

Putting People First

A Review of Disability Support Services
Performance and Quality Management Processes
for Purchased Provider Services



Prepared for

Hon Minister Ryall, Minister of Health

November 2013

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Executive Summary

At the heart of this project lies the essential recognition, that for disabled people to be safe, the systems that safeguard their well-being must be designed with an attitude of putting people first.

In line with the leadership role the Ministry has in overseeing the safety and well-being of disabled people, and setting the tone for the future, there is a need for the Ministry to:

- put disabled people first in all future decisions and actions relating to residential services
- support residential providers to place disabled people at the center of their service – and design it from this premise out
- lift the culture of the sector, by supporting good performance and the achievement of best outcomes

In short, the message the Ministry must communicate is that the safety of disabled people is paramount, and that anything less than this will not be tolerated.

Only one reason was given for contracting the panel to undertake this review – to learn from the past and improve in the future. This can be achieved by:

- **Supporting providers to offer high quality care and supports that place disabled people at the centre of their service**

When all providers place disabled people at the centre of their service, and adopt a policy of person-centered excellence, the need for high cost performance monitoring systems will diminish. The Ministry has a key role in achieving this, in setting direction, in clearly communicating what high standards of performance and outcomes look like – and in promoting and supporting this.

- **Giving disabled people a voice – the ability to speak out when unsafe, including the support to do this if they are unable to do so on their own**

Many disabled people have learnt to be silent about abuse through fear of retribution, losing services they depend on, or perceiving they deserve to be abused. As a result, many have become invisible. Thus, one of the keys to a better future lies in increasing the visibility of disabled people – by enabling them to speak out

- **Ensuring the processes that capture complaints, incidents, and issues, do so in a way that: (i) keeps disabled people safe, and (ii) resolves the complaint or issue**

A number of factors have a systemic impact on how safe disabled people are to speak up, the key one being knowing they *are* safe. This sense of safety arises from: (i) knowing they will be listened to, (ii) knowing complaints will be acted on and resolved, and (iii) knowing action will be taken to remove the perpetrators of the abuse from situations where they can continue to harm others.

- **Improving the effectiveness of performance management systems, so no providers – and no disabled people – fall below the radar**

The point when performance management systems become effective is when their design is based on the real needs of the people they are there to protect and when they cover all people needing protection. Anything less than this, suggests neglect, which in the worst case, leads to abuse.

Introduction

This external review was sought to test if the current processes involved in evaluating, monitoring and managing complaints by National Services Purchasing, support provider improvement and the safety and well-being of people with disabilities

The panel was asked to evaluate:

- i. the clarity of the Ministry's communications to providers on service delivery expectations
- ii. the effectiveness of the Ministry's processes to promptly identify and manage safety issues
- iii. the efficiency of the Ministry's processes in responding to the performance of contracted providers, including the ability to hold providers to account
- iv. the effectiveness of the reporting mechanisms and monitoring processes in place.

As the panel was developing its recommendations to improve the systems, processes, tools and resources required to achieve the above and strengthen provider performance, what it saw sitting at the core of the recommendations was one underlying message – the importance of putting people first.

In other words, the one thing that will make the difference is if the Ministry puts disabled people first in all its future decisions and all its future actions relating to residential services.

To achieve this and regain the confidence of the sector – in a way that is sustained over time – the Ministry needs to reassess how it manages performance in the disability sector. The key to significantly improving the safety and well-being of disabled people, is to take a systemic approach that covers all aspects of safety and care within residential services (the focus of this review).

Tinkering around the edges will not do it. Taking a piecemeal approach will not do it – or has not done it in the past. Improving each and every part of the system, however, will do it.

The recommendations provided over the following pages cover the major components of this system, with each of the recommendations working alongside and supporting the others.

These components can be grouped into four key areas. The panel likens these to the four legs of a chair – take one away and the chair falls over. Each of the following 'legs' supports the safety and well-being of disabled people – ignore one, and their safety and well-being reduces significantly:

1. Support service providers to offer high quality care and supports that place disabled people at the centre of their service, and enable them to live a good life
2. Give disabled people a voice – the ability to speak out when unsafe, including the support to do this if they are unable to do so on their own
3. Ensure the processes that capture complaints, incidents, and issues, do so in way that: (i) keep disabled people safe, and (ii) resolve the complaint
4. Ensure performance management systems are effective, responsive, and undertaken regularly enough, so little opportunity exists for people to fall through the cracks

1. Support Providers to Place Disabled People at the Centre of Their Service

The fundamental intent underlying this review is to improve the safety and well-being of disabled people living in residential services. The key to doing this, is to ensure providers place disabled people at the centre of their service and design it from this premise out.

Focus on Performance – on What Works Well

Providers are often heard saying, the Ministry only takes notice when something goes wrong. Providers are susceptible to the Ministry's view of them, as the funder and purchaser of services. Thus, if the Ministry focuses on wrong-doing, providers will make an effort to *not be seen* to be doing wrong and, accordingly, may act to cover up poor performance. If instead the Ministry places an emphasis on what is working well, and what constitutes good performance – or excellence in person-centered practice – providers will be much more likely to make an effort to be recognised for this.

While providers will benefit from this shift in culture and approach, the key beneficiaries will be disabled people.

As the purchaser of services, the Ministry's role is largely one of setting policy, determining the overall direction of disability support services, overseeing provider capability, and ensuring the quality of services and outcomes meet the required standards.

While monitoring for poor performance is one method of ensuring the required standards are met, supporting providers to achieve high levels of performance and people-centered services, is likely to have greater impact on the day-to-day well-being of disabled people.

To support this, the Ministry needs to develop an all-embracing document that clearly sets out the performance expectations it has of residential providers. At present, providers refer to the contract, including the Service Specifications, to identify the Ministry's performance expectations. As a result, many find themselves having to search out information that is only partially provided and in a piece-meal fashion.

Recommendation 1:

Embrace good performance and actively promote this, by:

- Clearly defining and communicating what constitutes good performance and expected outcomes – and monitor against these
- Supporting and encouraging best practice – and how this can be achieved
- Show-casing great examples – including how these were achieved.

If the Ministry focuses on wrong-doing, providers may cover up poor performance. If, instead, the Ministry focuses on good performance, and excellence in person-centered practice, providers will aim to be noticed for this

While monitoring for poor performance is necessary, it is equally necessary to support providers to achieve high levels of performance

The Ministry needs an all-embracing document that clearly sets out its performance expectations

*Benefit of doing:
Providers have a clear understanding of the performance standards and outcomes required*

Create a Culture that Supports Best Outcomes

From anecdotal evidence, organisational culture – of both the Ministry and providers – has considerable impact on the lives of disabled people.

A culture of ticking the boxes

People both internal and external to Disability Support Services (DSS) described its culture as one of ticking the boxes. Other terms used included: reactive, punitive, risk averse, intimidating, bureaucratic, and hard-working.

One of the reflections made by staff and others, is that people regularly act to cover their backs. Staff commentary suggests this occurs when they do not have time to perform the substance of a task and resort to doing only what is absolutely necessary. It also appears to reflect a perceived lack of tools and systems to achieve the tasks required.

As a result, many staff experience relatively high levels of stress, which for some includes the fear they might be blamed for outcomes over which they have little control. It is not surprising, then, that the culture is described as reactive and risk averse, and that staff act to keep themselves safe.

An Organisation that is Running to Catch Up with Itself

With the apparent lack of tools and resources, and the large number of new initiatives being worked on, staff seem stuck between a rock and a hard place. They work hard, but often seem unable to focus on what sits at the heart of their work – ensuring the systems and processes in place safeguard the quality of disabled people's lives.

Thus you have a paradox. The Ministry is currently working on a large number of new initiatives, with staff designing changes that aim to deliver significant improvements to the sector in the future. Yet there is not enough time or resources to do some of the basic things well, such as improve the systems and processes that keep disabled people in residential services safe.

A flow on effect – from Ministry to provider

When people in the sector were asked about the current culture of the Ministry and the impact this has on residential providers and the services and supports provided to disabled people, the answers given included:

- It drives good practice underground
- It stifles people working on the ground – squashed by protocol, policies, procedures
- Much time is spent on things that don't lead to quality of life

Organisational culture significantly impacts on the lives of disabled people

A 'tick the box' approach occurs when staff do not have the time or resources to complete the substance of a task

Similarly, staff act to cover their backs when they feel they have little ability to effect the outcomes achieved

The Ministry is working on a large number of initiatives to deliver significant improvements to the sector in the future, but does not have sufficient resources allocated to keeping current services safe

The impact of the Ministry's culture on providers is to drive good practice underground, as they too seek to cover their backs

- Providers feel they have to cover their backs
- Providers become less transparent

Recommendation 2:

Revitalise the culture of DSS, with the aim of re-focusing people's roles on the substance of the tasks they are there to complete. Ensure staff have the time and resources to enhance the systems and processes that safeguard the well-being of disabled people. NB: This may require reviewing staff levels to support sustainable improvements to the culture and systems over time.

Benefit of doing:

Staff focus on what matters – which results in better, safer services for disabled people

Restructure the Role of Contract Relationship Managers

Both Ministry staff and providers noted the importance of the relationship between Contract Relationship Managers (CRMs) and providers. However, CRMs stated that, in the main, they only meet with a few large providers regularly and didn't visit some providers at all. They also stated that they rarely visit more than one site, and often only the manager's office and, therefore do not visit many residences. This has clear implications for the CRM's ability to manage provider performance.

While relationships with providers are important, CRMs only visit some providers (and a few sites) regularly

In the words of Ministry staff and management:

“So many providers are doing their own thing, knowing no-one's looking... We rely on truthful data, far more than on the relationship ... We're juggling so many balls in the air at one time.”

“There are a lack of resources – our CRMs are focused on contracting, when they need to be more directly involved with Providers ... The contracting process is compliance driven; there are 61 steps in the process, with sign-offs being pushed further up. We need to be able to respond, be nimble, but the processes are so cumbersome.”

With little time and resources to visit providers, CRMs rely on provider honesty instead

In 2008 DSS was restructured and CRM roles shifted from a regional to a national structure, based on service-lines. With many now having to service the whole of New Zealand, or large parts of it, the costs and time associated with travel have proven prohibitive, and resulted in a significant drop in the regularity of provider visits.

Until 2008, CRMs had regional responsibilities and regularly met with providers in their area. Since then, the quality of their relationships with many providers has significantly reduced

With most CRMs now based in Auckland or Wellington, they are no longer privy to the communication and input from the range of people they used to be in contact with. For example, when based in regions, with oversight of all the services funded by DSS, CRMs would be in contact with all residential and community-based service providers, the Needs Assessment Service Coordinators (NASCs), local advocacy and support networks and potentially even doctors and taxi drivers. In this way, they had their ear to the ground

and heard much of what was going on.

Since their roles were restructured, much of this contact has been lost, with the exception of those service lines that are large enough for CRMs to still have a semi-regional focus.

In addition, where providers offer more than one service, such as residential facilities for people with intellectual disabilities, physical disabilities and respite care, providers can have three CRMs contacting them rather than one.

One of the main aims of shifting to a service line focus was increased consistency. However, there has been little improvement reported in this area. Instead, staff and providers have experienced a significant reduction in the quality of the oversight role due to the reduced frequency of visits and the concurrent reduction in the quality of CRM-provider relationships.

Recommendation 3:

Restructure the roles of CRMs around regional responsibilities, with all general CRMs given regional oversight of residential and community-based disability services, including service access through the NASCs.

Retain specialist roles in areas where senior or specialist skills are required. This may include overseeing:

- DSS's largest providers, for example, IDEA Services
- Services provided to disabled people with high and complex needs
- Equipment Modification Services

A national planning and development team could also be retained to work on new initiatives and major improvements or changes to existing service lines, as this would support national consistency.

Recommendation 4:

Review the role of CRMs to: (i) assess how they spend their time, with the aim of streamlining the role and re-focusing it on building and maintaining provider relationships, and (ii) ensure they are adequately resourced.

Encourage New Providers Into the Sector

As long as disabled people do not have a choice about which residential provider to use due to a lack of options, poor providers will continue to exist and disabled people will continue to experience services that are below par.

If instead, there was a choice between different providers and different care options, people would choose those who provided the highest quality service and supports. In this way, providers who offer services of a lower standard will no longer be funded by the Ministry, and will gradually exit the sector.

One of the main aims of restructuring was improving the consistency of service lines nationally; this has reportedly not been achieved

*Benefits of doing:
CRMs oversee the quality of provider services*

They also have the opportunity to communicate the Ministry's performance expectations to providers

Specialist expertise is retained where it adds value

*Benefit of doing:
Staff are allocated tasks according to where they can make the most difference*

While disabled people have no choice over which provider or option to use, poor providers will continue to exist

Increasing the number of organisations who provide care – and the number and types of support options – would, thereby, contribute to lower levels of abuse and increased levels of safety and well-being amongst disabled people.

Recommendation 5:

Encourage new providers of both residential services and other support options to enter the disability sector.

Benefit of doing:

More providers will allow greater choice and those offering high quality options will be chosen over those who do not

Encourage Peer Review and Peer Support

One insight gained from reviewing the sector is that abuse is more likely to occur when providers are isolated.

The panel has also heard that a number of ‘good’ providers have initiated various forms of peer support. This includes peer review, developing and sharing new ideas, and working co-operatively with like-minded organisations to jointly develop and share resources, such as staff training. In this way, they have developed small communities of practice, each organisation contributing to and supporting the others.

Good providers not only stay connected with one another, they also share knowledge and resources

Recommendation 6:

Support good practice by encouraging and supporting providers to take part in peer reviews and communities of practice – particularly where providers are isolated.

Benefit of doing:

Good practice is shared and adopted by a wider group of providers

Only Award New Contracts to Providers Who Hold Themselves to Sufficiently High Standards

The panel has been told of cases where providers have been in breach of their contract, had serious performance issues, or were not holding themselves accountable to achieving consistently high standards of safety, yet were awarded a new contract by the Ministry in one of its tendering processes.

This is akin to rewarding bad behaviour and sends a clear message to the sector that poor performance is acceptable.

This is even more of an issue if the provider’s performance is below par in an area similar to that of the newly tendered service.

Providers have been awarded new contracts despite not taking full accountability for achieving high standards of safety

Recommendation 7:

Do not award new contracts to providers who are in breach of their contract or who do not otherwise hold themselves accountable for achieving high standards of safety and performance.

Benefit of doing:

New contracts are only awarded to those with high safety standards

Provide a Range of Flexible, Quality Supports to Those with High and Complex Needs

In a recent survey, undertaken by the Complex Care Group¹, only one family with a child that had high and complex needs was happy with the care provided by their child’s residential provider. As a result, and despite the high level of support required, many families care for their disabled family member at home.

These children and adults often have multiple disabilities, including one or more of the following:

- A severe cognitive impairment
- A serious, on-going medical condition
- Poor communication – many are partially verbal or non-verbal and use behaviour as their means of communicating
- Autism
- Severe epilepsy

Due to the severity of their impairments and, for some, the inability to verbalise, people in this group are amongst the most vulnerable in the disability community. As a result, they can be subjected to relatively high levels of abuse. In order to increase the safety and well-being of this group, and their families, it is essential that:

- Residential providers who offer high and complex services have a culture that respects each individual’s needs and employ staff with the skills to:
 - i. communicate appropriately with those who are unable to verbalise
 - ii. recognise what different behavioural signals mean
 - iii. provide appropriate behavioural support
 - iv. provide the necessary clinical input.
- Alternative, more flexible supports are provided in the community to support disabled people and their families to live with dignity

Recommendation 8:

Only contract with residential providers who support those with high and complex needs, if they have staff with the requisite skills and experience.

Recommendation 9:

Support the development of more flexible support options to better meet the needs of disabled people with high and complex needs.

In a recent survey, only one family with a child that has high and complex needs was happy with their residential service provider

Due the severity of their impairments and their increased vulnerability, people with high and complex needs are more likely to suffer abuse

To reduce the incidence of abuse, residential services that support those with high and complex needs, must have a culture that respects the individuals it serves, and the expertise to provide effective services

Benefit of doing: Those with high and complex needs receive safe, effective care and supports

¹ Complex Care provides information and support to families with disabled children who have multiple disabilities, a serious ongoing medical condition, and/or behaviours that require a high level of support.

Attract and Recruit Disabled People into DSS

There is only one group of people who deeply understand the needs of disabled people – disabled people. Yet DSS does not currently employ any disabled people in permanent roles and only two on contract. If DSS is to lead the way in terms of future changes and improvements in the sector, it needs to attract and retain disabled people. This requires that DSS has a culture in which disabled people are supported and valued.

Please note: It is important that DSS does not employ disabled people as a form of tokenism, but only where they have the skills (or the capability to develop the skills) required. While consortiums and work groups provide valuable input, these should not be seen as a replacement for building the internal skills and understanding of DSS itself.

DSS may also benefit from employing people who: (i) are allies of disabled people, including family members or representatives of those who cannot speak for themselves, for example, those with severe, cognitive impairments, and (ii) have a high level of experience of disability.

Recommendation 10:

Attract, recruit, and retain appropriately skilled disabled people, and others with a high level of experience of disability and disability issues.

Develop KPIs to Drive Positive Outcomes

DSS currently funds disability services valued at \$1.1 billion, yet does not have KPIs against which to evaluate the performance of services purchased.

Organisations that work in complex environments, where what is relevant and of priority is qualitative, often pull back from developing KPIs. Yet high quality KPIs can also be used in these environments, if their design is based on those factors that drive positive performance and outcomes. Thus KPIs can be developed around the key drivers that contribute to positive outcomes for disabled people, and be included in PMRs and Service Specifications.

A word of warning: To fill this gap by developing KPIs that are quantifiable because they are easily measured, would be a mistake. The only value KPIs have is to drive positive behaviours – and to evaluate if the expected positive outcomes have been achieved. If KPIs do not reflect the key drivers of performance, then negative outcomes may occur instead.

Recommendation 11:

Identify what drives exceptional performance and design organisational and personal KPIs around this to support positive behaviours and outcomes.

There is only one group of people who deeply understand the needs of disabled people – disabled people

DSS would benefit from employing more disabled people with the capability to lead and influence the changes being made

Benefit of doing:

Change is led by those who have direct experience of what it is to be disabled

The development of KPIs, which reflect the key drivers of performance, would enable the Ministry to evaluate the quality of services provided more effectively

Benefit of doing:

The Ministry has greater capability to assess provider performance

2. Give Disabled People A Voice²

Disabled people suffer from many forms of abuse, a number of which reflect the nature of their disability and the care and support they need to enable them to live with some ease. Their need for this care has resulted in many learning to be silent³ for fear of losing access to a service or care-giver on which they depend. Others have learnt not to speak up through a fear of being punished, or experiencing a repeat of a previous negative incident.

When asked what stops you from speaking-up, members of People First⁴ stated:

"I might get into trouble"

"Afraid that I would have to leave the service if I complained"

"I have spoken-up before and nothing ever changes"

"Not being listened to or being heard, not being believed – management take the staff's side"

"I am frightened of a certain staff member"

"Sometimes staff tell us not to worry, that what we may want to complain about is not important"

"Backlash, nothing is going to be done about it. No-one is listening."

Other factors that keep people silent include: being so accustomed to ill treatment they regard this as the norm, the belief that they deserve to be abused³, difficulties with communicating, previous disparagement of their or others' complaints, and collusion amongst those involved who may deny any wrong-doing occurred.

This is compounded by the irregularity with which houses are audited and/or evaluated, and the inability of Contract Relationship Managers to oversee all facilities, particularly given the shift in their responsibilities from regional to national oversight.

These factors and others contribute to many disabled people being invisible. Thus, a key to creating a better future lies in increasing the presence of disabled people – by enabling them to speak out.

This freedom and ability to speak will also give disabled people greater power to make individual choices and effect change in their lives.

Many disabled people have been silenced

This has occurred as a result of:

– being punished for speaking up

– not being listened to or responded to when speaking up

– not achieving a better outcome or resolution when speaking up

Others do not speak up because they believe they deserve to be abused

Thus, many disabled people are silent and, thereby, lack the means to make the choices they want in their lives

² NB: The systemic factors which reduce disabled people's willingness to speak out are covered in the next section.

³ See 'The Hidden Abuse of Disabled People Residing in the Community: An Exploratory Study', prepared for Tairāwhiti Community Voice, by Dr Michael Roguski, June 2013.

⁴ People First is a self-advocacy organisation that is led and directed by people with a learning disability; it also provides its members with life-long learning opportunities and an easy read translation service.

A Trusted Person Enables People to Speak out

Under the current structure, DSS sits under National Services Purchasing, the National Health Board's funder and purchaser of services. Not surprisingly, when staff spoke of DSS's role in residential services, it was largely as the funder or purchaser of disability services, rather than as a body whose purpose is to ensure disabled people receive high quality, safe services. Given this is clearly a key aspect of DSS's role and its underlying intent, it is important that this is reflected in the design of roles and responsibilities.

This is important because at present, there are no roles whose purpose is to oversee the well-being of disabled people. Contrast this with the oversight provided by Child Youth and Family (CYF) and the Ministry of Social Development (MSD), where a social worker visits each child or young person in care every two months to assess their well-being and provide support as necessary.

No-one would argue against how vital it is to protect children and young people – they are some of the most vulnerable in our society. Why then do we accept that disabled people are less deserving of such support? Many are equally as vulnerable, and some maybe more so, particularly if they require the level of care offered by residential providers.

When asked, "What makes you feel safe to speak up?" people answered:

"Being listened to, and being heard and believed"

"Having people support and understand my views, not just say "you're not telling the truth"

"Having someone to talk to, that you can rely on, who's a support"

"A good person wanting to take your concerns seriously"

Thus a key to speaking up is having someone who you know will be there for you. As one person in such a support role stated, the first two times she visited a man in a residential service he told her he was happy. It was not until the third visit that he told her he hated it there. Accordingly, one of the keys to creating a support role that keeps people safe and enables them to speak up, is the strength of the relationship and the quality of trust that is built over time.

Recommendation 12:

Create a new support role, a group of people who build strong and trusted relationships with disabled people, and support them to stay safe and speak out when needed. These people may themselves be disabled, and the design and oversight of this role could be by a disabled people's organisation.

Through the role of CRMs, the Ministry has a relationship with, and oversees the role of, providers

It does not, however, have a relationship with and oversee the well-being of disabled people

The one thing that enables people to speak out is having someone there to support them

A key to the effectiveness of this support is the trust that is built over time

Benefit of doing: Disabled people feel supported to speak and act on their concerns

The Safety of Disabled People Must be Paramount

Disabled people are some of the most vulnerable in our society. They suffer from forms of abuse that many in the rest of society do not suffer, and over which they often have little influence or control. How we respond to their need for safety is a telling reflection of our society. As the Ministry charged with the prime responsibility for the health and well-being of disabled people, the leadership role the Ministry of Health takes in relation to this, is crucial to setting the tone for the rest of New Zealand.

While making the safety of disabled people paramount is key to the future of the sector, it also needs to be recognised, as some in the sector have stated, that this may be difficult to achieve.

Questions will arise, such as, how do you define abuse? And, what does having a policy of no tolerance for abuse mean in practice? These questions should not, however, be used as sufficient reason to back away from the intent – that all future actions and decisions made by the Ministry hold this as non-negotiable. Perhaps what it could do, is give rise to a healthy debate about just what these things do mean – and what is needed to lift the bar to implement them.

Recommendation 13:

The Ministry of Health adopts a policy of having no tolerance for the abuse that is inflicted on disabled people.

The safety of disabled people must be paramount in all future decisions and all future actions taken by the Ministry

While a policy of no tolerance for abuse may be difficult to define and achieve, this is not sufficient reason to step back from the need to lift the bar

Benefit of doing:

The safe-guarding of disabled people is paramount

Ensure Others Speak up, for Those Who Cannot Speak for Themselves

There are groups within the sector who are unable to speak for themselves, whose cognitive impairments make them less easy to understand, or who are partially verbal or non-verbal.

This group is reportedly under-represented in decisions affecting the sector, as well as decisions around the care and supports that they, and their families, receive. This is particularly important because it includes those who have high and complex needs and who can, therefore, be more challenging to care for.

Recommendation 14:

Ensure those who cannot speak themselves – and their families – are fairly represented at forums that result in decisions affecting their future care needs and the future of the sector.

Ensure those who cannot represent themselves, have others to do it for them

Benefit of doing:

All disabled people are represented in decisions that affect them

3. Ensure Complaint Resolution Processes Keep Disabled People Safe and Resolve the Complaint

A number of factors affect whether disabled people feel safe to speak up about issues or complaints. The most important of these, is knowing they are safe. In large part, this results from knowing: (i) they will be listened to, (ii) their concerns will be taken seriously, and (iii) action will be taken to resolve issues they raise. Thus, the very act of keeping people safe supports them to speak out.

The key to speaking up, is knowing you will be safe

Keep People Safe During an Abuse Investigation

Family members spoke of their experiences of reporting abuse and of the disabled person, or people, continuing to be subjected to abuse while their case was being investigated.

At present, disabled people can be abused while a case is being investigated

Disabled people also spoke of their fear of being punished if they speak up, which kept them quiet. Similarly, when people experience repeated negative experiences, particularly when intensified in an attempt to coerce them into withdrawing a complaint, they are less likely to continue to take a case.

If the potential exists for further harm to occur, the alleged perpetrator must be removed from having contact with the disabled person during an investigation

Accordingly, if there is potential for a disabled person to be harmed in any significant way once a complaint has been laid and the case is being investigated, there is a need to remove the alleged perpetrator from contact with the injured party(s) during this period.

As with many aspects relating to working in this area, this brings up the complexity involved in responding effectively when dealing with abuse.

Perpetrators come in many forms. They can be care-givers, family members, members of the public. They can be other disabled people. If a care-giver, the disabled person may depend on their care. In the case of a residential facility, this would require the provider to offer alternative care of the same type.

Complexities are involved, however, which must be taken into account

While in many cases it is clear who the alleged perpetrator is, there can also be issues around their identification. An example provided to the panel, was of a home of five men, who had been living together happily for some years. When a room became vacant, a younger man was placed in it by the Needs Assessment Service Coordinator (NASC). This person regularly taunted one of his flatmates, who finally lashed out. If the young man lays a complaint against the older man, who is the real perpetrator?

Disabled people should also be provided with support to assist them to overcome the abuse experienced

In addition to removing the alleged perpetrator, there is a need to provide support to the disabled person, or people, where needed. This could include: supporting them through the investigation process, arranging protection for them including removing them from the situation if necessary, arranging counselling to support them to cope with the abuse they have suffered, and

arranging medical support.

Recommendation 15:

Ensure disabled people are safe after laying a complaint, by: (i) removing the alleged perpetrator from contact with the disabled person if there is potential for that person to be re-harmed in any significant way, and (ii) provide supports that will enable them to overcome the effects of being abused.

Benefit of doing:

Ensures disabled can lay a complaint knowing they will be safe during an investigation

Undertake an Independent Investigation of Provider Services when a Significant Complaint is Laid

At present, when the Ministry receives a serious complaint in relation to a residential service, one of the next steps it takes is to contact the provider to find out what happened. If it has not already done so, the provider then conducts an internal investigation into the case and reports back to the Contract Relationship Manager. The outcome of this investigation then informs the series of actions the Ministry takes to resolve the case.

The actions the Ministry takes to resolve a complaint are based on the outcomes of an investigation that is undertaken by the provider

While it is appropriate for providers to be given the right of reply in response to a complaint being laid against them, and while it is evident that some providers will be open and transparent and deserve the trust implicit in the Ministry's actions, the reliance the Ministry has historically placed on providers to report back honestly is equally likely to have been misplaced.

The only way to obtain an accurate account of what happened is to undertake an independent investigation that is fair and equitable to all concerned

As long as there is a benefit to covering-up abusive or neglectful behaviour, and as long as there is an advantage to those involved to collude and find against the case put forward, these behaviours will continue.

The only way to obtain an accurate account of what happened is to undertake a rigorous, independent investigation of the incident(s), that is fair and equitable to all concerned. This should occur as quickly as possible after receipt of the complaint, to support the collection of all relevant evidence.

To be effective, those who undertake the investigation will need to have the experience and requisite skills to collect evidence from all of the people involved. Given the different types of abuse that can occur, and the range of impairments those involved may have, the skills required to collect evidence will differ in different cases. Accordingly, the investigators should be drawn from a 'panel of experts' who, as a group, have the combined skill-set needed to investigate the range of serious complaints that could arise.

Those who undertake the investigation must have the expertise to collect relevant evidence, the skills to communicate effectively with all involved, and the power to effect change

To be effective in achieving safe outcomes, the findings of the panel must be binding on the Ministry, whose role is to execute them and, thereby, hold providers to account for making the changes necessary to keep future residents safe.

Recommendation 16:

Set up a Panel of Experts to provide expert advice and support to the Ministry. Membership on the panel should be based on the fit between the individual's specialist knowledge and expertise and the range of skills needed to respond to the serious incidents, complaints and issues that occur in the sector.

This could include people with:

- the skills and understanding to communicate with disabled people who have severe cognitive impairments including a limited ability to verbalise
- knowledge and expertise relating to the different types of abuse disabled people suffer, including physical, sexual, and psychological abuse
- relevant clinical knowledge
- relevant legal expertise

Membership could also include appropriately skilled disabled people with a lived experience of the issues or abuse involved.

It is recommended that membership on the panel be for a set term.

Recommendation 17:

Conduct a timely, independent investigation into all serious complaints in a manner that is fair and equitable to all concerned. Those members of the Expert Panel who have the most appropriate skills undertake the investigation and report back to the Ministry.

Recommendation 18:

Ensure the findings of the Panel are binding, so the Ministry has the power to effect change and hold providers to account for implementing the changes needed. This is essential to assuring the future safety of residents.

Benefit of doing:

The Ministry is able to utilise people with the requisite skills, knowledge, and expertise to assist them to safeguard the well-being of disabled people

Benefit of doing:

The findings of investigations are fair and equitable to all involved

Benefit of doing:

Providers are held accountable for implementing improvements that result in safer services

Ensure Disability Legislation Protects Disabled People⁵

At present, legislation safeguarding disabled people from harm or abuse provides less cover than legislation protecting those who are able bodied. As a result, abuse cases can be dropped due to difficulties bringing a prosecution.

Current legislation lacks clarity in its ability to protect disabled people

For example, the Crimes Act is wide-ranging in its ability to protect disabled people, however, it can be difficult to collect sufficient evidence to prosecute, given the nature of some of the forms of psychological and

⁵ If a narrow view is taken, the following two sections fall outside the panel's Terms of Reference. However, the systemic impact of both areas on disabled people's safety and willingness to speak out is high. Accordingly while no primary research was conducted in either area, they have been included for completeness.

emotional abuse suffered by disabled people and the need to prove guilt ‘beyond reasonable doubt’. A stark example of this is illustrated by the comment of a police officer who investigated an accusation of sexual abuse. He is alleged to have said that no charges would be laid because ‘both parties had an intellectual disability.’

This inability to prosecute means disabled people can be more vulnerable to abuse given the lack of protection the law offers them in some instances. It can also lead them to being less willing to raise a complaint for fear of retaliation by the alleged perpetrator if prosecution is less certain.

The Domestic Violence Act, which covers physical, sexual, and psychological abuse, provides a more comprehensive definition of abuse. However, it only clearly covers abuse that occurs between parties who would ordinarily share a household or who have a close personal relationship. In other words, there is a lack of clarity around whether the Act covers abuse that occurs between a disabled person and their care-giver.

The systemic effect of the inability to prosecute results in many disabled people choosing not to speak out. In this way, abuse simply goes underground – leaving the victim and others unsafe, vulnerable, and continuing to suffer abuse they should not have to endure.

Recommendation 19:

That the Ministry of Health work with the Ministry of Justice to ensure the legislation covering disabled people provides the necessary protection to keep disabled people safe from serious harm.

The Crimes Act requires a level of proof that is difficult to collect in the case of emotional and psychological abuse

The Domestic Violence Act does not clearly cover the relationship between a disabled person and their caregiver

Benefit of doing: Disabled people receive a higher level of protection against abuse

Upskill Police so they Collect all Relevant Evidence

As long as valid cases of abuse are dropped through an apparent lack of evidence or an inability to prosecute, disabled people will continue to be abused and will be less likely to speak out about abuse.

Accordingly it is important that members of the police develop the skills to identify and capture all the evidence relevant to a case. This includes the knowledge to identify what evidence is relevant, and the ability to communicate effectively with those who have cognitive impairments or limited ability to verbalise. This could be supported by training a small number of police officers in regional offices, and ensuring communication aides that facilitate the collection of evidence are widely available.

The Ministry may wish to strengthen its relationship with Police to facilitate this, so there is greater understanding of the need that exists, and greater support for developing the training materials needed for this purpose.

Police can drop cases due to an apparent lack of admissible evidence

However this can reflect an inability to identify and collect all evidence relevant to the case

Recommendation 20:

The Ministry of Health work with Police to ensure there are sufficient police officers with the requisite skills and knowledge to capture all of the evidence needed to prosecute valid cases of abuse.

Benefit of doing:

Police have greater ability to protect disabled people and prosecute valid cases

Improve Collaboration Across Ministries and Agencies

A review of the Parklands case conducted by Child Youth and Family⁶ (CYF), clearly identifies the need to improve the interface that exists between CYF and the Ministry of Health (MOH). Of particular concern was the lack of mechanisms in place to ensure that appropriate information was shared. This manifested in a lack of communication by MOH to CYF regarding their concerns and the outcome of their investigation about Parklands.

A lack of mechanisms exist to support Ministries to collaborate effectively when working on joint cases

In their findings, CYF state:

“Communication and inter agency collaboration between Child, Youth and Family and the Ministry of Health could have been better. It looks as though each organisation focused on their individual roles and responsibilities and did not reach a shared outcome regarding the management issues that had arisen at Parklands.”

With no one Ministry or agency having oversight of the disability sector, effective means of collaborating are essential

With no one Ministry or agency overseeing the disability sector, collaboration and coordination across Ministries becomes essential. In addition to MOH, this includes CYF/MSD, ACC, MBIE, Education, Corrections, the Health and Disability Commissioner, the Human Rights Commission, and the NASCs.

At present, however, the collaboration and coordination that occurs, appears to be somewhat ad hoc, at times based on who you know rather than clear protocols, clearly defined roles and processes, and shared records and information systems.

Recommendation 21:

Enhance current memorandums of understanding between the Ministries and agencies involved in providing supports to the disability sector. Ensure these include formal protocols and clear roles and responsibilities around sharing information, making joint decisions, and designing the processes to be followed when working jointly on a case.

Benefit of doing:

Better outcomes and higher levels of safety are achieved for disabled people

⁶ This report was entitled, ‘Final Report into Child, Youth and Family’s involvement with the Ministry of Health and Linnaire and Neil Joslin,’ completed 16 September 2013. For further background on the Parklands case, please see Appendix Four, which gives a brief history of the case.

4. Improve Performance Management

Performance management includes both proactively managing performance (covered elsewhere in this report) and managing and monitoring service quality and outcomes to ensure required standards are achieved

This is essential both as a preventative measure and to safeguard the well-being of disabled people over time. The key to doing this successfully is to ensure residential providers are monitored effectively – assessed in respect of how well they meet the needs of their residents – and with sufficient regularity that no-one slips through the net.

The performance management systems currently used fall into two groups. Those that exist at the interface between the Ministry and providers and those that are internal to the Ministry. We look at the systems at the interface first.

The Contract

The role of the contract is to protect the interests of the Ministry, the provider and, above all else, the disabled people receiving the services contracted for. In line with the need to protect disabled people, the contract contains two clear weaknesses.

The need for the timely reporting of serious incidents or risks

One of the essential requirements of keeping disabled people safe, is the immediate reporting of safety risks and serious incidents.

Section 10.1 of the Service Specifications for Community Residential Support Services – Intellectual Disability (similarly for Physical Disability)⁷, states providers “are to immediately report to the Ministry of Health any critical incident or crisis that may result in media or political attention.”

In all other situations, as stated in Section 10.2, a provider is only “required to report 6 monthly on critical incidents and events – detailing the circumstances, dates, and persons involved, and outcomes.”

In future, the requirement to report immediately must be based on the seriousness of the incident or risk, rather than the likelihood of political or media attention.

Recommendation 22:

Providers must report all significant risks and serious incidents to the Ministry within 24 hours of becoming aware such an issue exists.

Effective performance management assesses if the needs of service users are met, with sufficient regularity that no one falls through the net

The main role of the contract is to protect disabled people receiving services

Providers are only required to report serious incidents or risks within six months – unless there is potential for media or political attention

*Benefit of doing:
Enables the Ministry to take timely action to resolve issues*

⁷ NB: The panel has only assessed these two Service Specifications for the purpose of this review.

The panel also notes the contract does not spell out what action(s) providers are required to take to notify the Ministry of significant issues or risks. Nor does it define the terms, significant risk or issue.

The only definition given is of a critical incident, which is defined in the Service Specification as, any unusual event which could:

- be life threatening for the service user
- be dangerous – the safety of the Service user is at risk of grave harm
- have significant consequences
- be a serious and grave crisis that may result in media or political attention

Both the lack of definition, and the lack of specificity in the latter definition, leave room for subjective interpretation. While it may be self-defeating to be too prescriptive, it is important that enough clarity is provided in the definition of these terms, that clear guidance is provided around what is to be reported and how it is to be reported. This will also ensure there is less room for misinterpretation and under-reporting.

Recommendation 23:

Develop clear definitions of significant risks, issues, and critical incidents, and a clear pathway for reporting these to protect the safety of service users.

While having a safety net that works is crucial, it is also important that the reporting of serious incidents and risks is seen as an opportunity for service providers to learn and improve, not just as a black mark against them.

A graduated system of options would support improved performance

Sub-standard performance can come in many guises. What is essential is that the Ministry manage this effectively. Yet the contract does not include any escalation clauses the Ministry can apply if a service provider fails to meet their obligations. In this event, the Ministry has only four real options:

1. Withhold some or all payments – an option that is reportedly not used, given the negative impact this is likely to have on residents
2. Remove residents – also used only as a last resort
3. Appoint a temporary manager – a clear signal in most cases that the end is near
4. Terminate the contract

Thus the contract lacks options and incentives for remedying breaches, by requiring that providers make improvements to existing services. It also lacks a graduated system of sanctions that sends a clear message that there are consequences to providing services that are below the standards required.

The contract does not identify the process providers are required to follow to notify the Ministry of serious risks or incidents

Nor does it adequately define terms such as significant risk or serious incident

*Benefit of doing:
Provides less room for providers to prevaricate or under-report issues*

The current contract lacks a graduated system for managing poor performance

Thus, while the Ministry may want to implement steps and supports to improve provider performance, it does not have the legal mandate to do this

Thus, while the Ministry may want to implement intermediary steps, such as providing a monitor, a mentor or other supports to work with the provider to improve service outcomes, it does not have the legal mandate to do this, if the provider does not concur.

Recommendation 24:

Include a clear escalation path in future contracts that allows for a staged approach to managing poor performance or non-compliance against contract.

In addition to the above, the contract has been criticised by providers as being too prescriptive and, thereby, limiting their ability to be innovative in response to the needs of the people they provide services and supports to. While it is beyond the scope of this review to assess the forty current Service Specifications to evaluate whether they allow for innovation, what is clear, is that all future contracts must place disabled people at the centre of the service, so the service and the contract is developed from the person out. In this way, the outcomes disabled people want and need will form the basis of future service design – against which performance is monitored and managed.

In line with this, the panel notes that two projects are underway to rewrite the Contract and Service Specification so they are more outcome-driven.

Performance Monitoring Reports (PMRs)

The one regular reporting instrument that sits at the interface between the Ministry and providers, PMRs, is strikingly ineffective.

Replace PMRs

Not one provider, nor any member of Ministry staff had a positive word to say about PMRs. Major criticisms included the lack of useful information contained in the report, the inconsistency in reporting standards, and the lack of timeliness with which Contract Relationship Managers (CRMs) received the report. In the words of two staff members:

“[The content] is sometimes meaningless. There is a lack of consistency of what is being reported on, and no identification of risks or trends”

“They are a complete and utter waste of time – they have no real value.”

Providers spoke of the time and effort required to complete the report, which could then disappear into a black hole. As one provider stated:

“You can write anything and no-one will notice.”

This is not surprising, given that PMRs are completed once every three or six months (depending on the nature of the service) and sent to Sector

Benefit of doing:

Gives the Ministry the mandate to improve services and keep disabled people safe

Future contracts need to support providers to place disabled people at the centre of their service and design it from there out

PMRs are universally seen as containing little useful information and a waste of providers' time

CRMs also receive them months after they have been completed

Services in Dunedin, from where they reappear some four to five months later. Thus, if a critical incident is reported, it can be received by a CRM up to 11 months after it has occurred. Similarly, where useful narrative is provided relating to challenges a service is facing or improvements they are making, CRMs may hear of this five months later – unless they personally take action to obtain a copy sooner.

The Panel notes the Ministry is currently investigating abolishing PMRs and looking at what they might replace it with.

Recommendation 25:

Replace existing PMRs with a report that focuses on quality of life outcomes, as well as challenges experienced, and improvements being put in place by service providers. Send this directly to Contract Relationship Managers, with a copy forwarded immediately to Sector Services (if still appropriate).

Benefit of doing:

PMRs no longer waste providers' time, and CRMs receive useful information in a timely way.

Evaluating the Quality of Provider Services – Certification Audits and Developmental Evaluations

Two processes exist to check if the quality of residential services meet the standards required, Certification audits and Developmental Evaluations.

Certification audits

Certification audits are required by the Health and Disability (Safety) Act, which gave rise to the Health and Disability Service Standards. A certification audit assesses whether a provider meets these standards, and is normally conducted once every three years.

Certification is widely viewed as auditing to a minimum standard

However, the Act only requires that houses with five or more people are certified. Thus, almost 60% of residential homes slip below the certification radar⁸. This threshold makes little sense, given people in houses of four or fewer are no less vulnerable to abuse nor less in need of quality services and monitoring, than those in houses of five or more.

It also excludes houses with four people or fewer

In addition, Certification and the Standards are widely viewed as a minimum standard designed largely for the health sector rather than for disability, with little attempt made to assess the quality of life, or outcomes achieved for disabled people. It covers: consumer rights, organisational management, continuum of service delivery, safe and appropriate environment, restraint minimisation and safe restraint practice. An alternative approach developed by The Council on Quality and Leadership in Canada, entitled Basic Assurances Certification, can be viewed in Appendix Three.

And little attempt is made to assess the quality of disabled people's lives

⁸ There are 1,626 houses under the care of providers, of which 966 homes have four residents or fewer.

With providers choosing and paying for the agency that conducts their certification audit, the potential also exists for a conflict of interest, with the potential for agencies to provide outcomes that better meet the needs of the provider, than the Ministry, so they will purchase their services again next time an audit is due.

Developmental Evaluations

Developmental evaluations on the other hand, place much greater emphasis on the extent to which the service is person-centred, with evaluators spending a significant proportion of their time meeting with disabled people and their families. The main areas they cover include: identity, autonomy, affiliation, attainment, safeguards, rights, and health and wellness. Being developmental in nature, the process used also identifies ways to improve the services and supports provided.

Developmental evaluations place greater emphasis on assessing residents' quality of life

However, a number of factors reduce their effectiveness as a tool to monitor the safety of disabled people. First and foremost is how few and far between the evaluations are. To date, houses have been evaluated on average once every twelve years. This ratio changed in July this year, further reducing the regularity with which most houses are evaluated, and is now determined by the square root of the total number of houses a provider has, multiplied by 0.6 if the provider is certified. This ratio translates to mean that if a provider has fifty houses under one contract, only four of the fifty houses will be evaluated every three years, or at the mid-point between certification.

They are also developmental in nature, with a focus on identifying improvements to services

Other concerns include the subjective nature of the process and tool, hence the extent to which the skill and experience of the evaluators are crucial to achieving a valid and useful outcome. In line with this, Ministry staff spoke of poor quality reports and inconsistencies in reporting, including variations in what gives rise to a requirement or recommendation. This definition is important, as anecdotal evidence suggests some providers only implement requirements and ignore recommendations.

However, they are few and far between

And the quality of reporting is variable

For these reasons and, in particular, the importance of safeguarding the well-being of disabled people, there is a clear need to ensure all evaluators have the requisite skills and experience, that report outcomes are of a consistently high standard, and occur frequently enough that houses do not fall below the radar.

Accordingly, greater reporting consistency is required

For the Ministry to make the most effective use of resources, frequency should reflect the risk profile of the house or provider. Accordingly, while it is recommended that houses be evaluated once every three years on average, this could range from once every six months, in the case of very high-risk providers, to once every five years, where providers have demonstrated consistently high standards of performance. When developing the risk profile of providers the 'early warning markers' identified in the assessment of the Three Cases should be taken into account (see Page 29).

The frequency of evaluations also needs to increase and reflect the risk profile of each provider

Recommendation 26:

Replace the current Certification audit and developmental evaluation with an enhanced developmental evaluation⁹, which assesses *all* residences on average once every three years. This needs to be supplemented by the safety requirements in the Standards that relate to disabled people, including:

- Safe medication practices and procedures
- Quality food and nutrition
- Waste disposal and infection control
- Safe facilities and environment
- Emergency Planning
- Restraint minimization

This also needs to be supplemented by:

- An assessment of the extent to which the house provides a warm and homely environment

Recommendation 27:

The Ministry contract for the use of the best developmental evaluation tool and process available in the market place. It is recommended that this cover:

- Identity and autonomy
- Choice and control
- Relationship & partnership
- Belonging and personal networks
- Competence and support to contribute
- Customized supports
- Safety and respect

This should also include a structured way of identifying where a provider sits on a continuum on each of the areas assessed, to support greater objectivity and consistency in reported outcomes.

Recommendation 28:

Require evaluation agencies to demonstrate the quality and consistency of their evaluators and report outcomes – with agency choice based on the achievement of consistently high outcomes.

Benefits of doing:

A best approach is used, with all houses evaluated, on average, once every three years

This assesses all relevant aspects of safety and ensures people live in a warm, homely environment

Benefit of doing:

Developmental evaluations are enhanced to reflect the need for greater choice and control, and to ensure disabled people are living good lives

Benefit of doing:

Improvements in the quality and consistency of outcomes

Better outcomes will also be achieved for disabled people if the reports are published openly, enabling people to choose services based on quality.

⁹ Please Note: This recommendation and the one that follows may require changes to the Health and Disability (Safety) Act, the Standards, and the contract (to cover the additional areas being evaluated). However, this change is essential if significant improvements are to be made to safeguard the well-being of disabled people in the future.

No-notice issues-based audits – a valuable tool that is under-utilised

In the year to June 2013, the Ministry only carried out two no-notice issues-based audits, suggesting a reluctance to use one of the most effective tools at its disposal for assessing potential issues and risks. These figures suggest:

- the threshold for deciding when to conduct a no-notice audit is too high
- there is some reluctance to use this tool; couched in words such as, “it is the person’s home, you can’t just go in.” This raises the question, which is better, keeping people safe or leaving them vulnerable to abuse?

Clearly there is a need to carry out no-notice audits in ways that are least intrusive and sensitive to the needs of residents. However, to use this tool so rarely is to not make use of an effective means of assessing – and quickly responding to – whether people are safe or not.

The panel would like to note that under current management the use of this tool has increased, with three no-notice audits conducted in the five months to 30 November 2013.

Recommendation 29:

Conduct no-notice issues-based audits whenever there is sufficient concern that the safety or well-being of a disabled person is at risk.

While the usefulness and value of this tool is clear, it is equally clear that it is of benefit to conduct the no-notice audits in such a way as to bring about the greatest learning and improvement – of services and outcomes. This would benefit current residents, future residents, providers and their staff.

The Ministry’s Internal Processes for Resolving Issues and Complaints

The following assesses performance management within the Ministry.

Enhance the processes used for managing issues and complaints

When asked to describe the process used to resolve issues and complaints, a number of staff made comments similar to the following:

“There is no real system for ensuring the Ministry highlights issues and responds appropriately. There is no check to ensure action is taken. So things can be missed.”

“I have no idea of a step-by-step process if there’s an issue. There is no clear process.”

The threshold for conducting no-notice audits appears to be too high

The question needs to be asked, “If your safety was under threat, would you rather someone checked if you were okay, or would you prefer to be left on your own to sort things out?”

Benefit of doing:

Priority is given to keeping people safe and well

A lack of clarity exists around the most appropriate response to an issue

While a clearer process has developed over the last six months, limitations and issues still exist that reflect the lack of formal tools and systems in place. This reduces the effectiveness and timeliness of actions taken as a result of:

- Not having clear definitions of risk – or the responses required in light of the different levels of risk
- Not having clear escalation points
- The lack of an IT system that brings together all the findings, reports, complaints and issues relating to a provider over time
- A lack of clear frameworks and guidelines, resulting in CRMs asking:
 - What is our role?
 - When do we escalate an issue – what is the threshold?
 - What do we do when.....?

In relation to these questions, a level of subjectivity exists that places too much dependence on the personal knowledge and experience of each CRM, rather than ensuring they are fully supported to achieve the best outcomes. This is well encapsulated in the words of one CRM:

“We just fumble our way through what to do with our complaints – we just do our best, we have no idea what we’re supposed to do and hope we have enough common sense to get us through.”

While clearer processes and guidelines are required to support more effective complaints resolution, the panel does not believe a highly prescriptive set of guidelines or frameworks will solve this issue. CRMs have a high level of complexity to contend with when responding to the different needs inherent in each case; thus, a highly prescriptive framework could be equally as flawed as the current lack of guidelines. Instead, a balance is required between clearer processes and roles, and expert advice and training.

Recommendation 30:

Design and implement a complaints and issues resolution process, which is based on:

- clearly defined levels of risk
- key thresholds and escalation points
- who does what when, i.e., clear roles and responsibilities
- effective case management methodology

Recommendation 31:

Provide CRMS with training to equip them with best practice knowledge and skills relating to managing disability-related crises.

There are no clear definitions of risk, or the different levels of risk,

no clear escalation points,

no system that captures issues and findings in one place, and

no clear guidelines around what actions to take, when.

The level of subjectivity in the system is too high, particularly given the inexperience of some CRMs, and the considerable complexity involved in some cases

Benefit of doing: CRMs are more efficient and effective in their role

Benefit of doing: CRMs are equipped to resolve complex cases, and achieve better outcomes, in a more timely way

Recommendation 32:

The Panel of Experts provides specialist knowledge, expertise and advice to support CRMs to resolve challenging or complex complaints and issues.

Benefit of doing:

CRMs are able to resolve issues more effectively

A single electronic management system is needed

At present, Disability Support Services (DSS) lacks the tools to manage risk effectively. With five provider databases, there is no one place or information system that captures all the reports, outcomes and findings relating to each provider. This reduces the visibility of risk, making it virtually impossible to gain a clear picture of how a provider has performed over time, or how they are performing at any given moment in time. Similarly, current systems do not provide a clear picture of whom the at-risk providers are, what trends are occurring, or what themes are emerging that may need to be responded to.

The current information system does not give staff a clear picture of provider actions or performance over time

The lack of processes and mechanisms for responding to issues and complaints and the ineffective information system – place a huge burden on staff. While it is one thing to recognise that good people can overcome poor systems, responsible management practice ensures staff are provided with the systems and tools that enable them to achieve the best outcomes possible.

Recommendation 33:

Implement a single electronic management system that brings together all information relating to providers and the disability sector – with urgency. The design must allow Ministry staff to gain a clear picture of providers over time, as well as risks, patterns and trends relating to providers in the sector.

Benefit of doing:

Staff have a clear picture of providers, and of patterns and trends occurring in the disability sector

Take action to close under-performing facilities

A key learning from assessing the three cases referred to in the Terms of Reference, is that many knew, for example, about Parklands “years ago”. Yet nothing was done. This was not about not knowing. It was about not acting.

Not closing facilities that provide sub-standard services was not about ‘not knowing’, it was about not acting

Moving forward, it is clear management need to make the hard decisions and take actions when necessary to safeguard the well-being of disabled people. This includes being proactive and working with providers to improve their service where this is below par. It also includes taking action to close services where disabled people are being harmed and there is no clear pathway forward to improving the quality of care. It also includes making every effort to relocate residents well and support them through the change.

This has improved dramatically

It is important to add, that under current management the willingness to take action and close services has improved dramatically.

Benefit of doing:

The safety and well-being of disabled people is given top priority

Recommendation 34:

The Ministry must act on the knowledge it has – and make the hard decisions including terminating provider contracts, where appropriate, in a timely way.

Lessons from the Three Cases

As part of its review the panel was asked to assess the Ministry's response to three high public profile cases of unacceptable treatment of disabled people. The following is a summary of the panel's findings. Background histories to the cases are given in Appendix Four.

How Proportionate Was the Ministry's Response?

Until early-to-mid 2012 the Ministry missed or did not heed warning signs that existed or issues that were raised in relation to the three cases. In short, it is difficult to talk of the action taken, when many of the actions were inadequate or non-existent.

The following provides an overview of the lessons arising from each of the cases.¹⁰

Parklands

The Ministry was ineffective in its dealings with Parklands until the decision was made to appoint Temporary Managers in June 2012. From this point on, the Ministry took responsibility for the situation that had arisen.

Lessons:

- Decisive action needs to be taken immediately when the Ministry is informed of services that are performing below the standards required
- This action should include:
 - putting in place a mentor or advisor
 - agreeing and implementing a communication and reporting plan, so the Ministry is kept fully informed of what is happening
 - clearly identifying the improvements required – and the need for evidence to show improvements have occurred
- Where improvement is not possible, terminate the contract as promptly as possible to reduce the suffering and harm caused to residents
- Create a culture where those in the know are encouraged to speak up, and accountability is given and taken for acting on this knowledge

Mary Moodie

The effectiveness of the Ministry's monitoring of Mary Moodie was minimal. Two audits/evaluations expressed concern about the mix of people in one house but were in the main optimistic. This brings into

Until early 2012, actions taken were inadequate

Lessons from Parklands:

Take decisive action when standards fall

Take action to improve the quality of care by putting a mentor in place

Develop and agree a reporting plan

Require evidence of improvements being made

If improvement is not possible, close the facility promptly to limit the harm and suffering to disabled people

Encourage those in the know to speak up

¹⁰ For a history and further background of each of the three cases, please see Appendix Five.

question the quality of the audits conducted. It also raises the question of why the Ministry relied so heavily on this tool alone. The apparent lack of knowledge reduced the Ministry's effectiveness in responding to the issues that existed.¹⁰

Lessons:

- Improve the quality of the audits/evaluations undertaken – in particular, ensure they assess disabled people's quality life
- Develop clearer protocols and systems for reporting complaints or issues of concern with the other agencies involved, e.g., NASCs
- When serious complaints or audit/evaluation requirements are received, take immediate action to resolve the situation
- Strengthen relationships between CRMs and providers, so the Ministry has a better handle on what is going on within residential services. Where possible, also strengthen lines of communication with the community of which the provider is a part

Te Roopu Taurima o Manukau

The Ministry took more than two years to protect the interests of the disabled people at Te Roopu Taurima o Manukau (Te Roopu) effectively – all of whom have complex disabilities. This was far too long. Particularly given the serious nature of the complaints against Te Roopu.

Lessons:

- Should a similar case arise again, appoint a senior staff member with experience in complex care to oversee the case immediately and ensure prompt action is taken
- When a District Inspector conducts an independent investigation and finds there is a case to answer, take immediate steps to keep existing residents safe
- Where serious allegations of abuse arise, expedite the process that leads to the appointment of an external monitor. While this process is underway undertake intermediary steps to ensure residents are safe and the situation improves. Possible options include:
 - put in place a highly experienced mentor to work with the provider
 - agree the outcomes required – and the need for evidence to show that improvement has been achieved
 - agree and implement a communication and reporting plan that ensures the provider keeps the Ministry fully up to date
 - put in place probationary management with an agreement that this will be removed when practices and systems reach the required standards

Lessons from Mary Moodie:

Improve the quality of audits and evaluations

Develop clear protocols for informing others

When a serious complaint is received, take immediate action

Strengthen the relationships between CRMs and providers

Lessons from Te Roopu:

Appoint a senior person to oversee the case

Take immediate steps to keep people safe

Put a mentor in place

Agree the changes required, and the need for evidence of improvement, and develop a reporting plan

If needed, put in place probationary management

A lesson that was common to all three cases

Lack of information sharing and reporting across agencies: In addition to MOH, several agencies had contact with Parklands: the NASCs, CYF, Audit and Evaluation Agencies, and the Health and Disability Commissioner (HDC). Similarly, families of residents at Te Roopu and Mary Moodie laid formal complaints with police and with HDC. Yet the Ministry does not appear to have records of the outcomes of these complaints. This lack of cross-agency communication and reporting indicates the need for better processes for sharing and reporting information.

Ensure effective communication exists across the Ministries and agencies

Early Warning Markers

The following have been identified as potential early warning markers that could warrant the Ministry placing a provider under watch – particularly if more than one of these occur at the same time:

When more than one of the following markers exist, place providers on a watch list:

- **Institutional approach:** In all three cases there is evidence that attitudes existed that were reminiscent of an institutional approach to the care of people with disabilities. This culture, which sees people as a group, rather than as individuals with individual needs and preferences, is a clear warning signal of a lower quality of care.
- **Changes in senior management:** In the cases of Mary Moodie and Te Roopu, a change in leadership had a direct link to a decline in the quality of the services. As changes in management will occur fairly frequently across the sector, it may only be practical to keep tabs on those organisations where such changes are accompanied by another early warning marker. However, the Ministry may want to keep a watchful eye on any large organisation that undergoes a change in leadership.
- **Poor governance:** Failings in governance – or a clash between the board, management and families – were a significant issue in the decline of services at both Te Roopu and Mary Moodie.
- **Rapid or inappropriate expansion:** Te Roopu expanded rapidly over a period of ten years. Parklands increased resident numbers from eight to nineteen. The Ministry should take a closer look particularly when this expansion is in response to financial concerns, or is not supported by a strong management team and a well-conceived business plan.
- **Isolation of providers:** Parklands was a small, rural provider disconnected from the rest of the disability sector. Environmental circumstances such as this should always be a signal that closer surveillance is required

An institutional culture and approach exists

Changes occur at a senior management level, particularly in a large organisation

There is a clash between the Board and management and/or families

Rapid expansion reflects financial concerns, rather than a planned increase in services

Providers are isolated

A Final Word

The Transition

That this review has been commissioned is an indicator – not just of hope but of possibility. The possibility to look again and start anew.

The possibility that this is a call to push the re-set button, the beginning of a new way of doing things in residential services based on putting people first.

The possibility that the new initiatives already being undertaken, and the recent willingness to take action to close failing services, are an indicator that this hope will be rewarded in practice.

This review was undertaken to learn from the past and improve in the future. To support this, it is recommended that the Ministry:

1. Obtain significant input from disabled people in all future decisions and actions relating to the implementation of these recommendations
2. Develop an implementation plan that gives priority to putting the recommendations into action
3. Put together a review team to oversee the plan's implementation and to ensure the necessary resources are allocated to achieving the outcomes required
4. Create a communication plan to keep key stakeholders up to date with the actions undertaken

It is also recommended that this report be disseminated as widely as possible, and that all key people in the sector are updated on a quarterly basis on the decisions made and the actions taken to implement the recommendations.

The commissioning of this review is a signal of the will to learn and improve

To achieve the outcomes required:

- *involve disabled people in the implementation of recommendations*
- *develop an implementation plan that is reviewed regularly*
- *communicate all key actions to stakeholders in the sector*
- *disseminate this report as widely as possible*

Addendum

As the panel conducted more than fifty interviews in its aim to understand the challenges facing the sector, other issues were brought to their attention that were outside the scope of their Terms of Reference. Two in particular were stated by so many people, always unprompted, and with such a high level of concern, that the panel felt compelled to add two further recommendations.

Two issues were brought to the panel's attention that are outside its Terms of Reference

Ensure the role of NASCs supports the well-being of disabled people

Key to the well-being of disabled people is their ability to choose the provider(s) which best meets their personal needs and preferences. Thus the role of the NASC should be more about providing the necessary information to make informed choices, than choosing services for disabled people.

There is a need for transparency and consistency in NASC decisions, and for disabled people to exercise personal choice over which provider best suits their needs

Recommendation 35:

Ensure the role NASCs play supports the well-being of disabled people. In particular, ensure there is transparency and consistency in information and decision making, and disabled people are supported to choose those services or provider(s) that best meets their needs, personal goals and preferences.

Review the quality of care-giving in residential services

The role that impacts most on the well-being of disabled people in residential facilities is their care-giver. While organisations can have great visions and policies, the one thing that contributes most to the day-to-day experience of disabled people, is the skills of their care-giver and the dynamic that exists between them and their care-giver.

The dynamic that has the greatest impact on the well-being of disabled people is the quality of care-givers that are provided by residential services

Factors that impact on the quality of care, include:

- Recruitment processes
- Staff development and training
- The culture and values of the provider
- Management style and supervision practices
- The quality of staff mentoring and coaching
- Performance management practices and processes
- Staff remuneration, and how proportionate this is to total funds allocated
- Abuse prevention, education, and training

This is affected by effective staff recruitment and training practices, a culture that supports person-centered excellence, and funding that is allocated appropriately

Recommendation 36:

Ensure providers offer a consistently high standard of care and support.

Appendix One: Terms of Reference

The key objectives of the review and the key questions the panel was asked to answer, are as follows:

External Review – Objectives

This external review is sought to test if the current processes involved in evaluation, monitoring and complaints management by National Services Purchasing support provider improvement and the safety and well-being of people with disabilities

The external review aims to evaluate:

- i. the clarity of communication from the Ministry to providers on service delivery expectations, performance monitoring, complaints and issues management and support/escalation processes
- ii. the effectiveness of the Ministry's processes to promptly identify and manage any safety issues or concerns regarding purchased disability support services
- iii. the efficiency of the current processes in responding to the performance of a contracted provider, and the ability to hold providers to account
- iv. the effectiveness of the reporting mechanisms and monitoring processes in place.

The review will make recommendations about any systems, processes, tools or resources that may assist the Ministry in strengthening the performance of contracted providers including options for incentivising performance improvement.

Key Questions

The external review will answer the following questions:

- What processes (mechanisms, policies, and procedure) does National Services Purchasing use to identify and respond to complaints or safety risks, or issues and risk presented by contracted providers relevant to contractual or quality expectations of disability support services?
- How effective and efficient are the current processes?
- To what extent are responsibilities clear in the management of complaints, and quality issues or risks regarding contracted providers?
- To what extent does documentation and processes make clear the Ministry's expectation of providers in delivery of services?
- What improvements should be made?
- What learnings can be identified for the future and shared with other Ministry of Health service deliver business units?

Appendix Two: Methodology

This review was divided into two parts: Phase One, which assessed the effectiveness and efficiency of the Ministry's performance management systems from an internal perspective. And Phase Two, which sought to identify the changes needed to improve the safety and well-being of people with disabilities.

In Phase One, the panel reviewed documents and conducted interviews with more than thirty staff using open question methodology. The large majority of those interviewed were from Disability Support Services. Five were from National Services Purchasing or other areas of the Ministry of Health.

The aim of this phase was to identify:

- The clarity of the Ministry's communication to providers on service delivery expectations
- The timeliness of current processes in identifying safety issues and concerns
- The clarity and appropriateness of roles and responsibilities when responding to issues
- The effectiveness and efficiency of performance management processes
- The effectiveness of external monitoring processes and performance reporting mechanisms
- The Ministry's ability to hold providers to account

In Phase Two, the focus shifted to interviewing people external to the Ministry. This initially focused on members and representatives of the disability community, and then shifted to include providers, external evaluators and evaluation agencies, disability advocates, the Health and Disability Commissioner, the Human Rights Commissioner, and representatives of other Ministries such as ACC, and CYF/MSD.

The underlying question the panel sought to answer during this phase, was: what is needed to give real confidence that future decisions and actions will safeguard or improve the well-being of people with disabilities? To answer this question, it sought answers to the following:

- What is working and what is not working for disabled people, and what needs to change?
- How can Developmental Evaluations and Certification audits be further strengthened?
- What other options would complement current monitoring processes and help keep disabled people safe, as well as enable them to speak out?
- What is working and what is not working from the providers' perspective?
- Can the role of CRMs be re-focused to make better use of this resource?
- How effective is the contract, and the Performance Monitoring Reports?
- What can we learn from other ministries and agencies, and what needs to change to ensure they collaborate more effectively in the future?
- What can we learn from those under the IDCC&R Act and the District Inspector role?
- What can the Ministry learn from the Three Cases: Parklands, Mary Moodie, and Te Roopu?

Following extensive document reviews and interviews, the panel developed its initial findings and recommendations and tested these with key members of the Ministry and people identified as experts in the disability community. It then wrote and compiled the final report.

Appendix Three: Basic Assurances® Certification

The Council on Quality and Leadership (CQL)'s Basic Assurances® require more than compliance with licensing and certification standards. Basic Assurances® looks at the provision of safeguards from the person's perspective. While the Basic Assurances® contain requirements for certain systems and policies and procedures, they go well beyond that. The effectiveness of the system or the policy is determined in practice, person by person.

Basic Assurances® are essential, fundamental and non-negotiable requirements for all service and support providers. Basic Assurances® are demonstrations of successful operations in the areas of health, safety and human security. Basic Assurances® form the bedrock of social stability.

Meeting Basic Assurances® is a prerequisite for being in business in our field. These assurances are not statements of intent; rather, they are statements of results. They define the essential, fundamental and non-negotiable requirements for all service and support providers, whether public or private, large or small.

Published in 2005, CQL's Basic Assurances® contain ten (10) factors and 46 indicators. These Basic Assurances® are a balance between concerns for individual Health, Safety and Security and the necessity of social constructs such as Respect, Natural Supports and Social Networks to ensure sustainable outcomes for people.

10 Basic Assurances® Factors

- Rights Protection and Promotion
- Dignity and Respect
- Natural Support Networks
- Protection from Abuse, Neglect, Mistreatment and Exploitation
- Best Possible Health
- Safe Environments
- Staff Resources and Supports
- Positive Services and Supports
- Continuity and Personal Security
- Basic Assurances® System

Each indicator is evaluated on two dimensions – System and Practice – and both must be present for the overall indicator to be considered present.

Systems are typically described in organizational policy and procedure and supported through staff training and other approaches. Organizational systems must be sustainable over time and flexible enough to be individually applied.

Practice is what we find happening in people's lives as a result of these systems. Organizational practice demonstrates how an organization's supports are put into action for each person.

Appendix Four: The Three Cases

The review team's Terms of Reference under paragraph 3(g) states:

A sample of cases will be assessed to determine if the Ministry of Health's response was proportionate during the period 2001 to 2013 inclusive. The sample will include Joslin Enterprises/Parklands; Mary Moodie Family Trust and Te Roopu Taurima O Manukau; and may include other providers.

In addressing this, the Panel has reviewed the Ministry of Health's files on the three cases. It has not conducted face-to-face interviews with people involved in the running or oversight of the three providers. However, as the Panel went about its investigations it noted anecdotal comments from a wide range of people on the way the three services operated. This subjective material was a useful backdrop but was not used as a primary source of information.

The following provides a history of the three cases.

Case 1: Joslin Enterprises Ltd / Parklands

Joslin Enterprises Ltd, commonly known as Parklands, provided a home for up to 19 intellectually disabled people. It was located on a 30 hectare Waikato farm, 25 minutes from Tuakau. Parklands opened over 20 years ago initially catering for only six to eight residents.

Between 2004 and 2012 Disability Support Services (DSS) conducted five audits/evaluations of Parklands. In addition, a no-notice issues-based audit was conducted in June 2012; and, two temporary managers were appointed in July 2012. Nine weeks later, on 28 September 2012, the Ministry of Health terminated its agreement with Parklands and residents were moved to other service providers.

In all but the April 2009 audit/evaluation, significant shortcomings were revealed. The number of requirements arising from each audit ranged from 10 to 17. The exception was an audit in April 2009 where only two 'required' improvements were called for.

A Ministry synopsis of Parklands had this to say about the 2004 audit report:

"The findings from the audit report in 2004 showed a service where people were 'contained' within a physical location unable to access activities or have freedom of choice that would encourage and support them to greater degrees of independence. Most activities occurred in the home workshop and the consistent outing was an all day trip away one day a week for all residents. Families were concerned that their family member had lost interest in doing activities they had previously liked and there was a lack of staff to help with skills and support to access community activities. Other issues concerned families' reluctance to make complaints or raise issues, individual's rooms were not personalised, choices or preferences of people did not appear to be sought, and casual staff were untrained."

In June 2006 the Ministry contracted SAMS to work with the provider to improve the quality of the service delivered to residents. This was done with the co-operation of the provider.

Some progress was made as was shown by a further audit of the service in 2007. Further, in December 2008, the provider contracted Insite Consultancy to help with staff training and another consultancy was engaged to assist with the development quality systems.

A 2009 audit paints a picture of considerable improvement. Regrettably, this progress in the provision of an appropriate service for Parkland's disabled residents was short lived.

In parallel with this, HealthCert commissioned a certification audit in June 2009 which resulted in the award of a two-year certification. The next HealthCert sponsored audit took place in May 2011 and a three-year certification given. A financial audit was also carried out in May 2011. This revealed that Parklands had received an over-payment of \$61,393 from the Ministry of Health. It was required to refund the over-payment, which added a further financial burden to a technically insolvent trader.

Finally, in January 2012, an evaluation/audit identified 17 requirements. Four of these related to the same standards that failed the 2004 audit scrutiny. This was followed by an issues-based audit on 26 to 28 June 2012, which identified 26 matters that needed to be addressed.

The seriousness of these audit findings prompted the Ministry of Health to appoint two Temporary Managers to the service in an effort to save the service. The Temporary managers took over the running of Parklands on 11 July 2012 and found they were dealing with a dysfunctional organisation.

In a detailed and highly critical report dated 26 September 2012 the two Temporary Managers said:

“There was no evidence that Parklands had referred a resident to a behaviour support provider through the NASC, nor had they brought [in] an expert (clinical Psychologist or similar) to work with staff ... to assist them to write up individual behaviour management (preventative) or crisis (reactive) plans. This meant that some residents were declined the opportunity to go into town or participate in ..., [a] Country and Western club, because of their behavioural history.”

The language used in this account is different but the sentiment is consistent with the finding of the audit in 2004, despite the nine-year gap between the two assessments. In plain English, residents at Parklands were not given the stimulus or support they could expect or deserved. Over the years nothing much had changed.'

The Temporary Managers began their task by developing an action plan, which addressed the June issues based audit requirements. The Ministry's approach was to work with the owners and their son, who had taken over the role of manager, to keep Parklands operating. This was despite a staff complement below that necessary to safely run the operation and an atmosphere of suspicion and blame. Agency staff were brought in to assist.

The owners' son became concerned that he might be caught in the fallout from Parklands' precarious financial position. After consulting with an accountant from whom he learnt the operation was insolvent, he gave his notice and left the next day.

Within a short time of the temporary managers taking over, it became apparent that saving the organisation in its current form was not possible and notice was given to the owners that their contract with the Ministry was at an end.

A series of bizarre events then took place including false accusations against one of the Temporary Managers. Matters came to a head on 3 September when the Ministry of Health notified the owners of

Parklands that its contract with the Ministry was being terminated. New homes were found for the residents and all were transferred from Parklands by Friday 7 September.

Case 2: Mary Moodie Family Trust

The Mary Moodie Family Trust (Mary Moodie) was established as a registered charitable trust in 1991. This entity formally took over philanthropist, Mary Moodie's, many years work as a carer of children with intellectual disabilities.

When Mary Moodie died in 1995 her properties in Sumner were sold and two new houses were built on a section in Ferry Rd, Christchurch. They accommodated 12 residents – six in each house. The residents had been in the care of the Trust and its predecessor organisation for many years, up to thirty-nine years in one case, and most since they were children. One house was named Mary Moodie House and the other Kelly Butler House.

The Mary Moodie Trust was contracted by the DSS to provide community residential services for people with an intellectual disability.

From June 2004 to April 2012, the Ministry of Health commissioned six audits/evaluations. From 2007 to September 2011 two Certification and two Surveillance audits were conducted.

The June 2004 evaluation audit report noted the work of the organisation's manager in building staff skills and experience while at the same time developing policies and procedures. The report expressed some concerns about the mix of people living in one of the houses and the consistency of support provided to them.

The next audit/evaluation in 2010 is reported as being largely optimistic in tone. It noted a strong individualised approach to personal health care needs, which was overseen by experienced staff. It noted that staff knew the people they were caring for.

A new manager was appointed in February 2010, and changes began to happen. New systems were introduced and long serving staff that couldn't come to terms with the changes left. Changes were made in the documentation system that were critically needed.

Concern about the care of the residents appears to have grown during 2011 and came to a head in August, when an anonymous complaint was made to the NASC. A Contract Relationship Manager and Senior Quality Analyst from the Ministry visited the two houses. Their visit confirmed the need for an evaluation of the services and the quality of life of the disabled people using them.

An evaluation undertaken in January 2012 identified eleven requirements where there had been three in an evaluation undertaken only 12 months earlier. In addition, an increase in the number of complaints about the service being offered at Mary Moodie, and a demonstrable breakdown in the relationship between the Trust board and the families of the residents. Of the eleven requirements, seven were rated high risk.

On 17 September ten of the twelve families/welfare guardians wrote formally to the local NASC (copied to the Ministry) concerned for the safety of residents and seeking alternative residential providers for their family members/charges. In this correspondence, they also listed a number of areas of concern and dissatisfaction with Mary Moodie and sought the NASC's urgent response to this.

As a result of this action and the earlier evaluation, the Ministry appointed Temporary Managers on 10 October 2012. Later statements by the Temporary Managers show that the manager appointed in 2010 had recruited staff who were not fluent in English, had little understanding of New Zealand culture, and little knowledge of the disabled community and its needs. In a report dated 9 November 2012, the Temporary Managers' also placed a different gloss on the situation that existed at Mary Moodie between June 2004 and February 2010 from that previously given. In giving their view on the background leading to the closure of Mary Moodie the authors said:

“It is clear that in the past [before the present manager was appointed] Mary Moodie has had a number of management, family and Trust Board issues ... Families in the past have called for the resignation of a manager and in this current situation, families again have asked repeatedly for the manager to leave and for the Trust Board to resign.”

The Mary Moodie board and management strongly contested the interpretation placed on many of the audit standards by the team that compiled the evaluation report. This was despite four open police files relating to events at Mary Moodie houses and a complaint being investigated by the Health and Disability Commissioner.

A recurring theme in the papers reviewed is the fear of retribution if a family member or resident complained about the quality of the service. The Temporary Managers in their report bluntly state:

The residents are too scared to complain, because past experience has taught them that complaining could be very punishing.”

The Mary Moodie board did not accept the decision of the MOH to appoint the Temporary Managers. The Trust engaged lawyers to represent its position which introduced an adversarial approach. This had the effect of delaying constructive resolution of disputed matters.

The Ministry's singular concern for the wellbeing of the residents came to a head in late November 2012 when it gave notice that its agreement with Mary Moodie was to come to an end on 7 December.

Ten of the twelve families/welfare guardians with family members/charges at Mary Moodie had pre-empted this action by the Ministry, and had already worked successfully with the NASC to find new accommodation for ten of the residents.

The Ministry made arrangements for the remaining two residents to find new accommodation. All residents were relocated to new providers by Friday 30 November 2012.

Case 3: Te Roopu Taurima o Manukau Trust

Te Roopu Taurima o Manukau Trust (Te Roopu) was formed after the closure of the Mangere Psychopaedic Hospital in 1999. The Ministry of Health purchases residential care services from Te Roopu for Maori with an intellectual disability, including those falling under the provisions of the Intellectual Disability (Compulsory Care & Rehabilitation) Act 2003 (IDCC&R Act). It is the provision of secure accommodation for people under compulsory care that sets Te Roopu apart from the Mary Moodie and Parklands cases.

Te Roopu forms part of a service structure that works with the National Intellectual Disability Care Agency (NIDCA). This agency is responsible for organising specialist reports to the Court and for the prescription of compulsory special care services.

In addition to very specific legislative control over complex and challenging intellectually disabled people, Disability Support Services (DSS) also has a part to play in ensuring services offered by Te Roopu to the mainstream disabled community are safe and adequate.

Despite this legislative control, the quality of the services offered by Te Roopu deteriorated very quickly in 2010.

When Te Roopu was first formed it was led by a charismatic and dedicated CEO. She, according to all reports, was a hands-on manager who knew in detail what was happening in her domain. From reports, she was not afraid to address issues as they arose – not always in a conventional way but none-the-less her management style was effective. She died in late 2009.

A new multi-tiered management structure then evolved which meant an end to the personal relationship that used to exist between the CEO and her staff. Te Roopu also went through a major expansion programme, with staff numbers growing from 133 in 2000 to 490 ten years later. The number of residences also increased from 12 to 54 in 2012, and the number of residents grew substantially to 226. While Te Roopu had its genesis in the Auckland region, it expanded its services into Northland, Waikato and Canterbury.

The first allegations of assaults against residents were made in October 2010. Between October 2010 and February 2011 further allegations were made regarding injuries to clients living in secure Te Roopu Auckland houses. These issues were notified as matters of concern to the District Inspector, the Regional Intellectual Disability Care Agency (RIDCA) and the Ministry of Health.

In February 2011, District Inspectors conducted two separate investigations using their powers under the IDCC&R Act. They found there were cases to answer with both. As a result, the Director General of Health, using the provisions of section 101 of the IDCC&R Act, commissioned a full inquiry, which began on in the middle of April 2011. A draft report was sent to Te Roopu and their lawyers, the RIDCA and the Waitemata DHB for their views. There was considerable criticism from all three parties. A final report was completed on 22 December 2011.

Parallel to the section 101 inquiry the Ministry undertook audits of 13 Te Roopu houses during June and August 2011. The first audits that were conducted in June 2011 found a number of deficiencies, including poor record keeping and poor compliance with clinical and behavioural management plans in some residences.

In September 2012 the Ministry's Chief Advisor Disability and IDCCR Act recommended to the Director General of Health that the report findings be accepted and that an External Monitor be appointed to ensure the deficiencies were addressed. The Director General gave his approval for this in December 2012, and the External Monitor took up the role on 4 February 2013.

The work of the External Monitor and that of a Quality Monitor has now come to an end, and governance, management and staffing matters appear to have been addressed and resolved. The culture of physical abuse also appears to have been addressed. However, monitoring of Te Roopu continues with the Ministry keeping it under close supervision through monthly meetings between a Contract

Relationship Manager and Te Roopu's senior management. A Senior Disability Advisor with significant experience in complex care under the IDCC&R Act also plays a critical oversight role with Te Roopu.

As a result of these actions, the Ministry is confident that its close monitoring of Te Roopu's services is resulting in significant changes in the culture and safety of people in the provider's care.

Te Roopu was too important to fail. It was the only organisation in the country providing Kaupapa Maori facilities under its contract, and the Ministry has undertaken to continue to assist Te Roopu to develop the important services it offers Maori.

An Overview of all Three Cases

The Ministry missed early signs of brewing trouble. Until recent times, actions were inadequate.

In all three cases the response to shortcomings in resident safety was slow. We accept that the Ministry was working with the providers to bring their services up to a minimum standard but we question whether the approach should have been allowed to go on for so long. It is unquestioningly the right of disabled people to call their accommodation 'home' and as such, to enjoy peaceful possession of it. But this should not be given as a reason for the Ministry to hold back when it knows that something is wrong. The long-term wellbeing of the disabled is the paramount objective of DSS. There will be occasions when minor interruption of routines and inconvenience to residents will be necessary to conduct an evaluation of services or carry out inquiries into the running of an organization. Further, in rare cases it will be appropriate to close a facility and the Ministry has recently shown it is now prepared to take this step. The review team welcomes this demonstration of resolve by the Ministry.

The three cases demonstrate a history of less than ideal service to the disabled. The system was creaking and residents of the three establishments, to a greater or lesser degree, suffered as a consequence. It is easy to blame this failure on the managers and the operational staff. However, there is a less definable but potentially bigger matter in the background that has had an influence on the provision of publicly funded services for the disabled. The health and disability sector has had 30 years of restructuring and change. New Zealand has seen hospitals reorganised as Crown Health Enterprises, Area Health Boards come and go, four funding organisations merge into one and then be absorbed into the Ministry of Health; and 21 District Health Boards created. In all this change, the funding and provision of services for the disabled bounced from one agency to another. Change can be unsettling. We believe that the uncertainty of multiple changes in the way services to the disabled were delivered and by whom, may have played a part in the delay in coming to grips with significant problems. In future, the emphasis must be kept on the wellbeing of people with disabilities.

David Russell

20/11/13