements. This total of \$17,254,981 (2010/11) has been set as the cap within which the proposed specialist service model needs to operate. Table 4 establishes (depending on the staffing mix) that approximately \$2.685m is the indicative cost of resourcing a single Regional Specialist BSS. For some regions clearly more than one team will be required. It does not necessarily follow that the aggregated costs will be multiplied by the number of teams, as support costs may benefit from economies of scale.

**Table 4:** Indicative Resource Plan for a Regional Specialist Behaviour Support Service

<b>Indicative Resource Plan for a Regional Specialist Behaviour Support Service</b>					
<b>Staffing Mix</b>	<b>FTEs</b>	<b>Base Rate</b>	<b>Total @ base rate</b>	<b>Plus 17.5% staffing on-costs</b>	<b>Total</b>
Psychiatrist(s)	0.5	175,000	87,500	15,313	102,813
Psychologist - senior (with leadership and managerial roles)	1.3	88,200	114,660	20,066	134,726
Psychologist - senior	1.0	88,200	88,200	15,435	103,635
Psychologist	2.0	67,750	135,500	23,713	159,213
Psychologist - trainee	2.0	52,550	105,100	18,393	123,493
Nursing (RN) with either Mental Health or Disability competencies	2.0	72,000	144,000	25,200	169,200
Speech Language Therapist	2.0	67,750	135,500	23,713	159,213
Social Worker	1.5	67,750	101,625	17,784	119,409
Occupational Therapist	1.0	67,750	67,750	11,856	79,606
Senior Behaviour Support Worker (Up to)	10.0	45,000	450,000	78,750	528,750
General Practitioner	0.3	150,000	37,500	6,563	44,063
MD Team Support	1.0	65,000	65,000	11,375	76,375
			<b>1,532,335</b>	<b>268,159</b>	<b>1,800,494</b>
Overhead Contribution - 10%					180,049
	<b>24.6</b>		<b>1,532,335</b>	<b>268,159</b>	<b>\$ 1,980,543</b>
<b>Occupancy and Support Costs</b>					
<b>Premises</b>	<b>Sq m</b>	<b>Rate/sq m</b>			
Floor rental (24 persons @ 15 sq m/person)	360				
Staff room/kitchenette @ 20 sq m	20				
Meeting room - 2 @ 25 sq m	50				
Consulting/assessment room - 2 @ 20 sq m	40				
Storage/cleaning - 1 @ 12 sq m	20				
Reception @ 20 sq m	15				
<b>Total sq metres</b>	<b>505</b>				
Provision for travelling and engineering space (20%)	101				
	<b>606</b>	225	136,350		
Occupancy Cost - 20% rental			27,270	<b>163,620</b>	
<b>Support Costs</b>					
Telecommunications			50,000		
Admin			40,000		
Publications/library/journals etc			20,000	<b>110,000</b>	
<b>Vehicles</b>					
	<b>No's.</b>	<b>Rate PA</b>			
Annual lease	15	7,500	112,500		
Running costs (\$500/mth)	15	6,000	90,000	<b>202,500</b>	
<b>Team Support</b>					
	<b>No's.</b>				
Computers/software	24	2,000	48,000		
Travel and accommodation - One outreach clinic per month - 3 persons @ \$2,500/visit (10 pa)			25,000		
General travel/accommodation			50,000		
Professional development			50,000		
National BSS Network Meetings - 2 pa			5,000		
Contingency provision			50,000	<b>228,000</b>	<b>704,120</b>
<b>Estimated Total Cost per Regional Service</b>					<b>\$ 2,684,663</b>

**Note:** Staffing on-costs are assumed as follows – 5% ACC, 4% Kiwi Saver, 2% Sick leave, 2% Training Leave, 2% Leave Cover, Contingency 2.5%

The project team considers that the Northern Region may well warrant two teams on account of scale and population. One team in each of Midland and Central is considered sufficient (at this stage) to manage the caseload. With respect to the Southern Region it is considered that there should be two teams (maybe of varying configurations) to cover the larger geographical area... The project team considers that there may be considerable transition risks associated with implementing a single South Island Regional Specialist BSS if it was to be via one of the two DHBs. Nevertheless, there would be an expectation of close collaboration between the two teams in such an arrangement.

On the basis of the findings the project team considers that there needs to be additional funds allocated to facilitate the national development of the Regional Specialist BSS.

Table 5 sets out an assessment of one-off and ongoing resources needed to facilitate and implement the proposed service model.

**Table 5:** Indicative Resource Plan for National Service Development of Behaviour Support Services

<b>Indicative Resource Plan for National Service Development of Behaviour Support Services</b>		
<b>Service Component</b>	<b>One off</b>	<b>Ongoing [PA]</b>
<b>Implementation</b>		
Implementation provision - (96 days + travel)	125,000	
<b>Service development</b>		
Service development - prioritisation	50,000	
Service development - national facilitation (2yrs)		50,000
<b>Regional Governance</b>		
Consumer forums (2 per annum per region)		30,000
Regional governance (4 per annum per region)		10,000
<b>National</b>		
Centre of Excellence		250,000
<b>Estimated Total National Cost</b>	<b>\$ 175,000</b>	<b>\$ 340,000</b>

## 10. Risk summary and proposed mitigation

There are a number of risks associated with adopting and enacting the recommendations. They include the risk of policy change, risk to existing services and transitioning to the proposed environment, capacity to implement and outcomes not being achieved. They are summarised as follows together with a suggested approach to mitigation.

<b>Policy and governance risk</b>	<b>Level of likelihood</b>	<b>Level of impact</b>	<b>Mitigation strategy</b>
Change in government policy re BSS services	Very low	High	Regularly brief
Failure to secure the endorsement or approval of key stakeholder(s) being the Ministry, designated DHBs and providers	Low	High	Actively ensure that endorsement can be achieved
<b>Services risk</b>			
<b>Services risk</b>	<b>Level of likelihood</b>	<b>Level of impact</b>	<b>Mitigation strategy</b>
Lack of progress inhibits development of specialist BSS	Low	High	Ensure that decisions are taken in a timely manner
NGOs and DHBs unable to propose viable service configurations	Low	High	Leadership by the Ministry to facilitate innovative proposal
Insufficient recognition of skills required, training and/or retraining	Med	High	Ensure that a well-funded training programme is part of the implementation plan.
Consumer/client safety and outcome	Low	Catastrophic	Well-resourced (money and skills) and organised training and transition programme
<b>Implementation risk</b>			
<b>Implementation risk</b>	<b>Level of likelihood</b>	<b>Level of impact</b>	<b>Mitigation strategy</b>
Costs have been underestimated	Low	Medium	Sound and rigorous assessment
Timing impact of costs being incurred	High	Low	Clarification under business rules to minimise any financial exposure
<b>Commissioning and evaluative risk</b>			
<b>Commissioning and evaluative risk</b>	<b>Level of likelihood</b>	<b>Level of impact</b>	<b>Mitigation strategy</b>
Non-compliance with specifications	Low	Medium	Sound implementation planning
Post-implementation evaluation exposes service limitations and increased patient risk	Low	High	Establish an evaluation framework as part of the implementation plan

These will need to be factored into the regional implementation plans and managed accordingly.

## 11. Recommendations

The project team recommends the following.

1. Regional Specialist BSS be established and distributed regionally (Northern, Midland, Central and Southern) across the country. Each team to be lead by clinicians and underpinned by joint governance arrangements between DHBs and NGOs with a focus on building consistent clinical and service capacity across the service continuum.

This responds to the findings of 'Variable maturity of relationships among providers and also between providers and specialist clinical services within DHBs' and 'Some beginning evidence of working together and joint work but not across all providers' and 'Little evidence of clinical leadership'.

2. A nationally consistent service pathway and revised service specifications be adopted and applied by the Regional Specialist BSS to deal with the present variability of access and service provision. The development of relevant quality and outcome KPIs should be part of any such revision. A prioritisation tool should be developed to assist in the management of referrals to Regional Specialist BSS.

This responds to the findings of 'Variability around how people gain access to BSS and variable access in terms of waiting times' and 'Inconsistent approach to behaviour support service delivery'.

3. A separate service specification for ASD clients be developed in accordance with the ASD guidelines.

This responds to the issue of eligibility and access for ASD clients.

4. As part of the implementation of Regional Specialist BSS, consumer advisory groups (which must include Māori and Pacific people) be established and resources allocated so consumers, families and significant others can contribute to and participate in the service.

This responds to the findings of 'Clients and their families indicate that they have little influence on the structures and service being provided'.

5. A consistent data-gathering and reporting system that reports on actual utilisation and outcomes be established.

This responds to the findings of 'Reporting to NASCs by providers is variable'.

6. The Ministry consider and detail the proposed role of a Centre for Excellence in the New Zealand context, with a focus on:

- creating training and clinical internship opportunities
- developing relevant research to support New Zealand-specific evidence-based practice
- providing a forum for clinical leadership and perhaps being a vehicle to host the establishment of a formal national behaviour support network with a focus on shaping processes and interventions that give value to clients, providers and funders.

This responds to the findings of 'Need for greater national quality approach including action research, the need for evidence-based practice, best practice which is outcomes orientated'.

7. The Ministry initiate an approach and engage with Health Workforce NZ, the various professional and regulatory bodies and training providers to:
  - review the current programmes being provided to establish a benchmark for disability support workers, and those employed in all BSS
  - better target disability workforce funding to the staff of all BSS, by encouraging and enabling disability support workers to access training specifically relating to intellectual disability
  - to develop a process to work closely with regulatory bodies of occupational therapy, nursing, psychology, social work and medicine to recognise the need of their disciplines to incorporate behavioural support into undergraduate and postgraduate programmes and ensure a career pathway relevant to behaviour support.

This responds to the findings on 'Workforce'.

8. The Ministry considers, for the longer term, some form of clinical integration between the Community Liaison Team service and the proposed Regional Specialist BSS.

This responds to the principles of 'service integration, value for money and sustainable utilisation of the clinical resource'.

9. Relevant changes are made to other specifications in contracts that relate to behaviour support such as:
  - needs assessment coordination
  - residential services
  - Community Liaison Teams.

This responds to the findings on 'variability in alignment with other special needs services'.

## Organisations and individuals consulted during the Behaviour Support Project

Organisation	Name	Position
IDEA Services Ltd	Gerald Ward	Clinical Leader Behaviour Support
	Sharon Brandford	Clinical Director
Tautoko Services Charitable Trust	Jan Perkins	Chief Executive
	Andrea McLeod	Chairperson
	Roz Lumsden	Behaviour Support Facilitator
Spectrum Care Trust Board	Chris Harris	Chief Executive
	Warren Herring	General Manager – Operations
	Kaye Leng-Tindall	Service Manager
	Linzi Jones	Clinical Leader
	Barry McGrath	Clinical Psychologist
	Erin Zhai	Behaviour Therapist
	Geoff Pratt	Behaviour Therapist
	Gill Mudford	Behaviour Therapist
	Jon Manson	Behaviour Therapist
	Natasha Hutchinson	Behaviour Therapist
	Raewyn Stevens	Behaviour Therapist
	Sarah Buckland	Behaviour Therapist
	Cheryl D'Silva	Administrator
Te Whanau O Waipareira Trust	Tania Te Tito	Kaiwhakehere
	Grace Winther	Team Leader
	Audrey Kingsley	Kaimahi
	Isobella Arnold	Kaimahi
Community Living Trust	Marese McGee	Chief Executive
	Bev Kohleis	Manager BAT
NZCare Group Limited - Explore Services	Donna Mitchell	Group General Manager
	Louise Mitchell	Service Manager
	Joan Cowan	Service Manager
Southern Behaviour Support Ltd	Karen Jackson	Director

<b>Organisation</b>	<b>Name</b>	<b>Position</b>
Canterbury DHB	Cate Kearney	Service Manager
	Ngairé Matthews	Manager IDCT
	Chris Daffue	Consultant Clinical Psychologist
Southern DHB	Karen Carter-Moore	Charge Nurse, Manager Intellectual Disability Service
	David Bathgate	Consultant Psychiatrist
	Steve Bain	Service Manager, Mental Health
Dunedin Community Living Trust	Barney Cooper	Chief Executive
	Adrian Higgins	Operations Manager
	Kurstyn Stedman	RIDSAS Manager, Care Manager, Behaviour Specialist
	Mike Brummitt	Behaviour Specialist
	Sarah Hayes	Behaviour Specialist
	Wendy Stedman	Intern Behaviour Specialist
	Angela Jowett	Intern Behaviour Specialist
Donald Beasley Institute	Brigit Mirfin Vietch	Director
Ministry of Health	Anthony Duncan	National Clinical Advisor IDCCR
Capital & Coast DHB	Roseanne Johnstone	Manager
	Frank Ngatai	Care Coordinator RIDCA
	Arlene Carian-Waiwai	Care Coordinator RIDCA
	Dian Birchall	Transition Coordinator RIDCA
	Jenny Gordon	Nurse MHID Team
	Micheal Dorafaoff	Team Leader MHID Team
	Anne Mathieson	Clinical Psychologist MHID Team
	Sandy Smith	Mental Health Nurse MHID Team
Waitemata DHB	Pauline Beck	Unit Manager
	Vicki Collier	Team Leader IDOLS
	Dr Joseph Sakdalan	Clinical Psychologist
Autism NZ	Allison Molloy	Chief Executive

<b>Organisation</b>	<b>Name</b>	<b>Position</b>
Auckland DHB	Adele Wakeham	Manager
	Rudi Kritzinger	Clinician
	Anita Martins	CNS Team Member
Parent to Parent	Peter Campbell	Chair
	Anne Wilkinson	Chief Executive
Brackenridge	Rachel Price	Manager High Needs Services
	Cheryl Cottle	Manager Training and Quality
	Julie Hampton	Behaviour Specialist
	Sandy Savin	Behaviour Specialist
	Lynlee Stanworth	Manager Adult Residential Services
Waikato DHB	Chris Floyd	Clinical Nurse Specialist Liaison Team
	Richard Blakey	Forensic ID Nurse

<b>Needs Assessment Service Coordination Organisations</b>		
<b>Organisation</b>	<b>Name</b>	<b>Position</b>
Lifelinks	Anne Simpson	General Manager
Support Works	Karen Bailey	Manager
Support Net	Renee Delamere	Manager
Support Link		
Capital Support	David Darling	Manager
AccessAbility Taranaki/Whanganui	Wendy Kopura	Service Manager
Access Ability	Sue Hansson	Manager
Disability Support Link	Kim Holt	Manager
	Lizette Huitema,	Care Coordinator
	Michelle Cameron,	Care Coordinator
	Barbara Walters,	Service Coordinator
	Leanne Heke,	Service Coordinator
	Susan Rogers	Service Coordinator
Northable	Noel Matthews	President NASCA
	Rosalie Eilering	Manager NASC

Taikura Trust	Maricar Donila	Practice Advisor
Focus	Helen Dore	Manager
Life Unlimited	Marlon Hepi	Manager
Options Hawke's Bay	Karen Mora	Manager

<b>National Disability Providers Network Workshop</b>	
<b>Organisation</b>	<b>Name</b>
Spectrum Care	Heather McGill
Dunedin Community Care Trust	Jan Walters
Dunedin Community Care Trust	Barney Cooper
Community Connections	Jo Mason
Community Connections	Amy Cole
Community Connections	Tracey Whale
Community Connections	Christine Spooner
Community Connections	Rose Morris
Community Connections	Maggie Rawnsley
Rescare Homes Trust	Tania Shine
The Supported Life Style Hauraki Trust	Sandra Higgs
Options – Manawatu Supported Living	Carole Sebborn
Neighbourhood Connections	Marie Calderbank
Tautoko	Jan Perkins
SILC Ltd	Terese Germon
SILC Ltd	Ellie Davies
SILC Ltd	Charlene Watene
Hawkesbury Community Living Trust	Jo McGavin
Te Roopu Taurima O Manakau	Lorraine Bailey
Iris Ltd	John Wade
Laura Fergusson Trust Canterbury	Sonia Pratt
Laura Fergusson Trust Wellington	Sue Thompson
New Zealand Disability Support Network (NZDSN)	Lynne Blair
New Zealand Disability Support Network (NZDSN)	Sandie Waddell
Pact	Thomas Cardy
Totara Farm Trust	Trudy McDonald

<b>Ministry of Health Disability Consumer Consortium Members</b>	
<b>Organisation</b>	<b>Name</b>
Rescare	Lena Berger
Carers New Zealand	Wendy Brenkley
Cerebral Palsy Society of NZ	Harvey Brunt
Cerebral Palsy Society of NZ	Allison Franklin
Deaf Blind NZ Incorporated	Merv Cox
NZ Down Syndrome Association	Neville Strong
Hearing Association	Heather Dawson
Autism New Zealand	Wendy Duff
Autism New Zealand	John Grealley
PIASS Trust	Lolomanaia Filiai
PIASS Trust	Simona Mataiti
People First	Phyllis McPherson
People First	Robert Martin
IHC Advocacy	Christine Morrison
Royal NZ Foundation of the Blind	Chris Orr
Deaf Aotearoa NZ	Karen Pointon
Parent to Parent	Venessa Rice
Ngati Kapo o Aotearoa	Lee Rutene
CCS Disability Action	Mathilda Schorer
CCS Disability Action	Jacqui Carlson
Mana Turi o Aotearoa	Patrick Thompson
Muscular Dystrophy Association	Jill Waldron
Association of Blind Citizens	Carolyn Weston
Brain Injury Association	Glennis Wilson
Brain Injury Association	Ngaire Wycliffe

## List of documents reviewed

1. *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs* – Report of a Project Group. Prof JL Mansell. Oct 2007. Department of Health, London
2. *Responding to People with Multiple and Complex Needs*. Department of Human Services. July 2003. Melbourne, Australia
3. *Guidelines for supporting People with Challenging Behaviours*. Atawhai, Whanonga Nanakia. 1999. Ministry of Health, Wellington
4. *Centre of Excellence for Behaviour Support: Centre Prospectus an Agenda for Change*. Queensland Government and the University of Queensland, Australia
5. *Challenging Behaviour: a unified approach – Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*. Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language. College Report CR144. June 2007
6. *Discussion Paper – Behaviour Support Discussion Paper for Sector Consultation*. December 2008. Disability Services, Ministry of Health, Wellington
7. Desk Files – Various Ministry of Health and provider documents
8. *Safe Lives for people with Intellectual Disability*. Donald Beasley Institute for the ACC
9. *Facing the Challenges* (draft). Tautoko Services (undated)
10. *Behaviour Specialist Services*. Tautoko Services. Alternative Suggestions (undated)
11. *The New Zealand Disability Strategy – Making a world of Difference Whakanui Oranga*. June 2001. Ministry of Health
12. *Mental Health and disability Support Services – Interface Project*. South Island Shared Services Agency Ltd
13. Behaviour Support Alliance (BSA) – various documents:
  - *Harnessing the Passion* – Record of Professional Conversations – Feb 2010
  - *BSA Principles* – March 2011
  - *Common Components Diagram* – undated
  - *Report to the Behaviour Support Project Team* – May 2008

## Précis of the interviews and discussions with contracted behaviour support providers during March and April 2011

### 1. Introduction

The project team had the objective of wanting to meet with all individual behaviour support providers and understand their issues and any views as to the future service models. Before each meeting a template was sent to ensure moderation to the extent possible and to give the provider time to consider the responses.

The project team is grateful for the openness and willingness of providers in their responses and appreciates the time they gave to preparation and meeting with the team.

### 2 Geographical spread

Behaviour support services are available across New Zealand although, as the table below indicates, there is limited choices and access in some areas and more choice in others.

Area	Provider(s)
Northland	Idea Services *
Auckland	Spectrum Care Idea Services * Te Whanau O Waipareira Trust
Waikato / Taranaki / Bay of Plenty	Idea Services * Community Living Trust
Taraiwhiti	Idea Services * Tautoko Services
Hawke's Bay	Idea Services* Tautoko Services Explore Services (for those who have left Kimberley Centre and also cover Hohepa )
Palmerston North / Whanganui / Horowhenua	Idea Services* Tautoko Services Explore Services (for those who have left Kimberley Centre)
Wairarapa	Idea Services * Tautoko Services Explore Services (for those who have left Kimberley Centre)
Wellington	Idea Services* Tautoko Services Explore Services (for those who have left Kimberley Centre)
Nelson/Marlborough	Idea Services* Tautoko Services
West Coast	Idea Services* Tautoko Services

Canterbury	Canterbury DHB Idea Services * Southern Behaviour support (children and young persons)
South Canterbury	Idea Services * Southern Behaviour support (children and young persons)
Otago including Central Otago and Oamaru	Idea Services* Southern Behaviour support (children and young persons) Southern DHB
Southland	Idea Services * Southern Behaviour support (children and young persons) Southern DHB

\* The primary focus of specialist services is adults with intellectual disabilities who live in IDEA residential accommodation or with IDEA contracted caregivers. In the Midland Region, which includes Hamilton, Rotorua, Taranaki, Taupo, Tauranga and Thames, and in Northland, IDEA also provides services to children and their families.

### 3 Virtual or actual presence

Providers have a variety of ways to provide presence. In large urban areas there is a concentration of teams to provide support and in other towns and rural areas coverage is provided through contracted psychologists, outreach staff or a small team staff presence. An area where no staff are actually present is the West Coast, South Island.

### 4 Referrals

The change in the BSS specification some time ago indicated that all referrals were to go through the local NASC, particularly when the BSS provider is also a residential provider. Referrals are received from a number of sources, including providers, GPs, families, DHB child health services and NASCs as the first point of referral.

With the exception of Canterbury DHB, Southern DHB and Community Living Trust, all referrals are now being channelled through NASCs. In the case of Community Living Trust external referrals go through the NASC but not internal referrals (this was suggested by the NASC).

### 5 Staff FTEs and qualifications

The largest provider has 29.1 FTEs and the smallest 3 FTE staff. The numbers reflect the geographical spread and size of the organisations.

Qualifications and experience are varied.

People working in behaviour support are from a variety of backgrounds, both professionally and in experience. They include clinical psychologists, nurses, occupational therapists, training officers, teachers, social workers, psychotherapists and behaviour support specialists (no specific qualification exists for this category of worker but they are often people undertaking clinical psychology training, have masters in psychology or are experienced support workers). One service which does not have a contract nevertheless has a number of staff with professional qualifications and intern staff undertaking university degrees. A small number of service providers have speech language therapists. In one DHB service there is a psychiatrist on the team. Another DHB service has access to psychiatrist input.

The range and experience of people working in the sector is varied and the workforce has been developed in the absence of any overall planning and agreement about the team structure at a national level. The Behaviour Support Alliance (BSA) has recognised the need for a competency-based approach and has undertaken some development work but this is in the beginning stages.

## **6 Governance arrangements**

Governance arrangements are dependent on the service; all NGOs have a board to which they are accountable for implementing the philosophy and values of that organisation. One large organisation has an advisory board specifically for BSS. The DHB services are within the wider DHB structure with accountability through the DHB reporting and accountability framework.

## **7 Demographics**

### **7.1 Waiting numbers and times**

Waiting times and numbers waiting are a snapshot as at the actual date of the discussions. As noted in the body of this report, data from the Ministry of Health completely reliable. This reinforces the need for a data set that provides consistency across all providers.

There is a wide range across providers and geographical areas. There is no consistent pattern relating to size and/or coverage although it is noted that the rural areas and children and young persons services have a longer waiting time, which is likely to be due to limited provider coverage.

Waiting times vary from no waiting list to 206 people waiting, and times from no waiting time to 18 months. Three providers have waiting times from one month up to six months. Two providers who cover the rural areas have the longest waiting times.

Of note is that people waiting longest are more likely to be those living in their own homes or with whānau, although it is expected that children and young people would be less likely to live in residential disability settings. Families are more vulnerable as they do not have the infrastructure that residential services have in place.

The lack of robust national data on age of people waiting has limited any substantive analysis of the age profile of the behaviour support population. While ethnicity data is not readily available from the discussions there is an acknowledged need for the emergent refugee and migrant population, as well as access for Pacific people and Māori, particularly in urban areas.

### **7.2 Management of referrals if also a residential provider**

Three current providers also have residential services.

- One provider ensures all referrals go via the NASC.
- One provider takes direct referrals if the person has previously been a client of BSS.
- One provider has a NASC which prefers the provider to deal with internal referrals.

## **8 Human resources**

### **8.1 Staff recruitment and retention**

There was some concern expressed early in the discussion process that the capacity to retain staff was affected by salaries and the ability (or lack of) to command greater remuneration from Crown organisations such as Group Special Education, DHBs and CYF. Consequently a specific question was asked about staff turnover and where possible indication of where staff had moved to.

Both DHB providers indicated a stable staff with minimal turnover. NGO providers experience turnover that ranges from 5% to 100% per annum depending on the staff classification.

Of interest in the discussion was to assess reasons why people remain and why people leave. All providers indicate a core staff, some of whom have worked for an organisation for many years.

We were told that NGO staff, while not remunerated at the same level, have a variety of other reasons for remaining in the service, including flexibility in working hours, autonomy and fit with values and philosophy of organisation. Providers have been looking at how to better reflect the DHB Multiple Employment Collective Agreement rates for staff and there is valid argument in terms of valuing the skills and experience but not necessarily the turnover being a widely articulated reason for exit across the sector. Rates of pay are not necessarily the reason staff leave the service.

## **8.2 Development and training**

Specific training in behaviour support approaches is a recognised gap which is exacerbated by a lack of New Zealand-specific academic research capability. Services have some qualified staff that have scopes of practice and need to keep their professional development current in order to retain practising certificates.

NGO training is provided in various ways, including attendance at seminars or conferences, team meetings, clinical discussions, journal clubs and relationships with the local university. Training for DHB staff is provided through DHB programmes. There were two comments about the appalling lack of training for behaviour support at the specialist level. Overall the consultation reinforced the need for structured training based on a competency framework.

## **9 Current service approach**

### **9.1 Managing referrals and prioritisation**

Prioritisation for referrals is mixed. Some rely on the NASC prioritisation; some who receive NASC referrals also have their own prioritisation. Services that did not have all referrals coming from NASC do their own prioritisation using a risk matrix or screening by a senior clinician and/or undertaking a home visit to assess the urgency. There are a number of individual tools developed by providers to assess urgency or risk and some use the Ministry's risk matrix.

In most services an intake process is based on all referrals coming to one point and then being assigned to relevant staff (either based on geography or spare capacity or specific skills). Systems for keeping clients informed of their status on waiting lists are not uniform and sometimes NASCs have the responsibility to do this.

### **9.2 Service delivery**

Services are delivered through lead staff with input from relevant peers. Service planning is based on functional and risk assessments in the client's settings, and with involvement of relevant other people. Planning systems are individual to each provider, developed over time and often in line with the overall organisational clinical or documentation requirements.

### **9.3 Review**

All service providers have formal review processes at regular intervals (usually three monthly). These timelines may be agreed with families. Some services have peer review following a set period to ensure greater professional accountability. NASC involvement in reviews is not common across the sector.

## **10 Systems**

### **10.1 Clinical leadership**

The clinical leadership systems are variable. The DHB systems and some NGO systems are robust and have been in place for a considerable time. Two providers have clinical advisory committees with requisite skills and experience who provide oversight; other NGOs have a relationship with private psychologists who meet at an agreed frequency to provide advice and counsel on specific cases. Two services have a clinical leader as an appointed position; one service has a representative on a wider organisational clinical governance committee.

### **10.2 Supervision**

All providers have supervision in place with a range of approaches using peer supervision, line supervision and external supervision. The frequency of supervision is varied and may depend on the role of the person receiving the supervision.

### **10.3 Relationship with DHB clinical services**

There are a range of informal relationships with DHB services such as Child Development Services, Mental Health Services and Regional Intellectual Disability Care Agency (RIDCA) where the DHB is the provider. These relationships are based on clinical needs and collegial relationships. Some providers hold the view that DHBs are not keen to liaise with NGOs. There is some work regarding access to Mental Health Services led by South Island Shared Services Agency Ltd but at the review date no outcome had been determined. While some NGOs described relationships as close, written formal relationships with any DHB service are rare. There is a small number of memoranda of understanding. One barrier that was observed by the reviewers is the view that there is a cultural divide that exists particularly where DHBs are perceived to not have a commitment to the Disability Strategy.

### **10.4 Other clinical liaison and relationships, such as specialist assessors**

Again these relationships are variable depending on history and individual's needs. One example of effective use of time and collaboration is joint assessments with mental health services for youth. Some ongoing relationships are impinged on by staff turnover, in particular at the joint Child Youth and Family /Ministry of Health 'high and complex needs' programme. Some providers spoke positively about their relationships with other behaviour support providers in their area, another indicated that there was considerable need for improvement.

## **11 Service models**

### **11.1 Multidisciplinary or transdisciplinary?**

There were a number of responses to this question with some providers favouring a transdisciplinary approach. Providers described this approach as offering complementary skills, a process for gaining input from a variety of disciplines, and professional collaboration. A transdisciplinary approach allows the capacity to interchange these skills. Professional respect is

also important, as is the ability for one professional to work as the lead in managing the case in question. There is also a view that any team needs to include support and key workers, and to be successful when working with families they also should be included as an important part of the team. One perspective shared was to apply the concept of Whānau Ora by providing an integration to wider services as needed to meet whānau needs.

## **12 Models**

### **12.1 Vision for structure**

All responses tended to be in the micro as opposed to the macro view, which is not necessarily surprising as there has been no helicopter view or strategic plan for the future. Responses also tended to be framed based on the service provider's own set of organisational and service circumstances. DHBs clearly favoured a strong clinical approach while recognising the NGO skills.

Comments from providers suggested that the future models must:

- include high-level strategic planning
- allow wider involvement across Government sectors, CYF, GSE
- be affordable but also value staff by paying comparable salaries
- offer capacity for early intervention, preventing further issues down the track – 'gets in earlier and works earlier'
- include a contractual framework that provides greater levels of collaboration and clinical networking
- cover all required skills
- professionalise the workforce
- strengthen the service provision through upskilling staff to prevent service failures which impact on the need for behaviour support
- offer a range of options
- allow for involvement in research
- be based on evidence-based practice
- be culturally responsive.

## **13 Indicators of successful service provision: what works and what doesn't**

### **13.1 Successful provision and what works**

Successful service indicators include responses from providers, NASCs and families both formally and informally, rate of referrals and internal audit outcomes. There is a need for:

- national policy direction
- evidence-based practice
- vision and values of the organisation translated into best practice at a service level
- effective triage based on sound clinical practice
- effective prioritisation
- comprehensive assessment
- individualised services and supports in place
- responsive, integrated services that provide a continuum of service and support
- strong measurement processes based on outcomes
- taking time to do the job right
- getting to know families
- client assessments in their own environments
- stronger relationships with other providers.

## **13.2 What doesn't work**

### **13.2.1 Eligibility assessments**

Capping of eligibility numbers is an issue for providers as this has an impact on individuals' capacity to access services. Some providers do not provide eligibility assessments as they have no clinical capacity to do so; others believe that they should be separated from the contract for behaviour support as there is an unhappy alliance in doing both. NASCs have not been consistent across the country in their approach to establishing eligibility and while some are prepared to look at a history of previous involvement in disability services such as special education, others require eligibility assessments in situations that are not necessarily clinically viable due to the person's capacity. There is a considerable level of frustration in this area.

### **13.2.2 Funding**

There are a number of issues relating to funding, one being the need for growth both in demographics to meet current and emergent populations and also the passing on of Consumer Price Index which has not typically been a feature of NGO funding patterns. The outcome is that NGO staff feel like poor cousins, particularly regards remuneration.

### **13.2.3 Contracting methodology, national focus**

The current contracting specification on outputs and volumes does not provide for an outcome-based approach. There is also a view that the Ministry of Health lacks the ability to influence the sector, which translates to some providers feeling disenfranchised.

### **13.2.4 Collaboration with other government disability organisations**

The ability to work with other organisations across government leads to duplication and frustration from families, sometimes due to differing organisational philosophy and values. The same could be said for some families who are not prepared to implement the strategies of the behaviour support plan.

### **13.2.5 Capacity of other services**

There is some frustration with the service issues leading to individuals needing behaviour support and a view that more work needs to be done in improving capacity in residential support services.

## **14 Summary**

The above information has been précised from a vast amount of opinions, facts and responses provided by behaviour support providers.

**June 2011**

## Responses from the Needs Assessment and Service Coordination survey April/May 2011

### 1. Introduction

As part of the work associated with the BSS project there was a presentation and consultation with the Needs Assessment Service Coordination Association (NASCA) at their meeting on 11 March 2011. The meeting was not attended by all NASCs so it was agreed that a survey would be sent out to ensure that there was a national response to the project.

### 2. Responses

Responses were received from the following NASCs.

NASC	Area
North Able	Northland
Taikura Trust	Auckland
Disability Support Link	Waikato
Support Net	Bay of Plenty
AccessAbility	Taranaki/Whanganui
Options Hawke's Bay	Hawke's Bay
Support Link	Manawatu
Life Unlimited	Gisborne/Lower Hutt
Capital Support	Wellington/Kapiti Coast
Support Works	Nelson/Marlborough
Lifelinks	Canterbury/West Coast/South Canterbury
AccessAbility	Otago and Southland

Questions relate directly to working with BSS and offer another perspective on the wider system.

### 3. Questions

#### 3.1 Prioritisation of referrals

- What process do you use to triage or prioritise and is this standardised across NASCs?

#### 3.2 Referral to behaviour support providers

- On what basis do you refer to behaviour support providers, assuming a choice exists?

### **3.3 Follow-up**

- What information do you require back from your referral to behaviour support providers, and how often (ie, ongoing, discharged etc)?
- Would a report template be useful to ensure ongoing information is provided to NASC from behaviour support providers?
- How often do you follow up to ensure that the service is being provided and what status?

### **3.4 Demographics**

Waiting list and time since referral from:

- families (through any source)
- residential services.

### **3.5 Reporting**

- What information is provided to the Ministry of Health regarding behaviour support?
- Do you use discretionary funding for behaviour support and if so why?

### **3.6 Equity of access**

- What issues exist in your area regarding equity of access between community (whānau/family based services) and residential services?

### **3.7 DHB interfaces**

### **3.8 Future shape of BSS**

## **4. Responses and discussion**

### **4.1 Referrals and managing triage or urgency**

There is no consistent approach to managing referrals across NASCs, with some NASCs undertaking triaging and providing information to the provider regarding urgency.

If the NASC does not handle all referrals to the provider (Canterbury DHB, Southern DHB, Community Living Trust), prioritisation or triaging may not be useful as that cannot be assessed alongside the direct referrals to those providers.

A small number of NASCs meet with the behaviour support provider on a monthly basis to discuss the referrals and work with them to assign urgency.

Of those NASCs who do triage, the basis on which they do so is primarily:

- significant risk of family or placement breakdown putting the person at risk of losing their home
- injury risk to self or others.

One NASC noted that RIDCA clients by the nature of their behaviours and complexity are very high priority.

NASCs who indicated that they don't triage or prioritise at this time assume that the behaviour support provider does. Exceptions to this are that all NASCs now work with IDEA Services to do the prioritisation (something that was agreed following recent mediation).

There are some aspects of the referrals system that are described as useful by NASC, including provision of written information such as *10 tips to support a client with challenging behaviour* issued by Tautoko Services.

Some behaviour support providers have a referral form which provides clarity around the information needed to prioritise.

### **3.2 Choice of providers**

There are only a small number of areas where choice is available due to the patchy nature of coverage. For the Central region, including Nelson and Marlborough, there is no choice and for IDEA Services the referrals are all for internal service users.

In those areas the only way to provide alternatives is if the family pays for the behaviour support provider's private service or the NASC's discretionary funding is used

One NASC refers on the following basis:

- disability eligibility criteria (intellectual disability and/or ASD)
- age (for IDEA Services Communication BSS)
- intensity and complexity of behaviours (such as sexualised behaviours, social communication challenges)
- capacity of service provider
- wait list times.
- two mainstream providers: Community Living Trust and IDEA services
- RIDCA access these two providers, as well as FIDS team.

Another NASC noted that if clients are already receiving a service from one of the providers it may more appropriate for them to stay with that provider for behavioural support – or it may be that it is more appropriate for them to go to another provider, so client fit is important.

### **3.3 Follow-up**

The majority of NASCs require some information from the behaviour support providers but this varies in its level of detail.

A small number of NASCs look for:

- acknowledgement that referral has been received
- time frame for assessment and intervention
- assessment report

- behaviour plan
- feedback on progress
- conclusion at service exit.

One NASC noted that:

- they meet regularly with providers
- providers identify if they have capacity
- provider advises when the referral has been received, and the client has been put on a waiting list, and when the service commences
- waiting times have recently decreased.

One NASC only receives acknowledgment of referral sometimes, and another while requesting acknowledgement and timeframes of first contact do not always get followed up. One NASC requires confirmation of the referral being received and accepted or declined. Notice of discharge is required when services cease.

Another NASC has case reviews monthly and receives a copy of all assessments carried out and the final report. They also sign off a service plan agreement and ask for receipt of referral in writing.

### **3.4 Report template**

A number of NASCs indicated that it would be useful to have a template to ensure ongoing information is provided to NASCs from behaviour support providers. One suggested a mechanism, possibly a check sheet, which ensures such information is provided. Final reports are very useful. Quarterly reports would also be useful.

One NASC commented that what would be more helpful is for clients to be seen more quickly.

### **3.5 How often do you follow up to ensure that the service is being provided and what status?**

One NASC meets with providers monthly generally to discuss capacity/vacancies and current clients.

A written report to NASC would be useful as this can be used as supporting documentation for other required funding approval pathways and informs the service coordinator for scheduled reviews. A number of responses noted that this varies – weekly to annually – depending on the reason for the referral or the level of need. One NASC follows up at annual reviews or if there is inter-sector involvement, such as Strengthening Families Group Conferences.

It is also noted that there are regular email and phone conversations between NASCs and behaviour support providers.

A trigger for follow-up can be if additional supports are requested or at the annual review or reassessment, or if the person indicates they have not heard from the support service.

### **3.6 Waiting list and time since referral**

There was a considerable range of responses to this question and the NASCs who indicated longer waiting times are in the regions where there is limited service provision because there is only one behaviour support provider, limited staffing capacity or a limited number of providers working primarily with families.

A range of comments were received; some examples follow:

- This varies – weekly to annually – depending on the reason for the referral.
- Nil clients in community waiting at present.
- Clients in residential services waiting – this is variable. Waiting times can be nil.
- Waiting time to up to several months.
- Currently six residential clients on waiting list with one provider. This is because they have existing services with this provider. These clients have been waiting four months. The other provider has no one on the wait list.
- Wait list maintained by behavioural support provider.
- Wait time up to 18 months.
- Families are not able to refer directly to the provider; however, we have been informed there is an 11 month wait list for one BS provider.

### **3.7 Reporting**

The Ministry requires specific reporting from RIDCA relating to issues for clients accessing BSS. For mainstream clients, all those with funding packages over the threshold have notes entered on Socrates, the client record system and database used by the NASCs.

NASCs are expected to inform the Ministry if there are any issues regarding capacity in their quarterly report. Providers also report directly to the Ministry.

### **3.8 Discretionary funding**

Some use of discretionary funding is reported, such as occasional use to address urgent need with high cost implications or if there are particular complexities requiring specialist input. It is also occasionally used for clients with sexualised behaviours, if the behaviour support provider has lost their specialist assessor for these clients, so the discretionary fund is used to refer to a private provider, or to get eligibility confirmed if there are two conflicting reports. It is also used for high and complex needs clients.

### **3.10 Equity of access**

Families that can afford to pay are able to get support sooner through the contract holder's private practice.

Some behavioural support providers are also residential providers. There may be a risk that these residential clients get priority over other clients.

NASC and/or the residential provider refer to behaviour support; timeliness again is at the discretion of the BSS.

People in the community are wait listed for very long periods when endeavouring to engage with the current contracted provider of the region.

### **3.11 Interfaces**

Interface with Child Development Services (CDS) is good with a team member participating in the weekly CDS inter-agency meeting.

Interface with Child and Adolescent Mental Health Service and Mental Health is affected by practices that result in one or other service left with sole responsibility for people, and the belief that the other should be joint working or funding.

- IDDD and Child Development Centre.
- We consult with providers above
- Cases are prioritised to determine urgency of service provision.

There can be robust debate over prioritisation of clients.

### **4.12 Future shape of services**

NASCs have a range of views about aspects of the services but no single view about how services should be structured.

A number of comments are reported below:

- There needs to be consistent access to clinical psychology expertise in relation to people with intellectual disabilities.
- We would like a system where all referrals are responded to with an initial one-hour visit that addresses any immediately apparent issues or environmental changes that may reduce behaviour ahead of full assessment or indeed remove the need for a full assessment.
- Providers should be required to assess and produce a written plan for managing the impact of any new person moving into a residential service, upon existing residents.
- Lengthy wait lists impact on eligible families' ability to access home fencing via ENABLE, as ENABLE requires a behavioural support assessment to be completed before they will consider funding home fencing.
- Behaviour support staff appear to frequently work in pairs on assessments. Is this necessary and to what level?
- It would be good to have one centralised multidisciplinary team including psychologist, psychiatrists etc to ensure clients don't fall between the gaps.
- Children with disabilities should be able to access behavioural support through Child Development Services, rather than having a referral sent to NASC for community services.
- It would be good to have Child Development assessments take place in child's home, rather than the child going to a facility for assessment, (foreign environment).
- Increased number of eligibility assessments being able to be done by a current national behaviour support provider would be good.

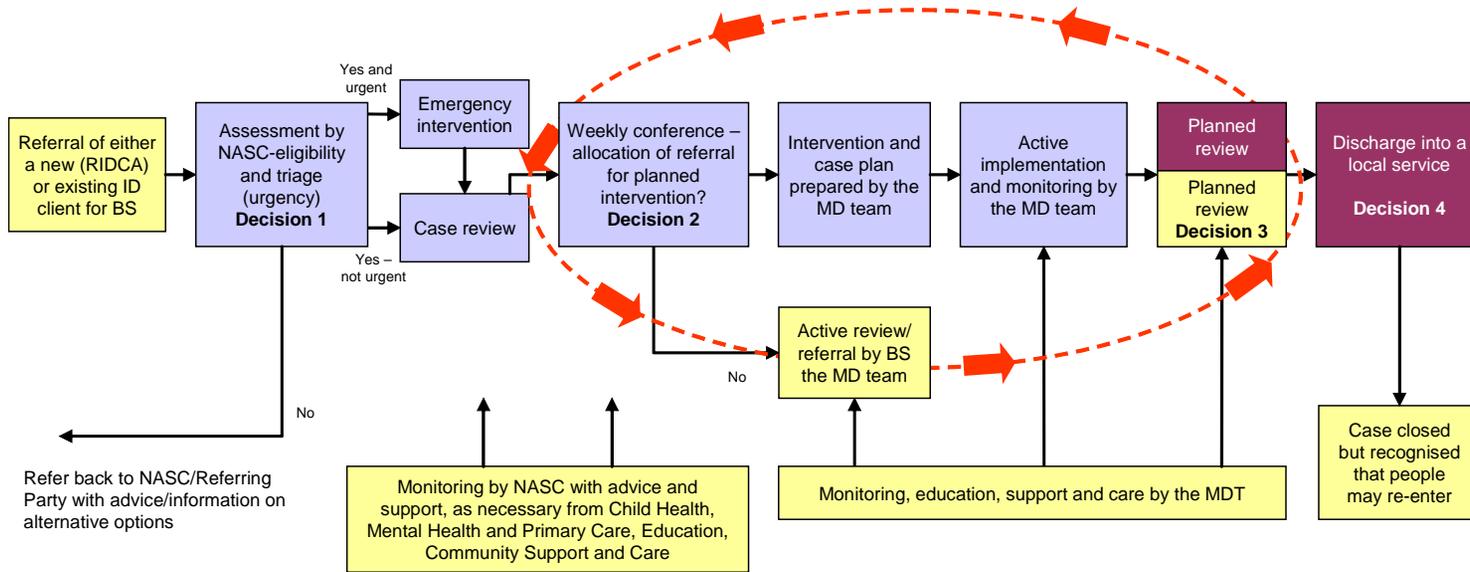
- More collaboration between school/education behaviour input and home/community-based behaviour input.
- Multidisciplinary team approaches to behaviour support when appropriate, preferably administered by the behaviour specialists as opposed to hospital services.
- The need for significantly reduced waiting times for families.
- Family input regarding behaviour interventions may be valuable as many struggle to implement programmes.
- It would be useful to have the behaviour support to providers as well as individuals, such as training with staff to work generically with people as well as one to one.
- If we did not have the ability to place a navigator where there are extreme complex family issues to support any behaviour plans and challenges we would not have the results we gain today. The navigator walks with the family and assists them to self-manage and future build thus ensuring a quality family unit again,
- If this was not available behaviour support services require a support person who has a specialist skill base to be employed from the time the assessment is completed and the plan is put in place, to walk with the family for a short-term, determined time, to ensure that the plan is working, that the family have the resilience to self-manage and then withdraw. This could come under the behaviour support services if the funding allowed.

## **5. Conclusion**

The variability across the NASCs mirrors the variability across BSS. Responses indicate that there is a desire for change and while responses are within the organisation's world view there is commonality regarding seeking consistent service provision, more effective communication and greater collaboration.

**May 2011**

## Appendix V: Behaviour support – service pathway and key decisions



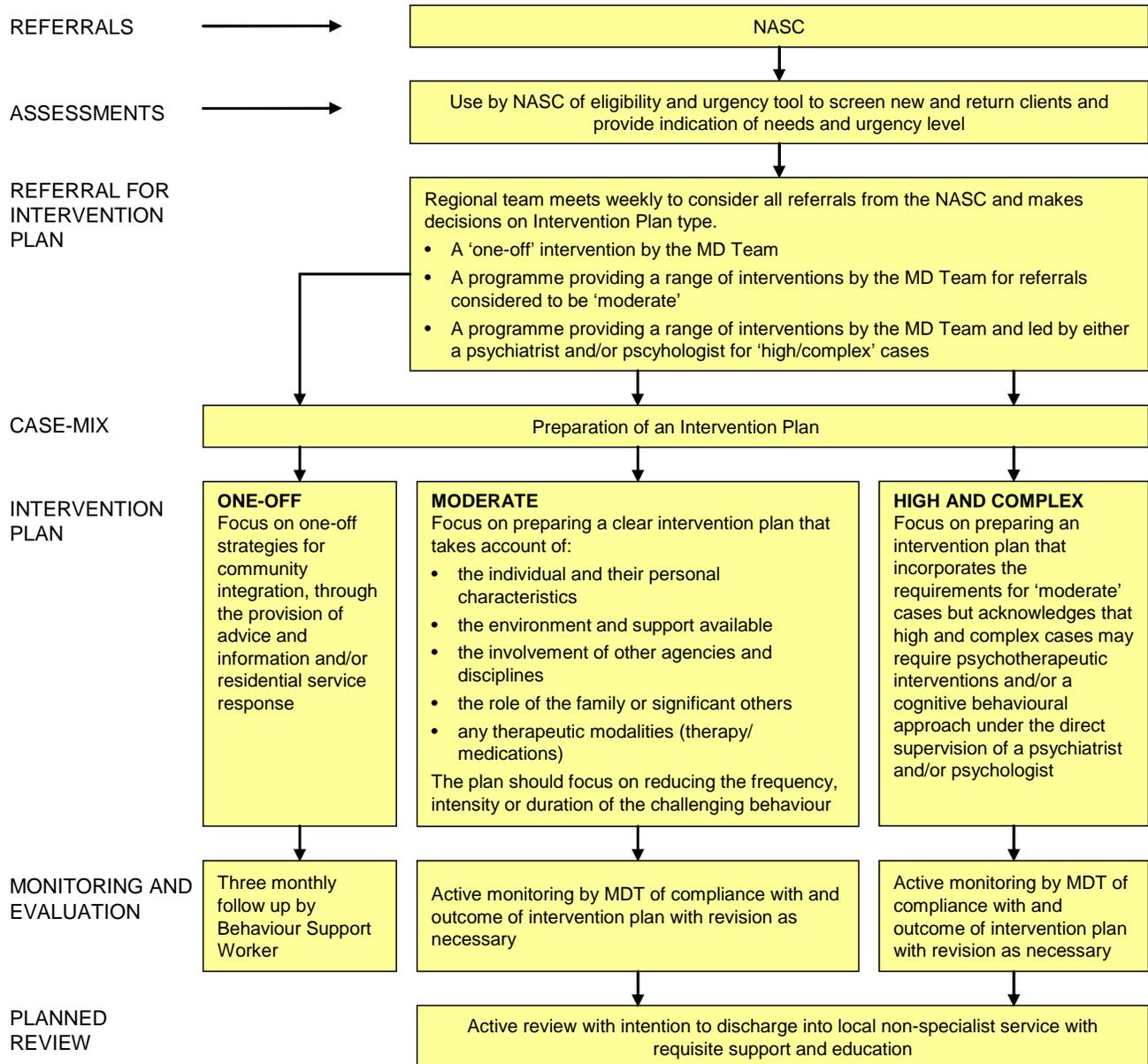
**Service Principles across the Continuum:**  
Consistent Access, Responsive (early intervention), Integrated, Evidence based, Clinically led and Sustainable

**Key responsibilities**

NASC or Provider	
BST	
Joint Decisions	

- Key responsibilities**
- Decision 1 – Does this referral meet the criteria for access to the specialist Behaviour Support Service?
  - Decision 2 – Allocation of referral for a planned intervention to include discharge and outcome expectations, training, any direct services and proposed therapeutic interventions
  - Decision 3 – Review of the Plan to determine how it is to be continued or modified to reflect the contribution of significant others, i.e. family, partner, school, other residents
  - Decision 4 – Discharge – a joint decision including the family and/or significant others

## Behaviour support – service pathway and descriptions of service



## Proposed Service and Governance Arrangements

<b>Option B – DHB responsibility</b> Transfer the present funding and service obligations in their entirety to DHBs to negotiate suitable local contracts for specialist BSS.		
<b>Description:</b> This model envisages the Ministry relinquishing its role of contracting directly with providers and transferring the present funding allocations to DHBs. The Ministry's role would be to determine what it wishes to see provided with that funding and to then require DHBs to organise the necessary range of services by either contracting or directly providing it themselves. The accountability framework would be incorporated into the Crown Funding Agreement and the DHB's District Annual Plan.		
<b>Parties</b>	Ministry, DHBs and suitable providers	
<b>Contracting arrangements</b>	DHBs (under guidance from the Ministry) prepare and issue an agreed national service specification for BSS with the DHB contracting with providers on local terms and conditions	
<b>Benefits</b>	<ul style="list-style-type: none"> <li>(i) National specification and active monitoring would enforce consistency of eligibility criteria</li> <li>(ii) DHBs would hold the local accountability for service performance</li> <li>(iii) A more unified system for long-term service planning, funding and provision that is clinically and financially sustainable (this is consistent with the National Health Board priorities for the health and disability sector)</li> <li>(iv) Closer linkages to DHB clinical services would provide for greater clinical leadership and opportunities for professional development</li> <li>(v) Maintenance of and access to a wider competence pool</li> </ul>	
<b>Risks</b>	<b>Risk description</b>	<b>Mitigation</b>
	DHB variability	Committed Ministry support
	Provider fragmentation	Establish local networks
	Residential providers may be conflicted if they are also the designated behaviour support provider	<ul style="list-style-type: none"> <li>• All referrals for behaviour support are managed through NASCs</li> <li>• Exclude residential providers from providing tier 2 BSS</li> </ul>
	DHB may be conflicted as both a funder and service provider	<ul style="list-style-type: none"> <li>• Transparent contracting processes</li> <li>• All referrals for behaviour support are managed through NASCs</li> </ul>
	Behaviour support as a service may lack profile within DHBs	Establish behaviour support as a national service or set up very explicit and reportable KPIs
	Service users and families unable to influence service design and outcomes	Require DHB to establish and resource consumer forums
	Governance	Within existing DHB accountabilities

<b>Option C – Ministry led</b> National funding and service obligations for specialist BSS continue with the Ministry with contracted regional service arrangements with preferred provider(s)		
<b>Description:</b> This model envisages the Ministry continuing to be responsible for all policy and funding aspects of BSS. In doing so it would continue to contract with preferred providers with the intention of building and maintaining regional capacity.		
<b>Parties</b>	Ministry, DHBs and suitable preferred providers	
<b>Contracting Arrangements</b>	The Ministry would continue to be the sole contracting party but would look to revise the current specification to provide for longer-term arrangements with preferred providers. The emphasis would be on enabling for longer-term service improvements and sector development rather than on compliance.	
<b>Benefits</b>	<ul style="list-style-type: none"> <li>(i) National specification and active monitoring would ensure consistency of eligibility criteria</li> <li>(ii) Capable of longer-term service planning, funding and provision that is clinically and financially sustainable</li> <li>(iii) Could contribute to investing in Multi Disciplinary Teams (MDT) workforce development</li> <li>(iv) Potential for a more responsive service</li> </ul>	
<b>Risks</b>	<b>Risk description</b>	<b>Mitigation</b>
	Some providers may not be preferred	Transparent process of criteria development and selection process
	Unless inclusive of clinical input, has the potential to perpetuate current service issues	Contract to require clinical links with DHB specialist services
	Residential providers may be conflicted if they are also the designated behaviour support provider	<ul style="list-style-type: none"> <li>• All referrals for behaviour support are managed through NASCs</li> <li>• Exclude residential providers from providing tier 2 BSS</li> </ul>
	Service users and families unable to influence service design and outcomes	Require providers to establish and resource consumer forums
	Governance	Establish a regional governance group with an independent chair

<b>Option D – Regional arrangements</b> The Ministry adopts the proposal to establish Regional Specialist Behaviour Support Services		
<b>Description:</b> This model envisages the Ministry mandating a national specification and facilitating the development of dedicated Regional Specialist BSS. This could involve contracting service provision within a region with a small range of preferred local NGO providers and at least one DHB in that region. The intention and focus would be on building and maintaining regional service capacity in order to optimise service outcomes.		
<b>Parties</b>	Ministry, DHBs and local service providers	
<b>Contracting Arrangements</b>	The Ministry would continue to be the sole funding party but would revise the current specification to jointly contract with regional providers and at least one DHB per region. The contracts would be of longer term with an emphasis on building service capacity and enabling regional service improvements.	
<b>Benefits</b>	<ul style="list-style-type: none"> <li>(i) National specification and active monitoring would ensure consistency of eligibility criteria</li> <li>(ii) Capable of longer-term regional service planning, funding and provision that is clinically and financially sustainable</li> <li>(iii) Would contribute to investing in local MDT workforce development</li> <li>(iv) Potential for a more responsive and regionally focused service</li> </ul>	
<b>Risks</b>	<b>Risk description</b>	<b>Mitigation</b>
	Some providers may not be preferred	Transparent process of criteria development and selection process
	Leadership of the change process	Dedicated investment
	Providers would need to cede some sovereignty	Interests of service users come first
	DHB may be conflicted as both a funder and service provider	Transparent contracting processes
	Service variability across regions	National consistent principles and criteria for access and prioritisation
	Residential providers may be conflicted if they are also the designated behaviour support provider	<ul style="list-style-type: none"> <li>• All referrals for behaviour support are managed through NASCs</li> <li>• Exclude residential providers from providing tier 2 BSS</li> </ul>
	Service users and families unable to influence service design and outcomes	Require providers to establish and resource consumer forums
	Governance	Establish a regional governance group with an independent chair

## Suggested Revision of Service Specification (DSS220)

**PURCHASE UNIT CODE: DSS220**

**SERVICE NAME: [Regional Specialist](#) Behaviour Support Services for People with Intellectual Disability Presenting Behaviours that Challenge**

### Philosophy Statement

The aim of the Disability Services Directorate is to build on the vision contained in the New Zealand Disability Strategy (NZDS) of a fully inclusive society. New Zealand will be inclusive when people with impairments can say they live in:

‘A society that highly values our lives and continually enhances our full participation.’

With this vision in mind, disability support services aim to promote a person’s quality of life and enable community participation and maximum independence. Services should create linkages that allow a person’s needs to be addressed holistically, in an environment most appropriate to the person with a disability.

Disability support services should ensure that people with impairments have control over their own lives. Support options must be flexible, responsive and needs based. They must focus on the person and where relevant, their family and whanau, and enable people to make real decisions about their own lives.

Note: Subsequent references in this document to “the person” or “people” should be understood as referring to a person/people with impairment(s).

### 1 *Definition*

The Ministry purchases [specialist](#) Behaviour Support to improve the quality of life for those people whose behaviour challenges their support networks, and/or places themselves or others at risk of harm and to provide support for skill development to enable their participation in their communities.

More detailed definitions are provided in the glossary of terms.

Behaviour Support Service is a specialised service, providing:

- **Assessment** – includes gathering information, building relationships and understanding the person’s situation. Assessment will consider: communication, social interactions, general functioning and the relationships of such factors with behavioural responses. Providers will use methodology that is evidence-based and reflects best practice in response to the person’s situation. The assessment process will integrate the different skills and expertise of contributing disciplines to develop a comprehensive understanding of the person’s situation. Specialist assessments can be sought during the assessment phase and will have a longitudinal perspective.

- **Planning** – includes goal setting, identifying proactive interventions, planning for the management of crisis situations, risk assessment and preparation/planning for the person leaving the Behaviour Support Service. Risk assessment methodology will be consistent with the guidelines for risk assessment developed in relation to the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003. A Behaviour Support Plan will be developed to support the person with consideration of their specific needs. This will also assist those people in the person's support networks to understand the person's behaviour and responses. The Behaviour Support Plan will incorporate and integrate the recommendations of all contributing therapists and specialists in a functional plan. The Plan will acknowledge the different needs of two key parties – firstly the person, and secondly the person's support networks which includes the behaviour support provider. The Behaviour Support Plan will consider, inform and align with the person's Lifestyle or Individual Plans including those developed in day service environments.
- **Implementation** – includes recognising incremental success/gains; direct education with the person; training and education for the person's support network so that they are able to implement Individual Behaviour Programmes. The focus should be on supporting the person in the environments in which they live, work, and socialise.
- **Monitoring and Evaluation** – ongoing involvement in the implementation and the review of Individual Behaviour Programmes with people supported by the Behaviour Support Service.
- **Consultation** - to services supporting the person, principally residential services and including vocational or day activity services.
- **Eligibility assessments** - NASC may refer to the Behaviour Support Service to determine if a potential DSS person has an Intellectual Disability. This can be a core function of the Behaviour Support Service.
- **Training, education and development** - for [carers](#), [families](#) and the wider community about Intellectual Disability and Behaviours that challenge.

Behaviour Support is purchased to provide a service on a regional basis, as detailed in the provider specific terms and conditions.

## 2 **Service Objectives**

### 2.1 **General**

The primary objective of the [Regional Specialist](#) Behaviour Support Service is to [assess](#), develop, implement, monitor and review a plan that successfully minimises the impact of challenging behaviours exhibited by a person, enabling him/her to develop maximum levels of independence and participation in the community. The Provider will achieve this by working with the person in the context of their whanau, and with family, welfare guardian, staff/carers (including those from residential and vocational services), advocates and friends (referred to as support networks).

All services purchased by the Ministry will be provided consistent with the aims and intentions of the New Zealand Disability Strategy (2001).

### 2.2 **Māori Health and Disability**

The Crown Statement of Objectives outlines the Government's medium term objectives for, and expectations of, the Ministry. In response to the Crown's Objective for Māori health and in line with its purpose statement, the Ministry has developed a Māori Health Strategy, *He Korowai Oranga*, and a Māori Health Action Plan, *Whakatataka*.

*He Ratonga Tautoko i Te Hunga Haua*, the DSD Māori Disability Action Plan identifies four strategic goals aimed at increasing responsiveness to Māori. The Behaviour Support Service is required to contribute to the implementation of *He Ratonga Tautoko i Te Hunga Haua* and the four strategic goals.

The four strategic goals are:

- Remove barriers for disabled Māori
- Increase Māori participation in the disability sector
- Develop effective disability services
- Work across sectors

Mauriora (positive life essence) is a key principle for Māori with a disability as opposed to Oranga (health) as described in He Korowai Oranga. Mauriora and the four strategic goals may be achieved through the application of Tikanga (practice and process) i.e. the use of te reo, appropriate protocols, participation in Marae activities and regular whānau, hapū or Iwi initiatives.

### **3 Service Users**

#### **3.1 Inclusions**

People with an Intellectual Disability, whose behaviour frequently interferes with, restricts or prevents their access to everyday routines, settings, activities and relationships.

#### **3.2 Exclusions**

Ministry funded Behaviour Support will not provide a service for people who:

- a) Do not have an Intellectual Disability ([except for those with ASD](#))
- b) Require services solely as a result of a mental health need as recognised by mental health services eligibility criteria - these assessments are funded by the Ministry through mental health assessment services or community mental health teams,
- c) Are eligible under the Injury Prevention, Rehabilitation and Compensation Act (2001) or
- d) For whom purchasing of services is not the responsibility of the Ministry of Health e.g. Special Education Services, Child, Youth and Family Services.

#### **3.3 Interface with Mental Health and other Specialist Services**

It is expected that some people receiving Behaviour Support will require the specialist assistance of other Specialist Services from time to time. The Ministry expects that in all such instances the Provider will work together with those Specialist Services to achieve the best outcomes for the person. Accordingly, you must establish effective relationships with other Specialist Services including Mental Health Services. (See Section 6, Service Linkages).

## 4. Service Access

### 4.1 Access Criteria

The Service must be available Monday – Friday during standard office hours (8am to 5pm) for the provision of core Behaviour Support Services. Outside these hours, referral should be made to NASC or Regional Intellectual Disability Care Agencies (RIDCA) in the case of emergencies. The Regional Intellectual Disability Supported Accommodation Services (RIDSAS) will provide the capacity to meet short-term emergency residential needs. (See Section 6, Service Linkages).

There may be individual circumstances that vary from this arrangement, whereby the Behaviour Support Provider agrees to be responsive outside standard office hours. Such circumstances are to be expected where the person and provider will require planned interventions or training sessions outside of the hours above.

People referred to the regional specialist behaviour support service will be seen within one week of the receipt of a referral, and an assessment commenced within 21 days, unless otherwise prioritised as urgent and in need of an immediate intervention. Where waiting lists are used to prioritise access to service, the criteria applied must be transparent and utilise recognised best practice guidelines to ensure those clients with greatest need are seen as a priority. Additional information should be gathered if necessary to assist in prioritising. NASC agencies must identify to the regional specialist behaviour support service Behaviour Support Services those clients they believe to need rapid access to service and advise their Ministry of Health Contract Manager of the urgency of the referral.

Behaviour Support is purchased to provide a service on a regional basis, as detailed in the provider specific terms and conditions.

The Provider should work towards ensuring that there are no barriers to access through cultural beliefs and practices.<sup>1</sup>

Access issues for Maori must be clearly understood and processes developed to minimise the barriers Maori experience in accessing disability support services. The Behaviour Support Provider should develop protocols with local iwi for responding to issues for Maori.

### 4.2 Entry To Service

Access to Behaviour Support Service is through referral by NASC or Regional Intellectual Disability Care Agencies (RIDCA).

Where referrals are from sources other than NASC/RIDCA the Regional Specialist Behaviour Support Provider ~~is to should~~ establish if the person has previously been referred to the local NASC Agency and if not should make a referral before proceeding with providing a service. This is to ensure all support needs have been assessed and responded to as appropriate, and that the person is confirmed as eligible.

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<sup>1</sup> Cultural denotes age, gender, ethnicity, disability or sexual orientation.

### 4.3 Exit From Service

The Provider will be responsible for making appropriate arrangements for people leaving the service and if necessary a referral given to alternative services.

People will exit the Behaviour Support Service when:

- the goals/objectives of the Behaviour Support Plan have been achieved,
- despite best efforts an effective working relationship has not been formed and other arrangements ensuring the person's safety have been made following an independent peer review of the circumstances,
- where there is collaborative agreement with the person and their support networks that no more can be achieved,
- when the person is no longer eligible for this service or,
- when the person chooses to exit.

People may re-enter the service through a subsequent referral from the NASC agency or RIDCA.

### 4.4 Inter-Region Transfers

The Behaviour Support Provider is expected to provide service to all people of the specified group wherever they live, or subsequently shift to, within the regional area.

The Behaviour Support Provider will work with Behaviour Support Providers in other areas of New Zealand to ensure continuity of service for people both moving into, and out of, the Provider's region.

Providers are required to ensure the timely transfer of relevant information including assessment, and support planning records to the new Provider subject to the provisions of the Privacy Act and the Health Information Privacy Code.

## 5 Service Components

### 5.1 Processes

#### 5.1.1 Specialist Assessment of Behaviour

People (once eligibility has been confirmed), will receive a comprehensive and functional assessment of their needs and circumstances. The assessment will include gathering of information, an examination of all factors (biological including screening for mental health issues, behavioural and environmental) that may have contributed to the challenges that prompted the referral, and the building of relationships. Providers will use methodology that reflects best practice and responds to the person's situation. The assessment process will integrate the different skills and expertise of a number of different disciplines to develop a comprehensive understanding of the person's situation.

The written specialist assessment report is to be made available (if so requested) by the agencies in receipt of Government funding to provide support for the person. The style of the report should reflect the individual circumstances of the person and their support network, and have appropriate authority gained for sharing information.

#### 5.1.2 Planning

On the basis of the specialist assessment an agreed Individual Behaviour Intervention Support Plan ("the Plan") will be developed with the person and their support networks. The plan details specific

strategies, activities, tasks and responsibilities (relevant to their assessment of either being one off, moderate or high and complex) that have been agreed on to respond to the challenges presented by the person, and includes identification of what must be achieved for the person to live a settled and safe life. The Behaviour Support Plan will incorporate and integrate the skills of the contributing therapists and specialists in the development of a functional plan.

Also included is the completion of risk assessment, as detailed in Clause 2. Goals are set and agreed, and potential crises are identified with contingency arrangements written and agreed. The Individual Behaviour Support Plan may include further specialist assessments and the use of other specialist services. The plan is reviewed by the Regional Specialist Behaviour Support Provider at regular (but no less than three-month) intervals (or as negotiated with the person and their support network) and is available in writing. The Individual Behaviour Support Plan is co-ordinated by the Behaviour Support Provider. To achieve this there must be:

- Agreement on goals and outcomes to be achieved with the person and their support networks so the Individual Behaviour Support Plan constitutes an understanding with regard to agreed activities, tasks and resources,
- Recognition that the person's support networks have the responsibility to implement the Plan as agreed with the Behaviour Support Provider.

The Plan should be the base from which service quality is monitored. The Plan should include a reassessment date where relevant.

### 5.1.3 Implementation

The Regional Specialist Behaviour Support Provider is responsible for co-ordinating implementation of the agreed Individual Behaviour Support Plan. This includes:

- training staff/carers in specified intervention techniques
- working alongside the persons support networks to implement and model interventions and techniques
- working with people individually or in small groups on specific issues
- acknowledging with the person and their support networks, incremental success/gains
- facilitating problem solving that responds to changing or unforeseen circumstances
- supporting the persons support networks in their work with people with challenging behaviour
- reviewing the progress of both the person and their support networks and advise on further or changing strategies/interventions
- approaching the NASC agency for access to one-off discretionary funds to provide resources where this will have a positive impact (refer to 5.1.8 for a detailed description)
- being available during standard office hours to provide ongoing advice and hands-on assistance (where appropriate e.g. through modelling or assisting in managing crisis situations), and being available outside of these hours for specific planned intervention in circumstances involving people receiving Behaviour Support
- promoting the use of non-aversive interventions in all aspects of their work
- assisting the person and their support networks to prepare for and visit with local specialists and mental health professionals – in some circumstances it may be appropriate for the Behaviour Support Provider to be present at the visit.

#### **5.1.4 Monitoring and Evaluation**

The **Regional Specialist** Behaviour Support Provider will monitor the implementation of the Behaviour Support Plan, working together with the person, and their support networks to evaluate the efficacy of the Plan and make alterations as necessary.

Time frame for reassessments will be determined from the Assessment and the Individual Behaviour Support Plan and monitoring of delivery, and will be noted into the Individual Behaviour Support Plan.

#### **5.1.5 Consultation to Support Services**

The **Regional Specialist** Behaviour Support Service:

- is available to service providers and funders who support the eligible population for consultation, advice and assistance in the planning and development of community based services that prevent, reduce or minimise the need for people with intellectual disability to develop challenging behaviour
- keeps abreast of the latest developments, innovations and best practice in the design, development and management of high quality community based services for people with intellectual disability
- acts as referral agent, providing ongoing support while working with the family/whanau, and assists in contacts with other services that are made in the context of the person's challenging behaviour, for example: medication reviews, psychiatric consultations, special therapies etc.
- provides **clinical and managerial** leadership in establishing effective cross-boundary and cross-disciplinary relationships and protocols between services for people with intellectual disability and community mental health services, including acute psychiatric services
- develops and implements a strategy that establishes a network of identified expertise within service providers that is aimed at building competence in this area that is permanently enmeshed in organisations, thereby reducing future individual referrals to the Behaviour Support Service over the longer term.

#### **5.1.6 Eligibility Assessments**

When a new person presents to the NASC agency/RIDCA, an eligibility assessment may be requested to ensure the person is eligible for funding from the Disability Support Services budget i.e. the person does have an intellectual disability. NASC may access eligibility assessments from a number of sources. **Regional Specialist** Behaviour Support Providers offer the expertise to provide an option for the NASC agency. The eligibility assessment will be provided for NASC only where the Behaviour Support Provider has the ability to complete the assessment in a timeframe negotiated with the NASC agency.

#### **5.1.7 Training and Development for the Wider Community**

The **Regional Specialist** Behaviour Support Provider will, along with NASC agencies and the designated MoH Contract Manager, confirm education and training priorities and volumes for the region and develop resources and programmes accordingly. This is separate from the training provided to individuals/agencies about a specific person

#### **5.1.8 Access to Discretionary Funding**

Access to discretionary funding is a mechanism of last resort and is expected to be used only rarely for one-off interim solutions that are short term in nature. Therefore, **Regional Specialist** Behaviour Support Services may, on occasion need to access specific services and/or resources for people with challenging behaviour so that effective interventions are timely and responsive.

For example:

- The establishment of a short term customised living arrangement for a person who is, in the interim, not able to live in mainstream community residential services because of the danger he/she presents to themselves and/or others. It must first be established through, liaison with the NASC that the person needs to access the capacity funded crisis/respite beds for this population, or consultation with the RIDCA that the person meets the criteria for support through the High and Complex (H&C) needs strategy. If the person is eligible for services through the H&C strategy, a referral should be made to the relevant RIDCA.
- The purchase of emergency and/or respite accommodation until a suitable placement can be found / negotiated.

Allocation of discretionary funding is the responsibility of NASC agencies (Appendix 3 of NASC Service Specification) and RIDCA and this has to be in accordance with the Ministry's guidelines on this matter.

## **5.2 Level of Service**

The service will be provided to those people who are referred. The initial assessment may screen out the involvement of the [Regional Specialist Behaviour Support Service](#) from further involvement.

## **5.3 Key Inputs**

### **5.3.1 Staffing**

The Provider will have sufficient competent and qualified staff from a variety of educational [and clinical](#) backgrounds to provide a level of service relative to person's assessed needs. Staff will have received training [and recognised qualifications](#) that enables them to deliver a service in keeping with the national Best Practice Indicators for Intellectual Disability Services (HFA, 2000).

The Provider will ensure they have a complement of staff with appropriate skills and qualifications, including resource within the staff team to provide regular input into Behaviour Support Plans, and supervision of staff by a Registered Clinical Psychologist [and/or a registered Psychiatrist with an interest or qualification in Intellectual Disability](#).

It is expected that the Provider will maintain an active commitment to staff development. This will include the provision of supervision and/or peer review, as well as professional registration of members of staff as appropriate.

The Provider will ensure that the staff has the following skills:

- An understanding of behavioural responses
- An understanding of communication and the relationship with behaviour
- An understanding of functional analysis and the relationship with behaviour
- An understanding of posture and movement and the relationship with behaviour
- An understanding of developing behavioural support plans and implementing these within the person's specific environment.

A suitable staff with experience in the area of Intellectual Disability and behaviour may include:

- [Psychiatrist with an interest or qualification in Intellectual Disability](#)
- Psychologists

- Speech and Language Therapists
- Occupational Therapists
- Social Workers
- Nurses
- Educators
- Child Development Specialists
- Autism Spectrum Disorder (ASD) Specialists
- Other specialists (such as a GP) with relevant experience.

Core staff competence should include, but not be limited to the areas of: disability knowledge, values (social theories of disability, integration, least restrictive alternative, the right to live in the community), consumer rights, non-aversive techniques, risk management, person-centred services, communication skills and behavioural management and, as appropriate, particular needs of people as they change.

The Provider will actively encourage, promote and develop Maori staff, to be employed at all levels of the service to reflect the population.

#### **5.4 Support Services**

Included in the purchase price are:

- equipment (such as office equipment and tools of trade)
- transport
- accommodation of staff members while travelling within the region
- administration costs
- organisational overheads
- team management.

#### **5.5 Settings**

[Regional Specialist](#) Behaviour Support Services are provided in those settings that best meet the needs and circumstances of the person and their support networks. Settings include but are not limited to the person's home, vocational or day activity setting and other facilities the person uses.

### **6 Service Linkages**

It is critically important that the [Regional Specialist](#) Behaviour Support Provider and other providers work together to ensure that:

- people have access to the full range of services
- disputes among providers concerning the intervention with any person are resolved in a timely manner.

[Regional Specialist](#) Behaviour Support Services are required to demonstrate and maintain effective linkages with these Key Agencies or Providers where appropriate:

- ID Residential service and supported accommodation providers
- NASC Agencies
- High and Complex service providers (RIDCA, RIDSS, RIDSAS)
- Community Liaison Teams
- Dual diagnosis services
- Allied Health Teams

- [Child Health Services](#)
- [Mental Health Services](#)
- Vocational services and day programmes
- Other Behaviour Support Services, [such as Group Special Education and Child Youth and Family](#).

Documentary evidence of such linkages must be available on request.

There are a number of other services that linkages must be established with:

- Maori primary and community care services
- other appropriate Maori and Pacific Island organisations
- other Mental Health services
- Consumer advocacy services
- other sector agencies.

"Where children/young people are receiving services from other agencies, the service provider will participate in intersectoral collaboration and co-ordination initiatives such as Strengthening Families".

[The Regional Specialist Behaviour Support Services will develop and maintain consumer advisory groups to provide relevant input and advice.](#)

## **7 Exclusions**

[Regional Specialist](#) Behaviour Support Services are specialist services that complement those services provided to people with an intellectual disability and their support network that are otherwise purchased by the Ministry of Health or other government agencies. None of the activity undertaken by the behaviour support provider is intended to replace, or reduce the need for, regular service provision to continue in the presence of input from a behaviour support provider.

For example, training provided by the [Regional Specialist](#) Behaviour Support Service will not replace standard orientation, induction and entry level training which residential and day service providers would be expected to provide in the context of their core business. Neither will behaviour support input remove the responsibility of the primary service provider to seek assistance from mental health, emergency, police or legal services where appropriate.

## **8 Quality Requirements**

The service is required to comply with the Ministry General Contract Terms & Conditions. In addition, the National Health and Disability Sector Standards will apply to this service as determining quality standards. Providers will use methodology that reflects best practice and responds to the person's situation. The following additional specific quality requirements also apply.

Best Practice Indicators for Specialist Support of People with High and Complex Behavioural Needs (HFA, 2000).

Best Practice Guidelines for People with Intellectual Disabilities with Challenging Behaviour (MOH, 1999).

Guidelines for the administration of the Intellectual Disability (Compulsory Care and Rehabilitation) Act, 2003.

The **Regional Specialist** Behaviour Support Provider will be required to abide by all relevant Policy including but not limited to:

- The New Zealand Framework for Disability Service Delivery - August 1994, Ministry of Health
- Standards for Needs Assessment for People with Disabilities – June 1994, Ministry of Health – updated in 2000, Health Funding Authority
- The DSS Strategy for People with High and Complex Behavioural Needs, 2000
- Ministry of Health guidelines that relate to the administration of the ID (CC&R) Act, 2003.

The **Regional Specialist** Behaviour Support Provider will also be required, under the terms of contract to abide by all relevant New Zealand Legislation including but not limited to:

- Mental Health (Compulsory Assessment and Treatment) Act, 1992
- The Intellectual Disability (Compulsory Care and Rehabilitation) Act, 2003.

The **Regional Specialist** Behaviour Support **Service** Provider will observe any relevant protocols and/ or Memoranda of Understanding negotiated between the Ministry and other government departments or agencies (details of all relevant protocols and Memoranda of Understanding will be supplied by the Ministry's Contract Manager)

### **8.1 Access**

- Access to services following referral must be provided in a timely fashion. People will be seen within one week of the receipt of a referral, and an assessment commenced within **21 days one month**, unless otherwise prioritised (see Clause 4.1).
- People accessing Behaviour Support Service will have access to information as set down in the Health and Disability Commissioner's Code of Rights.

### **8.2 Person/Family/Whanau Involvement**

Person, family and whanau members and advocates ~~are~~ **should be** central to service delivery. This requires:

- a. That the person be given an opportunity to identify who to include or exclude from their assessment and treatment process
- b. That people and their support networks be provided information on how they can be involved in processes. The person, and their support networks, where applicable, will be involved in the development and implementation of Plans, and this is recorded in the Plan.
- c. That the person and their support networks be informed of complaint procedures.

### **8.3 Acceptability**

Acceptability of services will be monitored on an ongoing basis. All surveys must follow the Ministry Guidelines for Consumer Surveys (available from Ministry offices). The methods used will identify the acceptability of the following areas of the service as indicated by people, support service providers, support staff, welfare guardians, family, whanau and the person's advocates.

- a) Information distribution
- b) Staff professionalism
- c) Staff cultural sensitivity
- d) Staff communication skills
- e) Respect for privacy
- f) Rights of the consumer
- g) Level of choice

- h) Informed consent
- i) Participation in community-based activities
- j) Ease of use of Secure services
- k) Complaint and feedback systems

#### 8.4 Safety

The Provider will have a set of documented policies / protocols for the following aspects of service delivery:

- managing disruptive behaviour in the least restrictive way possible
- minimising potential risk to individuals of physical or sexual abuse from others
- minimisation of the use of restraint
- Promoting health practices that align with Ministry of Health strategic intent (such as healthy eating, push play, smoke free workplaces etc).

#### 8.5 Effectiveness

- Interventions undertaken by the Behaviour Support Provider will result in the person exiting from the Behaviour Support Service on achieving the outcomes in the Plan, and identifiable improvements in their Quality of Life<sup>2</sup>. Re-referral is on the basis of a review of the existing Plan, and presentation of new challenging behaviour. No more than 30% of clients are expected to be re-referred within 12 months.
- Staff who support clients of the Behaviour Support Service develop skills necessary to work successfully with these people.
- Methods of assessment and implementation are agreed as acceptable within the cultures of the respective Providers, and meet professional practice guidelines. Services for people are provided in a co-operative and collaborative way according to agreed protocols, with evidence of positive communication between Providers. This particularly relates to Behaviour Support, Dual Diagnosis and RIDCA funded High and Complex Providers. Evidence will be available in the form of Memoranda of Understanding, written protocols, formal meeting minutes, service action plans or other written communications.
- Where joint ventures or partnership approaches are formed to deliver the services, evidence of robust [governance](#) systems and structures for service development and policy review is expected to be included with information provided to the Ministry through the reporting cycle (such information may include summary information from advisory group meetings)
- Information is provided to the Ministry through the reporting cycle to assist in planning for future needs and service development.
- Providers will work together to minimise the risk of political and media complaints as a result of the behaviour of people. The [Regional Specialist](#) Behaviour Support Provider will inform the Ministry Contract Manager immediately they become aware of a potential complaint that is likely to attract media attention.
- There is documented evidence of improved quality of life for people as a result of the relationship with the [Regional Specialist](#) Behaviour Support Provider. Exit consumer survey or independent evaluation of consumer satisfaction may provide this information.

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<sup>2</sup> A commitment is expected from both the provider and the Ministry to investigate, select and implement the regular use of suitable outcome measurement methodologies to provide evidence of the efficacy of interventions that are developed for people who are supported by the service.

## 9

**Purchase Units**

Purchase Unit Code	Purchase Unit	Measure	Purchase Unit Measure Definition	Purchase Unit Definition
DSS220	Service	Client	Provision of Behaviour Support Service	Count of people receiving service on the first day of the month
	Eligibility assessment	Assessment		Assessment of potential person to determine eligibility for DSS funding
	Specialist Support	Service		Training event facilitated by the behaviour support provider

## 10

**Reporting Requirements**

Purchase Unit Code	Purchase Unit	Purchase Unit Measure	Reporting Requirements	
			Frequency	Information
DSS220	Service	Client	Quarterly	<i>Quantitative Reporting</i> 1. Number of people referred (new and returns/follow up) per month (refer to above Purchase Unit definition) <sup>3</sup>
DSS220	Eligibility assessment	Assessment	Quarterly	2. Number of assessments completed

<sup>3</sup> Deleted from Quarterly Quantitative Reporting:

- Average length of time spent per person referral
- Number of people referred by Ethnicity (NZ European/Pakeha, NZ Maori, Samoan, Cook Island Maori, Tongan, Niuean, Other Pacific Island, Other)
- Number of people referred by Gender (Male, Female, Unknown)
- Number of people referred by Age (0-16 years, 17-30 years, 31-50 years, 51-65 years, 65+ years)
- Number of people referred by normal domicile (Community residential home, Family home, Own home, Other)
- Number of people receiving service per month (Planning, Implementation, High priority (active), monitoring and evaluation, Low priority (passive) monitoring and evaluation, Reassessment)
- Number of people on waiting list of service per month. Provide count of each category (Assessment, Planning, Implementation, Reassessment)
- Number of referrals received per month
- Number of training events held and number of people attending training events.

DSS220	Specialist Support	Service	Quarterly	<ul style="list-style-type: none"> <li>3. Numbers waiting for assessment who have waited more than 7 days</li> <li>4. Numbers of persons for whom there are active intervention plans</li> <li>5. Number of people who have had their cases closed and outcomes assessed</li> </ul>
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- Narrative reports<sup>4</sup> can be submitted at any time if there are issues that you wish to raise e.g. that impact on the service's ability to respond to referrals.
- Templates supplied by you will require a monthly information breakdown but will be submitted quarterly.

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<sup>4</sup> Deleted from Quarterly Narrative Reporting:

- Number of people referred for service per month by NASC
- Information about identified service gaps
- Areas of growing demand
- Issues as identified by Provider
- Progress towards development of outcome measurement methodology as per section 8.5
- Content of training events.

# The Development of a Contracting and Governance Framework for Specialist Behaviour Support Service

## An Alternative Approach for Contracting and Governance

### 1. Background

The present arrangements whereby providers are contracted to funders to provide a service (or range of services) as defined by an accompanying service specification is inherently an adversarial arrangement. For providers the default is to do no more than is set down in the specification (and less if they can get away with it). For funders the default is to limit liability by defining the service in terms of specific requirements and reporting obligations. For example, contracts which require a specific skill mix or dedicated FTEs may penalise providers for reducing staffing, which limits providers from innovatively managing costs. Conversely the same contracts have poor mechanisms for ensuring that the employed FTEs provide value in terms of outputs/outcomes for clients. Similarly a specification that requires and funds face-to-face activity works against a provider developing more effective and demonstrably efficient mechanisms of providing longer-term support arrangements that would increase the clients' and their families' capacity for maintenance and self-care.

The reality is that there is often little trust, a lack of incentives for providers (particularly of a longer-term nature such as investment in service development), and many exhaustive reporting and external control requirements.

In summary the present arrangements for procuring specialist BSS are typified by:

- variable trust among the parties
- a focus on risk minimisation
- a highly specified external control regime to which accountability is framed
- limited (if any) opportunity for creative collaboration and innovation.

This paper sets out a different possibility characterised by the notion of 'alliance contracting', which may present some opportunities in the context of regional service arrangements for specialist BSS.

### 2. What is alliance contracting?

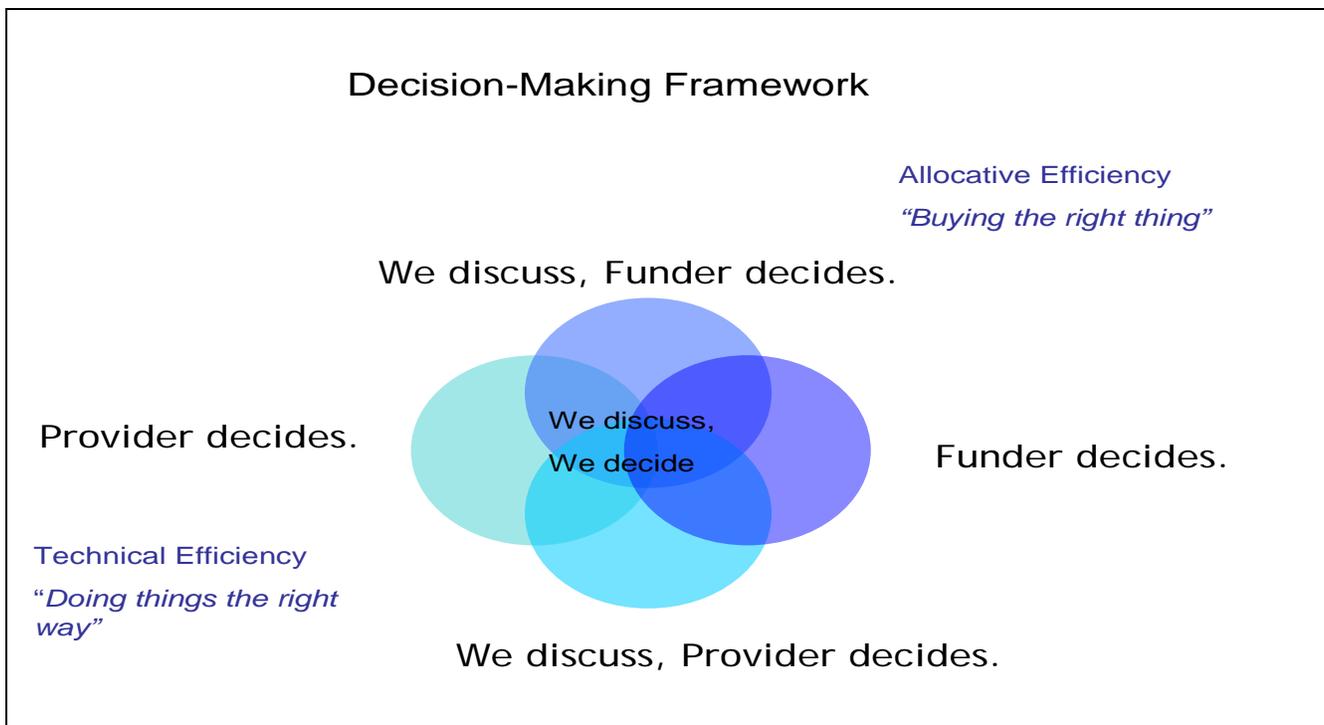
Alliance contracting embodies a decision-making process that makes clear which decisions remain the role of the Government (or its funding agents such as the Ministry and/or DHBs) and which decisions should be devolved to the service providers and ultimately be made at the clinician/client interface.

The process explicitly recognises that allocative efficiency ('buying the right things') has to be achieved at a population level and cannot be determined by a particular provider organisation. It remains the role of the Government (via the Ministry of Health and/or the DHB) to determine the allocation of public funding to achieve the best balance of outcomes for the population. Wherever possible this will involve consultation with providers and/or the community but in some cases these decisions may be taken centrally. In summary the Government and the funders within DHBs retain the right to define 'what is to be funded' and the outcomes that need to be achieved with public funds.

The balancing side of the decision-making process is to move as many decisions as possible into the providers and clinicians by devolving the determination of how the required outcomes should be achieved. This will involve fewer specifications and a reliance on quality processes and transparency of information to assure accountability and best value for money. Alliance contracting explicitly recognises that providers and clinicians (working together) are in the best position to effect improvements in service effectiveness and consequently improve efficiency.

The final piece of the decision-making is the opportunity to jointly decide where resources released due to improved effectiveness and efficiency could best be applied. This will constitute the core of the contractual relationship between the Ministry and/or the DHB and the provider organisations/networks constituting the regional service, and governance arrangements responsible for specialist BSS.

The decision-making process is represented in the diagram below.



### 3. Proposed contractual model

The contractual approach proposed is based on the alliance contracting model which has historically had wide use both locally and internationally in large scale, complex construction projects involving multiple companies. **The essence of an alliance contract is more in the process than in the formal contract.** The foundation lies in the different approach to cooperation between funders and providers. Trust instead of distrust is the basis of an alliance contract, although a clear and transparent contract is still needed to support this spirit of trust. An alliance contract seeks to move away from the traditional 'adversarial' approach in which parties are first of all competitors, or risk-minimising in their behaviour. Alliance contracts involve a collaborative process which aims to promote openness, trust, risk and responsibility sharing and the alignment of interests between funders and providers in achieving outcomes. The focus is on the best

arrangement for service delivery rather than on self-interests, which is typical of traditional contracts.

The traditional method of contracting is to draft for the worst. It remains important to have the contract specify ultimate remedies in a contract, but traditionally its emphasis is on what happens when everything goes wrong rather than managing the relationship to ensure that things go right and all resources are applied to fixing problems or dealing with issues as they arise.

This alliance approach is a further move away from the concept of arm's length funding arrangements and holding providers independently accountable. In the case of specialist BSS, an alliance arrangement recognises that the Ministry of Health remains accountable for the quality and appropriateness of services delivered to the target population and as such needs to be actively engaged at all levels in quality, client safety, performance improvement and value for money. It acts as a reasonable foundation for a 'whole of system' approach in terms of 'what' will be funded. Providers and clinicians bring perspectives of innovative opportunities to improve quality of service and outcomes – 'how' the service is to be provided.

In reality contracts are all about relationships. People are always behind the contracts and responsible for the management and delivery of the agreed outcomes. This does not mean that there are not provisions for dealing with worst case scenarios but sets an expectation that contractual remedies are an absolute last resort.

Alliance contracting is different from 'partnering', which usually involves traditional type contracts that have an overlay of specific relationship principles.

One of the key benefits of adopting an alliance framework is that it is not necessary to disrupt current organisational structures or subvert the sovereignty of their decision-making. This will significantly shorten the timeframe to establishment and avoid a great deal of potentially disruptive debate between organisational and professional groupings, allowing new arrangements to evolve over time rather than locking in rigid structures.

Alliance contracting recognises that disputes will occur, but provides for most disputes to be resolved using an informal dispute resolution procedure. This usually consists of first, resolution at the operational level then, if need be, senior management level, followed by the alliance board and then, possibly, mediation.

Alliance contracts tend more toward risk sharing and less toward allocating the risk to one party. This is the logical consequence of cooperating in the early stages of development. Early cooperation also provides the possibility of an early risk analysis. An early analysis is a condition for the attribution of the risks to one of the parties, preferably the party that can steer the risk.

#### **4. Key features of alliance contracts**

An alliance contract cannot function without a true spirit of cooperation. This means that parties have to invest in better and more frequent communication which facilitates the building of across-system teamwork. The alliance contract is much less detailed and leaves many of the decisions to an alliance board. Decisions can therefore be taken at a more appropriate moment when additional information is available, particularly if it may not have been available at the time the contract was developed. The alliance contract will have enough provisions and checks and balances to prevent the spirit of cooperation from turning into tunnel vision. In addition, the alliance board plays an important role in mitigating conflicts and increasing efficiency.

The core idea is that the alliance principles support and drive the actions of the parties during the process. Examples of alliance principles follow.

- Decisions are made on the basis of 'best for purpose', which could also be phrased as 'best for client' and/or 'best for system'.
- Working collaboratively, based on principles of good faith and trust.
- Not a legal entity, individuals retain identity, but an active alignment of parties' interests, and relationship embodied in the contract.
- Agreed core principles – workshops will form the basis of alliance.
- An alliance management team at the interface level and an alliance board for 'top level' decisions (usually, all decisions to be unanimous).
- Responsibilities clearly defined within a 'no blame' culture.
- Comprehensive dispute resolution provisions which have very limited recourse to the courts and termination ability, for breach of the contract.
- Innovation is to be encouraged and provide a key driver to success.
- Key performance indicators to measure the providers' performance.
- the parties to provide reasonable access to all personnel, materials and other resources needed for a successful project; and
- All communications to be open and based on a relationship of trust and honesty.

## **5. Governance arrangements**

This will be further described as it will need to reflect the proposed service model. However, if it is to be a regional service arrangement which is closely linked to DHBs then an alliance board for that region could be made up of DHB interests, providers/clinicians and the Ministry. Servicing of these could come from within (subject to negotiation) with the four regional support agencies (Northern, Midland, Central and Southern).

## **Acknowledgement**

This paper has been materially informed by a paper prepared by Ms Carolyn Gullery – General Manager Planning and Funding, Canterbury DHB – for the Expert Advisory Group overseeing the rollout of Better Sooner More Convenient – 7 December 2009.

**June 2011**

## References

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- <sup>i</sup> Ministers of Health and Social Welfare. 1992. *Support for Independence for People with Disabilities – A New Deal* (A Government statement on the funding and delivery of Health and Disability Services).
- <sup>ii</sup> American Association on Intellectual and Developmental Disabilities (AAIDD) website:  
[http://www.aamr.org/content\\_100.cfm](http://www.aamr.org/content_100.cfm)
- <sup>iii</sup> Ministry of Health. Nov 2010. *Behaviour Support Issues* (an internal paper)
- <sup>iv</sup> Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language. June 2007. *Challenging Behaviour: a unified approach – Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*. College Report CR144
- <sup>v</sup> Hughes D, Daysh R. 2008. Ministry of Health Discussion Paper: *Behaviour Support Discussion Paper for Sector Consultation*, Ministry of Health Disability Services
- <sup>vi</sup> *ibid*
- <sup>vii</sup> Ministry of Health. Nov 2010. *Behaviour Support Issues* (an internal paper)
- <sup>viii</sup> Mark Goldman, Clinical Lead, NHS National Leadership Council
- <sup>ix</sup> Scally and Donaldson 1998 (adapted)
- <sup>x</sup> Ministerial Report. March 2009. *In Good Hands* p2  
<http://beehive.govt.nz/sites/all/files/In%20Good%20Hands%20Report.pdf>
- <sup>xi</sup> Report of the Ministerial Review Group. August 2009. *Meeting the Challenge: Enhancing Sustainability and the Patient and Consumer Experience within the Current Legislative Framework for Health and Disability Services in New Zealand*  
<http://www.beehive.govt.nz/release/ministerial+review+group+report+released>
- <sup>xii</sup> Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language. June 2007. *Challenging Behaviour: a unified approach – Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*. College Report CR144 p52
- <sup>xiii</sup> Emerson E. and Forrest J. 1996. Community support teams for people with learning disabilities and challenging behaviours: Results. *Journal of Mental Health* 5(4), 395. Retrieved from EBSCOhost
- <sup>xiv</sup> Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language. June 2007. *Challenging Behaviour: a unified approach – Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*. College Report CR144
- <sup>xv</sup> *ibid*
- <sup>xvi</sup> Van de Ven AH, Ferry DL. *Measuring and Assessing Organisations*. John Wiley, New York, 1980.
- <sup>xvii</sup> *Our national health: a plan for action, a plan for change*. The Scottish Office, Department of Health 2000
- <sup>xviii</sup> NHS Confederation. 2001. *Clinical Networks – A Discussion Paper* © NHS Confederation, 2001
- <sup>xix</sup> *ibid*