# Building safe and respectful cultures
**in disability services for people with disability**

## Report

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For the Disability Services Commissioner

**June 2019**

It's
OK
to complain

Disability
Services
Commissioner

Photo by Kate Disher-Quill

The image on the front cover of the report was part of a violence and abuse prevention initiative of the Disability Services Commissioner called **the together project**.

It was an opportunity to open up conversations between people with disability, families, friends, support workers, and broader community members around the key questions of what makes us all feel safe, happy and respected – through the medium of inclusive all-abilities wrap art.

We asked questions of our artists as they sat wrapping art with us: What makes you feel valued? What makes you feel listened to? What makes you feel equal?

It was the start of some great conversations. When we talk, ask and listen, we learn what really matters to each other.

**the together project**

Disability Services Commissioner is an independent voice promoting rights and resolving complaints about disability services.

**Building safe and respectful cultures in disability services for people with disability - Report**

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## A note on terminology:

**Abuse** means any of the following:

- violation of an individual's human rights resulting from the actions or inactions of any other person or persons

- violent behaviour towards a person that is physically, sexually, emotionally, psychologically or economically abusive. It includes behaviours that are threatening or coercive, or in any other way control or dominate the person and cause that person to feel fear for themselves or another person

- restrictive interventions (such as chemical restraint, mechanical restraint, and seclusion), and forced treatment and interventions that are not authorised or permitted by legislation or an order from a relevant court or tribunal.

**Neglect** means unreasonably failing to take care of a person's physical, psychological or financial wellbeing. This may include any of the following:

- physical neglect – the failure to provide adequate food, shelter, clothing and protection

- medical neglect – the failure to provide medical or dental care

- emotional neglect – restricting the social, intellectual and emotional growth or wellbeing of a person.

The Disability Services Commissioner considers both abuse and neglect to be a form of violence.

**Disability** – This research drew from the interactional understanding of disability (Shakespeare 2014), which understands the experience of disability as a holistic one. The effect of impairment is acknowledged alongside social and systemic factors, which together comprise people's experience of disability.

**Disability service (the service)** – means a service specifically for the support of people with a disability, which is provided by a disability service provider.

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# Foreword

The early stages of this research project began in 2012, with the release of the **Disability Services Commissioner's (DSC)** *Learning from complaints occasional paper 1: safeguarding people's right to be free from abuse.* The paper noted that a primary abuse prevention strategy should be addressing factors such as 'culture, attitudes and relationships within services' to build 'cultures of respect'.

The government's response to the 2016 *Victorian Parliamentary Inquiry into Abuse in Disability Services* took this work further, empowering my office to conduct research into abuse and neglect in the provision of disability services, and mechanisms for preventing abuse and neglect.

**Building Safe and Respectful Cultures** is a research project born from this early learning from complaints, findings from the Parliamentary Inquiry, and feedback from the Abuse Prevention and Response Forum that my office ran in September 2017. It became clear that while there are many initiatives addressing secondary and tertiary prevention of abuse, primary prevention was an area that still required further work – and so we adopted research from the United Kingdom into early indicators of concern as the framework for our project.

It was important to us that our research methodology should reflect the philosophy of the project – safe and respectful cultures, meaningful relationships, and empowerment of people with disability. Co-design was a guiding principle of the project, with the establishment and engagement of the project advisory group, engagement with Voice at the Table, and employment of our community researchers. Actions speak louder than words, and, as an office, we choose to model the safe, respectful and inclusive cultures that we promote.

As the disability sector waits for the establishment and conduct of the *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability,* it is critical that disability services examine their own workplaces to ensure that **Building Safe and Respectful Cultures** is central to day-to-day quality person-centred practices.

This research may have been conducted with a small sample size, but it reflects the experiences of many people with disability, families, staff and organisations. The findings and recommendations arising from this research align with findings from our years of experience in handling complaints.

Catching things early; quality communication; meaningful relationships; little things are the big things – these core concepts can become, and should become, actions for change that can be applied to many different disability service settings.

My office will continue to develop resources, training and interactive workshops based on the findings of this research project, with the input and contribution of people with disability who have the lived experience of using disability services.

I would also encourage others who are inspired by the findings of this project to consider drawing on this research in a longitudinal larger-scale research project. The time is ripe with the *Royal Commission* and transition to full-scheme National Disability Insurance Scheme (NDIS) to examine organisational cultures in disability services.

I take this opportunity to thank everyone who has contributed to this research project, including our community researchers, academic researchers, DSC researchers and staff.

I thank all the research participants – people with disability, family members, staff members – for allowing our researchers into their lives and sharing their thoughts and feelings with such honesty.

I thank the three disability services that took part in this research project. Their openness and engagement with this project at a time of sector-wide change reflects their commitment to **Building Safe and Respectful Cultures** in their organisations.

Finally, I thank those who have picked up this report in the spirit of learning and development. I encourage you to use this report to further promote the rights of people with disability using disability services and to develop organisational cultures that better protect people's safety and wellbeing.

**Arthur Rogers**

Disability Services Commissioner

June 2019

# Executive summary

**This Building Safe and Respectful Cultures pilot project aimed to learn more about the culture of services for people with disability and identify some practical approaches that might be both useful now and relevant for future development.**

This was a co-produced research project, completed by a team of academic researchers, staff from the Disability Services Commissioner (DSC) and community researchers, people with lived experience of disability. The project ran between June 2018 and April 2019.

Previous research indicates increasing recognition of the significance of violence, abuse and neglect perpetrated against people with disability. There has been less emphasis in research and practice on identifying the conditions that promote safety and respect, and on ways to identify and highlight concerns about quality in these areas in disability services. Questions of power relations, relationships, caring and the intersection of people's rights to safety are under-addressed and there are important gaps in research and policy on these issues.

This project took place in an active and shifting policy environment in Victoria, and more broadly. With a range of initiatives underway to address abuse and promote safety in response to the *2016 Victorian Parliamentary Inquiry into Abuse in Disability Services,* it is timely to consider ways to embed safety and respect into culture and practices across disability services.

# Project design

The project aimed to understand the role of culture in promoting safety and wellbeing and addressing the conditions that lead to violence, abuse and neglect in disability services. The research team used **social ecological theory (see Appendix 1)** as an overarching conceptual framework, combined with the **early indicators of concern** (the indicators) **(see Appendix 2).** Social ecological theory helped us explore the ways that people in different roles in the services understood their experiences and the effects of systems, and to analyse the ways that these intersected. The indicators are a prevention tool, used to record concerns and put them together with other observations to identify concerns early.

Three disability service providers were recruited to the project, over four sites:

- two supported accommodation houses in suburban Melbourne, part of a large provider

- a skills-focused service for younger adults with intellectual disability in suburban Melbourne

- a regional service providing individual and group support to a wide range of people, most with intellectual disability.

# Research design

To assess the effectiveness of the project design, we used a mixed methods approach to gather information. Each of the participating services was invited to:

- take part in interviews

- attend a supervision workshop

- attend a workshop about the indicators (community of practice approach)

- attend music sessions

- participate in action learning sets (community of practice approach)

- allow observation of routine interaction

- complete surveys on supervision and occupational stress

- to provide data on incident reporting.

# Results

## Understanding core concepts underpinning safe and respectful cultures

Safety and respect are abstract concepts, and it is difficult for people to respond to questions posed directly about either 'safety' or 'respect'. For this reason, all the people participating in interviews and focus groups were asked to share the ways that they understood the related core concepts of

- care and support
- safety
- choice and decision making, and
- problem solving.

### Care and support

People conceptualised care in two ways – activity based, such as being assisted to complete activities or routines; and relationship based.

Many people with disability placed a priority on having someone to talk with when they were feeling sad or upset, as well as the emotional care that was provided in these relationships. Being invited to do new activities they liked was another way that people felt cared about, as this showed that their preferences had been considered. Being a good friend was very important to several people.

Staff discussed the practical ways in which they provided support and facilitated activities and access to information as a core part of their role. They talked about the importance of rapport in building a working relationship, but also about the need to maintain boundaries around privacy and information sharing.

Family members thought that the relationship of care was positive and supportive when rapport was strong. They valued workers who focused on using the rapport in their working relationships to help people with disability to manage anxiety, distress and agitation. Some family members commented that the care that people with disability gave to each other was not acknowledged as strongly as they thought it could be.

## Safety

People with disability spoke about physical and emotional safety. Feeling physically safe was important for the people who had previous experience of violence, abuse and neglect. People with disability spoke about feeling unsafe because of other people using the service. To feel physically and emotionally safe, people with disability talked about how it helped them to have someone they knew well whom they could talk to (mainly staff and family). Being able to have a break to manage stress, minimise distress, reduce conflict or restore energy mattered. It helped to have access to a private space, or at least one away from noisy and disruptive spaces. Not everyone felt they had this access to people or places.

Some staff focused on the relational nature of building a sense of safety for people with disability as part of their role. They talked about the importance of being able to look for and recognise subtle signs that people with disability were feeling uncomfortable, concerned or unsafe and to act to address these.

Families valued the quality of relationships between staff and their family member, and many had a sense of trust in the staff as people who would act ethically to keep their family members safe. Families also mentioned past experiences where people with disability were not safe, including instances of violence and abuse, and situations where items had gone missing. They talked about more complex, difficult to negotiate issues that were recent or current in their family members' lives, generally concerning other people also using the service.

## Choice and decision-making

Most people with disability using services indicated they were able to make choices about the activities and programs that comprised their daily routines. They were generally pleased about this. Some people said they knew what to do if they had a problem with their service, and these people mainly talked about seeking help from senior staff at their service. People with disability generally spoke about having a say about activities in the service, and not about their involvement in decision making about relationships or wider quality of life issues.

Several people with disability said that it can be hard to speak up. This was for a range of reasons: feeling shy; because it was hard to speak up to staff when they said no; when a trusted member of staff was not available to speak to; because of the effects of pain and fatigue associated with their disability; and when there was conflict with other people with disability who also used the service. Some people had previous negative experiences, which affected their confidence, willingness and capacity to speak up.

All staff described encouraging people with disability to make choices about daily activities, from basic daily decisions about food choices through to collaborative program development. Some staff stressed the importance of looking for signs that people with disability were either satisfied or unhappy and being proactive in approaching them to resolve any emerging issues before they became problems. In most of the service contexts, staff were supportive of the rights of people with disability to talk with them about concerns. However, staff did not necessarily equip people with the tools to speak up or recognise the barriers to speaking up for people with disability.

Family members generally felt that services were responsive to requests to change program activities, and in some cases were proactive in offering options where people with disability indicated they were not fully engaged. Several described an informal 'open-door' approach to providing feedback, which they felt encouraged their family members and other service users to feel comfortable in speaking up. Some family members actively encouraged and promoted supported decision making, while others conveyed a position more in keeping with substitute decision making, having more reliance on the service system to take responsibility for taking care of family members.

## Problem solving

People with disability, families and staff members all spoke about the importance of being able to choose who they can approach with a problem.

Some people with disability felt it was important to speak to known and trusted people, and others were pleased to have access to senior staff. People with disability said that staff were available to assist with solving problems, but also that it was hard to approach staff sometimes. Some people talked about how it took time to build confidence, and that they were more comfortable speaking with staff they knew well or had known for a long time.

Some staff expressed the view that while problem solving is part of their job role, their core duties were to help people fulfil daily living activities, and sometimes they needed to prioritise this over problem solving and people needed to wait until they were less busy. Other staff spoke about scaffolding opportunities for building confidence in problem solving into daily activities. Staff emphasised the importance of good rapport and a personal connection, but also the need for all staff to be able to communicate effectively with all participants to minimise the impact of staff turnover and absence.

Family members thought it was important that they and their family members had ready access to managers and staff who knew their family member well. Where families felt services responded well to problems about the program or activities, staff and management had provided an 'open-door' for people with disability to share their views. They had listened carefully, responded quickly, involved families, worked collaboratively to design alternatives that people were satisfied with, and checked in about how the new options were working out.

## Facilitators and constraints to safety and respect for people with disability in the services they used

A series of factors influenced the cultures of safety and respect in the services. Using the social ecological framework, the results of the research were analysed to highlight both the layers in which safe and respectful cultures are in play, and the interactions and intersections between the domains.

While there were elements that both helped and hindered the development of safe and respectful cultures, perhaps the most striking finding is how complex many of the features are.

These are summarised in Table 1 and detailed further in the report.

| | Facilitators | Constraints | Complexities |
|---|---|---|---|
| **Personal and intrapersonal factors affecting safety and respect for people with disability** | • Relationships based on trust and familiarity<br>• Feeling heard<br>• Having multiple ways to express views and feelings | • Not being taken seriously<br>• Feeling unable to speak up<br>• Peer-to-peer harm<br>• Disrespect<br>• Lower standards applied to people with disability<br>• Limited agency and power | • Speaking up is hard to do<br>• Problem-solving strategies might not help you become safer<br>• Safety strategies can be lacking in depth<br>• The passivity of the 'participant' role<br>• Impact of the wider world on young people's relationships in services |
| **The effects of relationships of support in building safe and respectful cultures** | • Relationships that recognise positive qualities and attributes in others<br>• Using multiple ways to support people in difficult times / with sensitive issues | • Impact of challenging behaviour and interpersonal conflict<br>• Misuse of power by staff<br>• Staff not seeing relational support as a priority<br>• Gratitude and hesitancy to 'make a fuss' by families | • The little things are the big things<br>• Balancing competing needs and preferences<br>• Difficult for some staff and families to see the perspectives of people with disability<br>• Stress and a sense that other people don't understand<br>• Unresolved conflicts / tensions between the rights of people with disability and the rights of staff<br>• Fragility in staff sense of security and safety in role |

| | Facilitators | Constraints | Complexities |
|---|---|---|---|
| **The role of organisations and systems in building safe and respectful cultures** | • Well-organised environments<br>• Policies, procedures and guidelines developed for the service context<br>• Practical strategies in services that bring policies to life for people with disability<br>• Trained and supported staff<br>• Education and opportunities to practice safety-making for people with disability | • Impact of resource and time constraints on capacity to support people with disability and staff<br>• Resource constraints impeding effective responses to problems<br>• Staff who are under-skilled or ill-equipped to provide preventive support<br>• Lack of support, supervision, career planning for staff and managers | • Differing levels of knowledge about policies, procedures and implementation<br>• Role clarity and boundary setting for staff<br>• Tension between rights of people with disability and the rights of staff<br>• Difficult balance between compliance, risk and rights discourses |
| **The effect of wider social and cultural factors on the services used by people with disability** | • Increasing knowledge of human rights<br>• Pride in role, strong values base | • Activation of rights<br>• Risk of support relationships fracturing<br>• NDIS dominating practice and structure | • Many – outside the remit of this research (e.g. poverty, exclusion, social isolation, discrimination, community attitudes) |

Table 1: Facilitators, constraints and complexities to safety and respect for people with disability in the services they used

## Four themes emerged from the results which cut across all the levels. These are:

1.  **People at all levels of the research felt it was very difficult to make change**

2.  **Multiple sets of rights need to be brought into view**

3.  **Fewer resources and pressure to deliver efficient services make it harder to create safe and respectful cultures**

4.  **Three practice approaches stood out as strategies to actively build safe and respectful cultures**

### 1. People at all levels of the research felt it was very difficult to make change

At all levels, many people felt they had little personal capacity to change their circumstances or to make change to improve the lives of people with disability. Most of the people involved in this research were in a state of vigilance. Almost everyone was stressed and conveyed a sense that other people do not understand what it is like to be in their situation.

The community of practice approach, where people with disability, staff and family members attended the indicators workshops together, was highly valued by participants. Feedback indicated that the activities drew out a sense of equality and community and helped participants from all of the groups to hear perspectives from others more clearly.

## 2. Multiple sets of rights need to be brought into view

There is a need to raise expectations around choice, decision making, safety and relationships for people with disability.

The level of choice is constrained by lack of agency, but also by lack of vision about potential alternatives. For the NDIS to be transformative for people with disability, meaningful choices, time, advocacy and support for decision making needs to be available to allow people to make decisions about significant matters in their lives, including where and how they spend their time.

Prioritising relationships for people with disability involves support for building and sustaining friendships between people with disability; articulating and navigating working relationships between people using services and people providing them; and providing clear frameworks for relationship-driven support within services.

Similarly, for people to feel and be safe in the services they use, their priorities and perspectives need to carry weight.

In no other community is it considered acceptable to continue to spend time with people you fear or from whom you have experienced violence, abuse and neglect.

While most of the time, people with disability and workers described relationships based on mutual regard and trust, at some important times the rights of one or both groups to safety, decision making, participation and privacy were tested. These are discussed at length in this report.

In a few difficult cases, the rights of both groups were tested at the same time. These times were about the right to be safe, the right to be supported and the right to be treated with respect. These examples highlighted the difficulties that disability service providers have in responding to the intersecting rights of people with disability in complex situations where instigators of violence, victims and witnesses hold different positions and responsibilities in the organisation.

### 3. Fewer resources and pressure to deliver efficient services make it harder to create safe and respectful cultures

All the services taking part in the study described a context in which they were under pressure to reduce resources and increase efficiency in service delivery. While some of the changes were welcome improvements (such as increased opportunities for individual support), time and resource constraints imposed changes to ways of working making it harder for staff and managers to create safe and respectful cultures.

Demands on the resources of services in the current NDIS climate meant staff were less available for people with disability, and managers had less time to engage in supervision. At a personal level, it affected the perceptions of people with disability regarding how ready staff and managers were to listen, and the ability of families to find people they can talk to and have the confidence to bring up issues.

It was not possible to resolve many of these tensions at the origin of the problem, and people with disability, individual workers, families, and managers were all trying to alleviate the pressures as best they could.

### 4. Three practice approaches stood out as strategies to actively build safe and respectful cultures

Participants strongly favoured relationship-focused support. Across all groups, they wanted more relationally focused support and stronger attention to building positive practice and raising expectations.

Three practice approaches stood out as strategies to actively build safe and respectful cultures:

- relationship-based practice
- embedding a prevention approach into support
- reflective practice and supervision.

# Implications for action

## For people with disability

- Develop and tailor strategies that support people with disability to make and sustain relationships of greater depth, including:

  - > ways of having greater control over who supports them
  - > recognising the significance of family, geography and culture
  - > ways to explore friendship
  - > making space and opportunity to grieve when relationships are broken or lost.

- Provide opportunities and multiple ways for people with disability to have a say – about positive, neutral and complaints-related issues; and about the small indignities that are important to them and that grow into larger concerns if they are not addressed.

- Develop practical education and strategies to support people to see results from practising having a say, speaking up and enacting their rights.

## For relationships of support

- Relationships are at the heart of developing safe and respectful cultures. Working to develop positive and equal relationships where each party to the relationship can influence the other is the core task across the sector.

- Build skills in staff to recognise and respond to the safety strategies that people with disability use when they feel worried or unsafe. This builds capacity and agency in people with disability and supports a sense of safety and respect in the services they use.

- Prioritise action on issues raised with staff and management. Increasing feedback loops and accessible reporting back on action taken will build confidence in people with disability and families to raise issues of concern and ideas for improvement.

- Blurring of boundaries can cause confusion and introduce dilemmas. Articulating and working through roles may help reconcile some of the tacit boundary confusions that lead to tensions around safety and respect.

- Look for opportunities for people with disabilities, staff, families, managers and the wider community to train and work together in ways that build trust and rapport. Using creative approaches (such as art and music) may assist in approaching issues about communication and power in ways that build capacity, including for people who do not use words.

### For organisations and systems

- Consult with people involved in any change before it takes place and consider the potential impact of change on the lives and relationships of people with disability, staff and families.

- Increase the use of accessible information and ensure it is systematised, so that all key information about safety and respect in services is available to people in alternative formats.

- Make time available within rosters and staffing allocations to build and maintain relationships. For example by establishing and including relationship-based activities for people with disability to choose; minimising disruption to staff allocations; ensuring adequate time for sharing necessary information; and responding to requests for preferred worker–client pairings.

- Provide staff with supervision that builds a supportive and accountable relationship. As part of this, support staff to reflect on the place of relationships and relationship-based practice, adopting a prevention approach to support, and explore where and how they can prioritise this in their daily practice.

- Offer staff training that is regular, evidence based and responds to issues they face in their daily work.

- Review complaints processes:
  - > Ensure that internal and external complaints systems are or can be used by people with disabilities themselves.
  - > Consider ways of differentiating between levels of concern in reports of incidents and complaints to recognise patterns over time.

- Review the extent to which organisational, administrative and domestic demands keep staff away from the core task of interacting with people with disability.

- Build on positive practice at the senior manager level across organisations to establish and sustain a collaborative interagency community of practice focused on safe and respectful cultures.

- Work collaboratively across organisations to make inroads into 'wicked' problems such as:
  - > raising expectations for people with disability – improving measures of safety, respect and what constitutes a 'good' life
  - > addressing client-caused injuries to staff, as well as working conditions and occupational health, safety and respect, and wider employer responsibilities
  - > developing indicators for leadership in planning and support that focus on prevention of isolation and minimising risk of harm, and maximising opportunities for choice and control.

## At wider levels

- Relationships need to be prioritised in planning and funding mechanisms to maximise possibilities for new and more progressive approaches to community inclusion for people with disability.

- More streamlined and less confusing NDIS planning and funding is needed to help people make more innovative choices.

- Many prevention activities are broad scale and work at the societal level. They are currently not funded. The NDIS needs to continue to develop policy and funding frameworks for prevention work.

- Access to independent advocacy for people with disability and families is needed, especially people who do not have family or other natural supports who are engaged with their care.

# Introduction

**The Disability Services Commissioner's (DSC) mission is to safeguard the rights of, and improve services to, people with disability.**

DSC is committed to preventing and responding to violence, abuse and neglect of people with disability. We do this using an holistic approach that builds on primary, secondary and tertiary interventions to ensure a robust and integrated system where the safety of people with disability is paramount.

We aim to minimise the risk of harm, while maximising the choice and control people have over their own lives.

- Primary prevention aims to prevent abuse in the first instance

- Secondary prevention aims to identify and respond directly to disclosures of abuse

- Tertiary prevention aims to remedy any negative and harmful consequences of experiencing abuse and put in place measures to prevent its re-occurrence.

Historically, DSC has focused on prevention, with an emphasis on primary prevention in relation to complaints, through our Capacity Development functions in supporting people to speak up with their concerns, secondary prevention in our Resolutions functions, and tertiary prevention with our Resolutions and Investigations functions acting as a corrective safeguard after abuse has occurred.

In addition to strengthening DSC's powers to investigate allegations of abuse, 2017 changes to the *Disability Act 2006* required DSC to also support the Victorian disability sector through enhancing capacity to prevent and respond effectively to allegations of abuse and neglect. An effective response or tertiary system is a fundamental building block for primary prevention. A comprehensive approach must account for the entire continuum of addressing violence and abuse – from primary through to tertiary prevention, to help achieve better outcomes for people with disability.

# The aim of the project

This pilot project sought to learn more about the culture of services for people with disability and identify some practical approaches that might be useful now and relevant for future development.

The project aimed to improve our understanding of the role of multi-tiered approaches in promoting the safety and wellbeing of people with disability in disability services. To do this, the team piloted a series of approaches informed by the research into early indicators of concern and designed to address the cultural conditions necessary to prevent abuse.

# Project advisory group

The project advisory group (PAG) included people with disability and the wider disability and research community in Victoria. Two members of the advisory group came from the Voice at The Table (VATT) project. VATT is an initiative aiming to increase the number of people with cognitive disability sitting on boards, committees and advisory groups.

The PAG undertook training with VATT project facilitators to ensure all members had an understanding, and a commitment to strengthening inclusive meeting practices.

# Structure of the project

The project ran between June 2018 and April 2019. Fieldwork took place between September 2018 and January 2019.

This was a co-produced research project, completed by a team made up of academic researchers, staff from DSC and community researchers people with lived experience of disability.

The academic researchers, Peter Oakes and Sally Robinson, led the design of the project, development of the fieldwork, analysis of the results and writing of the report. Peter led the quantitative research and Sally the qualitative interviews. Sally developed and completed training and team-building activities with the community researchers and DSC staff. A team of Registered Music Therapists, Fleur Smith and Matthew Lewis were led by Melissa Murphy. They developed the music workshops and conducted them at the sites and undertook focus groups.

Three community researchers (Peta Ferguson, Francesca Lee, and William Ward-Boas) and three DSC staff members (Marianna Codognotto, Jodie Nicks and Dina Theodoropoulos) worked in researcher pairs, contributing to the fieldwork design, completing the fieldwork interviews and were involved in the analysis of the results.

**Aug**

**1. Interviews**
Round 1 with 18 participants*

**7. Observation of practice**
Round 1 across 3 sites

**2. Indicators Workshops**
across 3 sites with 61 participants*

**Sep**

**6. Asset Stress Survey**
35 received

**3. Supervision Workshops**
for 16 participants with supervisory responsibility

**5. Action Learning Sets**
for managers and CEOs
4 x monthly sessions

**Oct**

**8. Supervision Surveys and Incident Data**

**4. Stand Alone Music Workshops**
with 38 participants*

**Music Focus Groups**
with 34 participants*

**Nov**

**1. Interviews**
Round 2 with 18 participants*

**7. Observation of practice**
Round 2 across 3 sites

**Dec**

**Jan**

\* people with a disability, family members and staff

**Figure 1: How the project was put together**

# Previous research

In this brief overview, we acknowledge and draw on the systematic review contracted by the DSC to frame this project, conducted by Araten-Bergman, Bigby & Ritchie (2017)[1]. We suggest that readers looking for in-depth analysis of best-practice supports in disability services for prevention of abuse turn to this review.

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*1 -  Araten-Bergman T, Bigby C, & Ritchie, G. (2017). Literature Review of Best Practice Supports in Disability Services for the Prevention of Abuse of People with Disability. Report for the Disability Services Commissioner. Living with Disability Research Centre, La Trobe University.*

## Violence, abuse and neglect against people with disability

Research and policy interest in violence, abuse and neglect of people with disability has increased in recent years, albeit from a very low base. From this recent literature, a clear picture emerges of a group that experiences high rates of harm, with particular risk for people with intellectual disability and people who live in residential settings (Dowse et al., 2013; Ottmann et al., 2016; Hughes et al., 2012).

Previous research points to a need for new ways of thinking about violence, abuse and neglect of people with disability (Mikton et al., 2014; Goodley & Runswick-Cole, 2014; Robinson et al., 2017a). Alongside this evidence base, entrenched abuses in service systems and poor evidence of change in response to various inquiries following the uncovering of abuse and neglect indicate that something different is needed.

# The increasing focus on prevention

The numerous reports and investigations that have followed incidents of abuse have highlighted the importance of culture, climate and leadership in establishing relationships and environments that offer both opportunity and safety for people who remain vulnerable to abuse and exploitation (Francis, 2013; Flynn, 2012; Senate Community Affairs References Committee, 2015). This is supported in the research on unethical/harmful workplace decisions in industrial and other settings, which suggests protective features include focusing employees' attention on multiple stakeholders, following principle-based rules and clearly articulating what is and is not acceptable behaviour (Kish-Gelpart et al., 2010).

Some have referred to this issue as a wicked problem – one in which the proposed solutions may serve only to worsen the problem (Marsland et al., 2015). For example, increased regulation and paperwork and the resulting scrutiny can bring about a culture of fear, or at the very least mistrust (Warmington et al., 2014). This leads to increased levels of occupational stress, which in turn increases the propensity of staff to be more controlling in their interactions and so increases the risk of abuse (Oakes 2000; Petner-Arrey & Copeland, 2014).

Given the devastating impact of abuse, the role of prevention has been highlighted in research focused on violence and abuse. As Araten-Bergen et al. note in their systematic review, much of this work has been focused on primary prevention and aimed at people with intellectual disability (for example, Lund & Hammond, 2014; Ottmann et al., 2016; Daniel et al., 2013). The central finding of the systematic review was the evident need for prevention approaches to evolve beyond a 'response-to-risk' approach into a broader framework that conceives of the safety of people with disability as part of their quality of life (2017, p. 5).

The indicators of concern research conducted by one of the authors of this report was a response to this concern (White et al., 2003; Marsland et al., 2007). Evidence from the original indicator research showed that people did have minor worries or concerns about settings that were later found to be abusive (Marsland et al., 2007). These concerns were not enough to warrant triggering an official process, but they represented early signs the service was at risk. In addition to this, subsequent research has shown that family members are reluctant to raise minor concerns or small indignities for fear that the reaction would be either disproportionate or would jeopardise their relative's care and support (Marsland et al., 2015).

# Conditions that promote safety and respect

There appears to be little research which brings together a focus on the mutual needs and rights of people with disability and staff central to the culture of disability services.

Evidence from people with disability themselves points towards increasing attention to both prevention and relational elements of paid support. To prevent harm, people with disability report across multiple studies that they do more than avoid abuse. They work to actively build safer lives. To do this, people prioritise relationship building in support, building trust, using known supporters, seeking out workers who listen, and using support that enables them to maximise control in their lives wherever possible (Robinson et al., 2017b; Northway et al., 2013; Daniel et al., 2013).

There are, however, many limits to the successful implementation of safety building strategies. For many people, these are intersections of personal and systemic factors, including the dominance of paid support and increasing casualisation of the support workforce, and lack of availability of tailored education, to assess risk in context (for example 'stranger danger') and for informal peer learning opportunities (Flynn & McGregor, 2017; Coulson-Barr, 2012).

Recent disability research draws from theories of care that recognise mutuality in care relationships, acknowledging both the agency of people with disability and the barriers they often face to being acknowledged as active contributors in relationships of care (Power, 2013; Fisher et al., 2018; Robinson et al., 2017b). Research with young people with disabilities by Sullivan et al. (2016) found that they experienced barriers that restricted positive relationships, including social and physical isolation that limited the places they could encounter others and constrained valuing and support within relationships, limiting their agency. These studies demonstrate the importance of relationships not only for the social and practical features, but also for developing a deeper sense of self, particularly around identity and belonging.

There is a large and diverse body of research on staff wellbeing and managing organisational factors contributing to occupational stress, which contributes to the literature on safe and respectful culture. This includes bodies of work around staff stress and burnout, strategies for supporting staff in their roles, and models of care. Two sets of research are of particular interest to this project.

One concerns the significant challenges posed by high staff turnover, due to the disruption it brings to established and valued relationships (Lewis & West, 2014). The focus of this literature is on ways to address this, including staff-focused initiatives, person-centred care and structural analysis (for example van der Meer et al., 2017). The second is around the ways that staff view their roles and capacity to enact change. In a study by Quilliam et al. (2018), frontline staff recognised the value of their contribution in the depth of knowledge of setting and people, but they felt powerless in their roles due to exclusion from organisational dialogue, stress and exhaustion.

Researchers in organisational culture have described the processes of 'meaning making' that happen within care contexts, and the ways in which this is shaped by political, economic, technical and legal dimensions. Relationships based on care can be in tension with organisational cultures around autonomy. Unless this is recognised and reconciled, there can be cultural clashes rather than mutually supportive elements of a rich organisational culture (Rytterstrom et al., 2012). For example, in disability services discourses about duty of care, normalisation and (lack of) capacity are deeply entrenched and can be used by staff to justify disempowering processes (Jingree, 2015). Research analysing culture in group homes (Bigby et al., 2016) found a series of shared characteristics they identified as coherent, respectful, enabling for people with disability and motivating for staff. These included clear leadership, shared values, shared responsibility for practice, quality enabling teamwork, person-centred practices and openness to outsiders and new ideas.

# Intersection with policy

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is intended to protect the rights and dignity of people with disabilities. It lays the foundation for a robust human rights framework and is evident in policies, practices and inquiries in both Victoria and nationally. The legislative and policy context gives clear direction on the importance of quality assurance and safeguarding of all people with disability to live free from violence, abuse, and neglect.

## Current and ongoing initiatives in Victoria

There are several current and ongoing initiatives that look at prevention and reporting of violence, abuse and neglect. As part of its response to the *2016 Parliamentary Inquiry into Abuse in Disability Services,* the Victorian Government is taking a lead in strengthening safeguards to prevent abuse and promote the human rights of all people with disability through Victoria's disability abuse prevention strategy that looks at three key pillars:

- individual – capacity building, natural supports and advocacy

- provider – leadership and culture, quality and safety practices

- sector – workforce supply and screening, provider regulation.

While we seek to add value to initiatives already occurring in the sector to address violence, abuse and neglect of people with disability, we avoid replicating any of these initiatives.

## State and national inquiries

- *Equality, capacity and disability in Commonwealth Laws,* the report of the Law Reform Commission's 2014 inquiry

- *Reporting and investigation of allegations of abuse in the disability sector* – Victorian Ombudsman 2015

- *Violence, abuse and neglect against people with disability in institutional and residential settings*, Community Affairs Reference Committee 2015

- *Victorian Parliamentary Inquiry into Abuse in Disability Services* – Family and Community Development Committee 2016, and the government's response

- *Royal Commission into Family Violence* and Victoria's implementation of all recommendations

- *Royal Commission into Institutional Responses to Child Sexual Abuse*

- *Royal Commission into Aged Care Quality and Safety*

- *Royal Commission into Abuse of People with a Disability*

## Strategic and policy initiatives of relevance

- *National Disability Strategy* 2010–2020

- *Victoria's disability abuse prevention strategy* 2018

- *NDIS Quality and Safeguarding Framework and Code of Conduct*

- *Absolutely Everyone: State disability plan 2017–2020*

- *Ending Family Violence: Victoria's Plan for Change* (10-year industry plan)

- *Safe and strong: a Victorian Gender Equality Strategy*

- *National Plan to Reduce Violence against Women and their Children*

- Change the story: a shared framework for the primary prevention of violence against women and their children in Australia

- *National Framework for Protecting Australia's Children 2009-2020*

- *Keeping our sector strong: Victoria's workforce plan for the NDIS*

- Victoria's registration and accreditation scheme for the disability workforce

- Disability Workers Exclusion Scheme

- Victorian Charter of Human Rights and Responsibilities

- United Nations Convention on the Rights of People with Disabilities

- Australian Human Rights Commission 2014 report, *Equal before the law: towards disability justice strategies*

- Victorian and Equal Opportunity and Human Rights Commission 2014 report, *Beyond doubt: the experiences of people with disabilities reporting crime*

- Victorian Code of Conduct for Disability Workers

- *Occasional paper 1: safeguarding people's right to be free from abuse – Disability Services Commissioner*

- *Literature review of best practice support in disability services for the prevention of abuse of people with disability* – La Trobe University, commissioned by the Disability Services Commissioner

- *A review of disability service provision people who have died 2017–18* – Disability Services Commissioner

- Family Violence Information Sharing Scheme

- Child Safe Standards

- Australian Human Rights Commission's 2018 report, *A future without violence: quality, safeguarding and oversight to prevent and address violence against people with disability in institutional settings*

- Human Rights Watch's 2018 report, *I needed help, instead I was punished: abuse and neglect of prisoners with disabilities in Australia*

# Project design

**The project aimed to understand the role of culture in promoting safety and wellbeing and addressing the conditions that lead to abuse and neglect in disability services.**

The research team used **social ecological theory** as an overarching conceptual framework. Social ecological approaches are well known and thoroughly used in social research, including in research about abuse and safety of people with disability (Lounsbury & Mitchell, 2009; Bronfenbrenner, 1986; Hollomotz, 2009; Robinson, 2013). They situate people as active agents who both shape and are shaped by their environments. This helped us in making sense of the ways that people with disability understood themselves and their relationships; the importance of the interactions and relationships between families, staff and managers; and the significance of policies, systems and wider social forces on culture in services and the ways that people felt about their capacity to influence change.

The four interacting domains of the social ecological approach were used as an analytical framework and are used to structure the results of the research in this report. They highlight both the layers in which safe and respectful cultures are in play, but also the interactions and intersections between the domains. You can find more information about the social ecological approach at **Appendix 1**.
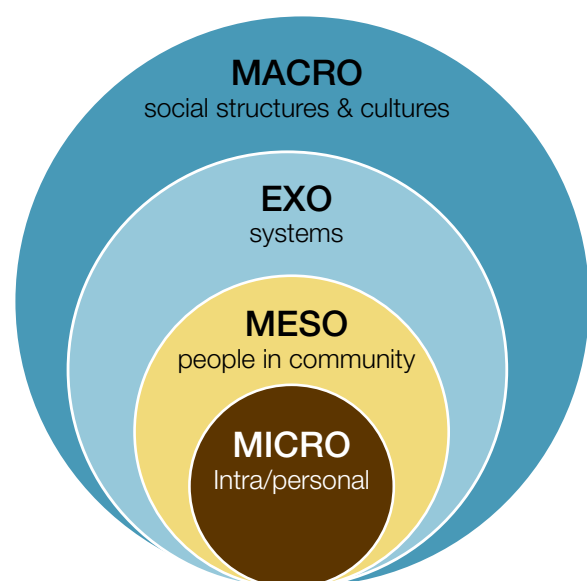


**Figure 2: Social ecological model**

The pilot research was also informed by the **early indicators of concern (the indicators, Appendix 2),** which framed the research questions and guided the selection of methods and tools to seek responses from people involved in disability services as participants, family members, staff, and managers. The indicators were developed as part of research in disability services in the United Kingdom which sought to identify early indicators to prevent abuse from occurring. (White et al., 2003; Marsland, Oakes & White, 2007). They are also being applied in residential and nursing home contexts with older people (Marsland, Oakes & White, 2015).

The indicators are a tool to record concerns and put them together with other observations to catch concerns early. They comprise a series of indicators that might be noticed by those visiting a service or by the people who live and work there. These may not be clear examples of harm or abuse that would prompt a complaint or investigation process. Rather, they are the small indignities and low-level worries that, when recognised, highlight potential patterns that should be addressed as early as possible to improve service quality and a sense of safety for service users. In effect, the indicators are a prevention strategy, as they prompt people to intervene early and have restorative conversations before a situation worsens.

The design of the project reflected the exploratory nature of the pilot study. It aimed to improve understanding of multi-tiered approaches to the indicators, as well as focusing on cultural conditions and involving people across all levels of the service system.

Each participating service was invited to take part in interviews and workshops. In addition, services allowed observation of routine interaction and completed surveys on supervision and occupational stress.

The workshops were a distinctive feature of the project, designed with the intention of bringing people with disability, families, staff and managers together in new ways to reflect on elements of their shared culture, consider opportunities to build positive culture, and identify constraints to safety and respect they could change.

## Indicator workshops to introduce and explore the indicators

The indicator workshops and the initial music workshops were designed to operate together on a single day for each of the three services.

The aims of the indicator workshops were for participants to:

- practice communicating about how they are feeling

- learn how to talk about anything that is of concern and may be difficult to talk about

- learn about the indicators of concern tool and how to use it.

The first half of the workshop was facilitated by a member of the research team and comprised mainly small group exercises. These exercises involved learning to listen to people who might be trying to communicate a concern, and building the confidence required to raise an issue or concern. There followed an accessible presentation taking participants through the indicators and enabling participants to ask questions and discuss them in groups. The second half of the workshop was facilitated by a member of the research team and lead music therapist. It comprised both small and large group activities that explored new ways of communicating and working together. This included expressing emotions through percussion instruments and finishing with a whole group song composition.

## Stand-alone music workshops

The rationale for the music workshops was to address two fundamental features that relate to safe and respectful cultures: equalising power and promoting communication, particularly with people whose voices are least heard. Engaging in the creative arts provides the potential for individual benefits, while also addressing individual disadvantage within a community and supporting a sense of cohesion (Barraket, 2005). The creative arts may also include visual arts, dance and theatre. In this case, a community music therapy approach was used (Pavlicevic and Ansdell, 2004).

Music workshops were facilitated by three different registered music therapists.

The lead therapist facilitated the music component of the initial indicator workshops. The following five weekly workshops in each service were facilitated by local registered music therapists: one therapist in the three metropolitan service centres and one in the rural centre.

Goals for participants of the music workshops were to create a song, composition or other artefact, and to explore ways in which music may be used as a resource in an ongoing way beyond the life of the program. To do this, each therapist used different music therapy methods in each service, responding to the needs and strengths of attendees. These included:

- requesting and singing familiar songs together

- composing songs to express ideas

- playing instruments together

- movement to music

- listening and relaxation.

# Supervision workshops

The supervision workshops were offered to managers and leaders with supervision responsibilities. They were built from models of supervision used in training and therapeutic settings, and were adapted for direct staff who are supporting people with disability. The principal model adopted was the 'functional' model of supervision (Inskipp and Procter, 1995) which incorporated three central elements:

- **education** – ensuring that supervision sessions include elements of learning

- **restoration** – ensuring that supervision sessions incorporate an element of personal care and support

- **correction** – ensuring that tasks are completed, policies are followed and good practice is maintained.

All three elements were informed by a simple process of reflection known as 'what, so what, now what' based on the work of Driscoll (2000), where people were encouraged to pause and reflect on key events, think through what happened and talk about why it happened.

Most of the sessions involved working through activities exploring and practising the different elements of the supervision model. In addition to this, participants were able to discuss the practical aspects of introducing supervision and reflection into the services for which they were responsible. In each organisation, there was a discussion of the specific challenges relating to organisational policies and more general challenges relating to the sector.

# Action learning sets

Action learning sets (ALS) were developed to provide structured opportunities for senior leaders to lead cultural change and be part of a community of practice where they could learn from each other in a setting that was accountable and positive. An external consultant within the disability sector was engaged to facilitate four ALS sessions to encourage open dialogue between service providers.

The model of support to the ALS community of practice developed in response to the needs and preferences of the group. It was established that whatever model or approach was used, three central features needed to be present in some form:

- It was underpinned by a community of practice, involving people from different organisations working together to develop safe and respectful cultures

- Action-focused preparation and learning with accountability was built into the sessions

- There were opportunities for safe reflection about matters of concern and safety.

# Research design

To assess the effectiveness of the project design, a mixed methods approach was used to gather information. Both qualitative and quantitative data was collected from participants to gain richer understanding of the issues from the perspectives of people with disability, family members, staff and managers.

Qualitative methods were used to explore perspectives of safety, and facilitators and constraints to respectful cultures with people with disability, family members, staff and managers.

The research received ethical approval through Staffordshire, Southern Cross and Melbourne Universities.

Seventy people spoke to the research team.

1. Repeat **Interviews** and focus groups were offered to people with disability, family members, and staff.

2. People with disability, family members and staff were asked to attend **Indicators Workshops**.

3. People with supervisory responsibility were asked to attend a **Supervision Worskhop.**

4. People with disability, family members and staff were asked to attend **Music Workshops.**

5. Two senior managers from each service particiapted in **Action Learning Sets.**

6. All staff were asked to complete the **ASSET occupational stress survey** (35 responses).

7. Interactions between staff and people in the three services was measured by the **Quest Observation** Profile on two occasions.

8. All services were asked to complete a measure of **quality of supervision (LASS) survey and incident reporting data** however we received insufficient responses for analysis.

**Aug**

1. Interviews
Round 1 with
18 participants*

7. Observation of practice
Round 1 across 3 sites

2. Indicators Workshops
across 3 sites with 61 participants*

**Sep**

6. Asset Stress Survey
35 received

3. Supervision Workshops
for 16 participants with
supervisory responsibility

5. Action Learning Sets
for managers and CEOs
4 x monthly sessions

**Oct**

8. Supervision Surveys and
Incident Data

4. Stand Alone Music Workshops
with 38 participants*

Music Focus Groups
with 34 participants*

**Nov**

1. Interviews
Round 2 with
18 participants*

7. Observation of practice
Round 2 across 3 sites

**Dec**

**Jan**

* people with a disability, family members and staff

**Figure 3: How the project was put together**

**Repeat interviews** were offered to people with disability, family members, staff and managers. Interviews were offered both before and after the other measures and conducted by pairs of community researchers and DSC staff. Interviews were designed to explore participant perspectives of safe and respectful cultures and the experience of support for the different groups. Twenty-four people took part in interviews, with half completing repeat interviews.

**Focus groups** were completed by the lead music therapist with participants after the music workshops to explore their understanding of core concepts around safe and respectful cultures. These were primarily people with disability. Thirty-four people took part in focus groups.

Several quantitative measures were used to seek information from staff and managers. All quantitative measures were published and validated.

- Interactions between staff and people receiving services were measured by the Quest Observation Profile (Oakes, 2000). This introduced direct observation of practice and allowed researchers to observe the extent to which interactions between staff and people with disability reflected a safe and respectful culture.

- All staff were invited to complete the ASSET occupational stress survey (Faragher et al., 2004) anonymously. This validated measure explores the perceptions of the job, attitudes towards the organisation and effects of stress held by members of staff. This allowed the research team to assess the extent to which staff feel under pressure.

- All services were asked to complete a measure of the quality of supervision in the period between the supervision workshops and the end of data collection. This was a sessional measure of quality of supervision (LASS) survey (Wainwright, 2010). The aim here was to explore the extent to which supervision goes beyond simple setting and monitoring of objectives. LASS scores are not reported in this report as too few were completed.

- Changes in the number and severity of incidents were explored with incident recording. It was anticipated that because of participation in the workshops, the number of minor incidents reported would increase and then decrease, and the number of serious concerns reported would decrease. This is not reported as there were differing interpretations within services about what constituted a minor incident and required documenting.

# Recruitment

Recruiting organisations to participate in the project was challenging, which was not surprising. The sensitive nature of the study, the short timeframe for the research, and the current sector transition to the NDIS combined to create a demanding context for service providers. DSC approached several organisations and offered administrative support and assurances of confidentiality to take part unless duty of care obligations did not permit this. Difficulties in recruitment led to a delay of just over one month to the planned fieldwork stage. This was within the parameters of what might be expected in an applied research project.

Due to a fixed end date for the project, this meant the period for fieldwork was reduced from three to four months down to two to three months, and it ran into January, which is traditionally a quiet time for Australian service providers.

# Participants

Three disability service providers were recruited to the project. All three were in Victoria, Australia. To protect the privacy of individuals and organisations, no identifying details are provided. The providers included:

- two supported accommodation houses that are part of a large provider supporting many people with disability. Both were in a city suburb and provided support to people with a range of cognitive disabilities. Two locations were included, with the second location ensuring that the music workshop was completed with a small group of people with high and complex support needs whom staff felt often missed out on these kinds of opportunities

- a skills-focused service for younger adults with a range of intellectual disabilities, located in an outer suburban area

- a service operating in regional Victoria, providing individual and group support to a wide range of people, most with intellectual disability.

Participants in the workshops and interviews were drawn from these organisations. Surveys were sent to key managers in the services to send out to relevant staff who participated in the project.

# Data analysis

## Qualitative data

Audio from interview and focus group material was recorded with consent and transcribed. Social ecological framing and the interview questions were used to scaffold thematic analysis of the qualitative data from the interviews, which was coded for shared meaning using NVivo qualitative analysis research software. Participants' experience of the music workshops and the meaning they made of their involvement were used to develop key themes by the researcher who conducted the focus groups, and these were interwoven with the emerging themes from the interviews.

Further analysis was completed using iterative categorisation (Neale, 2016), a systematic approach that helps to cluster coded data and make the trail of analysis more transparent. This was important in taking the analysis to an accessible level and confirming the emerging results, which the academic researchers did on three occasions, discussing primary research themes with the community researchers and in the wider team.

## Quantitative data

Quantitative material in the form of paper-based questionnaires (ASSET occupational stress survey and LASS, incident data) was collected and entered into an Excel spreadsheet. Observation data were collected through visits to services by DSC staff and entered into the standard spreadsheet. In the case of the quality of supervision (LASS) survey and incident recording, insufficient responses were received for analysis. A small number of free-text responses were received in the ASSET Occupational Stress survey, which were incorporated into qualitative data analysis. The Observation Profile also had room for free text observations and reflections to be recorded. These were used to inform wider discussions of interview data.

It was not possible therefore, to conduct statistical comparison. However, there was enough data from the Observation Profile and the ASSET occupational stress survey to provide some descriptive analysis and draw out some possible trends. The Observation Profile analysis involved establishing the percentage of observations in each category of interaction leading to tabular representation of these figures before and after the project. The ASSET survey gave average scores across all three services for each element of the occupational stress model (Faragher et al., 2004) to provide some descriptive analysis and draw out some possible trends.

Analysed results of the ASSET occupational stress survey are provided in **Appendix 3** and the Quest Observation Profile in **Appendix 4**. Discussion of the quantitative results and the accompanying reflections are otherwise blended with the other research results for policy and practice impact.

| Activity | People with disability | Family members | Staff | Managers |
|---|---|---|---|---|
| **Indicators of concern and music workshop 1** | 32 | 10 | 16 | 3 |
| **Music workshops (x 5)** | 27 | 2 | 9 | - |
| **Supervision workshops** | - | - | 16* | - |
| **Action learning sets (x 4)** | - | - | - | 6 |
| **Round 1 interviews** | 6 | 6 | 6 | - |
| **Round 2 interviews** | 7 | 5 | 6 | |
| **Number of repeat interviews** | 4 | 4 | 4 | |
| **Focus groups evaluating music workshops** | 23 | 1 | 10 | - |
| **Observation of practice** | 3 service sites x 2 occasions | | | |
| **ASSET stress surveys** | - | - | 35 | - |

Table 2: Participants in research activities

*One service of the three included in the study did not participate in the staff supervision workshop.

# Ethical considerations

The project team recognised that introducing discussions about concerns and safety carried some risk for the individuals and organisations involved. This needed careful consideration before and during the fieldwork so that people could feel able to talk openly, and to align the research process to abuse prevention and response policies.

A careful and considered approach was taken to minimise the likelihood of the project causing distress to people involved, particularly people with disability. In addition to compliance with university ethics approval (Staffordshire[1], Southern Cross and Melbourne Universities), the project was designed to align with the standards and requirements of DSC around prevention of and response to violence, abuse and neglect. At all stages of the project, including signing of consent forms and interviews, DSC outlined limited confidentiality and duty of care requirements.

The research design minimised direct discussion about negative experiences. For example, interviews focused on factors that promote safety, and not on constraints to safety; and the workshops provided opportunities for people to

1 - *Peter Oakes was located at Staffordshire University at the outset of the project and led ethical approval processes through this university.*

express their perspectives in less direct ways. It is important to note that people spoke about their experiences broadly, not just their experiences of the service they were using at the time of interview. No participants withdrew from the research, and no distress was reported during the project.

The involvement of the community researchers in the qualitative research was an important measure in building the confidence of people with disability about consent and feeling comfortable in withholding some information. For some staff and families, the role of the community researchers was also significant and welcome, signalling a different way of recognising people with disability as holders of expert knowledge of people with disability. Particular support was needed for community researchers who were drawing on lived experience as well as professional skills. In addition to training at the start of the project and regular group team work, structured interview-team debriefing, and reflections were completed after each interview and debriefing was offered with senior research team members to provide support for fieldwork staff.

All names used in this report are pseudonyms, and service and place names have been de-identified to protect the confidentiality of the individuals involved.

# Results

Safety and respect are abstract concepts, and it is difficult for people to respond to questions posed directly about either 'safety' or 'respect'. For this reason, all the people participating in interviews and focus groups were asked to share the ways that they understood the related core concepts of

- care and support

- safety

- choice and decision making, and

- problem solving.

This approach built from the early indicators of concern framework, which points to the importance of recognising positive practice and identifying potential concerns at interpersonal and systemic levels in building safe and respectful cultures.

In this section, we first discuss how these core concepts were understood across the services. From this collective understanding, we then turn to an exploration of factors that shaped the experience of safety and respect in the services in different ways:

- intra-personal factors which facilitated and constrained feelings of safety and respect for people with disability in the services they used

- the effects of relationships of support that people with disability had with staff and families, and the relationships between staff, families and managers

- the role of organisations and systems in building safe and respectful cultures

- the effect of wider social and cultural factors on the practices and relationships in the services.

# Understanding core concepts underpinning safe and respectful cultures

## Care and support

People conceptualised care in terms of activities and relationships.

Some people with disability saw evidence of caring in the way staff made physical changes to their environment. This included making modifications to ensure they could safely move around or making sure they had a quiet space to rest when needed. Doing activities together was noted as a way that they were cared about, along with being invited into new activities, as this showed that their preferences had been noted and considered.

Many people with disability placed a priority on having someone to talk with when they were feeling sad or upset, and they valued the emotional care that was provided in these relationships. This was an important role filled by some staff, although it was sometimes hard to talk with staff unless they were well known. Mutual teasing with workers was mentioned by two people as something that they enjoyed, but at times this seemed to tread a fine line between camaraderie and feeling less than fully respected.

People with disability themselves felt mixed levels of confidence about helping other people, with some people feeling scared because they get confused and mixed up, and others feeling intimidated by the demands of other people. Being a good friend was very important to several people.

Staff described the routine tasks of their roles as assisting with personal care, household tasks, and going out into the community. They discussed the practical ways they provided support and facilitated activities and access to information as a core part of their role. As part of this, they spoke about how these things are organised. Structured into each of the services to varying degrees were systems for recognising achievement and personal identity. These included everyday rituals for welcoming and farewelling people each day and the patterns of the day (morning tea routines and so on), as well as birthdays and milestones. More structured ways of recognising achievement and personal development included participant achievement awards, advocacy groups and client meetings. Each of these provided structured opportunities for people to express care and encouragement for each other.

Within these structures, staff talked about the importance to them of the relationships that they developed with people, both for their own enjoyment of their work and for doing their job well. Several staff talked about the importance of rapport in building a working relationship, but also about the need to maintain boundaries around privacy and information sharing. They spoke of noticing small changes in behaviour and appearance as flags/signifiers to not only check in with the person but to address problems as soon as practicable.

Families looked to see that the physical care needs of their family member were being met, that organised activities matched interests, and that they were physically safe. They observed the services and were pleased with several practice elements that they felt indicated care. These included celebration of milestones and achievements, effort in greeting and farewelling each person every day, seeing how the staff related with their family member and others, relationships between people using the service, and communication about routine and extraordinary issues. To assess how satisfied their family member was, families talked about whether they came home happy, their growing confidence over time, and their certainty that they would be told by their family member if there was a problem or concern.

Liam would tell me [if there was anything wrong], he comes home and his language might be limited but he certainly gets things across. He came home and told us, for example, Monday night, that he cried because one of the workers is leaving. He said to us as soon as he got in, he said, "Oh, I just feel so sad". I thought that was a pretty clear indication.

(Tamara, family member)

Most families thought that the relationship of care was positive and supportive when rapport was strong. Family members valued workers who used rapport in their working relationships to help people with disability to manage anxiety, distress and agitation.

Some family members commented that the care that people with disability gave to each other was not acknowledged as strongly as they thought it could be. These people noticed and valued the support that people with disability provided to each other in their daily lives.

You know, as soon as she comes in or Vance comes in and she's at [the service], their faces light up. They almost hug each other, you know what I mean? He puts light into their souls. Are you with me there? And the same with the others too … When Vance comes in, it's to do with his smile. And his probably warped sense of humour.

(Alan, family member)

## Safety

People with disability spoke about physical and emotional safety. Feeling physically safe was particularly important for people who had previous experience of violence, abuse and neglect. They talked about the absence of danger or violence in their lives as an important safety signal. Having a safe place for themselves and their possessions was also important, and they valued the physical safety of their environment.

Sometimes when I'm in bed at night and I hear the front door, I get a little bit worried. 'Cause I don't know who's coming through the door … sometimes if the knob's left on the different thing and people are coming in, I'm thinking, oh, I'm thinking, do I have to put something in front of my door? So anyone coming through the door can't open up my bedroom door.

(Fern, person with disability)

For others, knowing that nothing bad was going to happen in this place was an indicator of safety. Having access to a private space, or at least one away from noisy and disruptive spaces was important for many of the people with disability. Being able to have a break to manage stress, minimise distress, reduce conflict or restore energy mattered. Some people were stressed by changes and adapting to new situations.

To feel physically and emotionally safe, people with disability talked about how it helped them to have someone that they knew well that they could talk to. This was someone who could be trusted with sensitive information, and someone who understood and who cared about them. People said they felt safe when they had someone they could talk to if they had a problem, for example with someone else in the service treating them badly. They most often mentioned staff and their families as the people they looked towards for support to feel safe, and felt it was important to have access to people who understand you.

> … [B]efore I came here, I never did any of that. I was too scared to open up!
>
> (Grace, person with disability)

Several people with disability spoke about feeling unsafe because of other people using the service. There were unresolved problems between peers using the services for some of the people with disability who were interviewed, and some whose family members spoke with us. They raised examples of ongoing difficulties, including their personal distress when other people were angry, shouting or upset. It was sometimes hard for people to effectively escape this, and to manage tensions with other people they lived with or spent time with each day. The lingering effects of conflict and discord can be seen in the response of one person to 'get in first' and pre-empt the verbal attack that may come from other service users. Some people relied on staff to help them leave situations they found distressing.

> I always go up to Tim. One of the staff members … Oh, if he knows that I'm getting upset and getting teary, he will come outside.
>
> (Tracy, person with disability)

Some staff focused on the relational nature of building a sense of safety for people with disability as part of their role. They talked about the importance of identifying when people are unhappy or potentially unsafe at an early stage and acting to address these issues by providing options. These included developing alternatives for people to leave a program or activity when they felt uncomfortable or unsafe because of the challenging behaviour of another person in the group; not forcing someone to do something they don't want to do; and coaching people through shyness or a barrier into feeling safe to talk about a problem.

Staff talked about the importance of being able to look for and recognise subtle signs that people with disability were feeling uncomfortable, concerned or unsafe and to act to address these.

It's all about the client's choice. You know, if they don't feel safe or if they're having a bad day and they don't want to go bowling, they don't have to go bowling. They don't have to be forced to. They can go and sit in the corner and read a book or sit anywhere they want, you know, it's up to them to feel safe.

(Warren, staff member)

Families valued the quality of relationships between staff and their family member, using words like 'trust', 'respect' and 'care' to describe how they felt that staff treated people using the service. This built a sense of trust in the staff as people who would act ethically to keep their family members safe. They provided examples of times that staff had resolved problems using an educative approach or sorted out a delicate situation in a way that maintained everyone's dignity and saved embarrassment.

Families mentioned past experiences where people with disability were not safe, including situations of violence and abuse, and where items had gone missing. They also talked about more complex, difficult to negotiate issues which were recent or current in their family members' lives, generally concerning other people also using the service. In some of these instances, family members expressed worry about the safety of their relative, but at the same time gratitude to staff for working in difficult circumstances, their feelings of guilt about not identifying a problem earlier, and (at times) doubt about whether their family member was telling the truth about allegations of harm.

A few family members commented that they felt less need to watch the actions of the service and staff closely as this sense of trust developed over time. Several families appreciated close supervision provided by services and felt that the 'open-door' policies meant staff knew where everyone was at any point. Several family members spoke about the importance to them in feeling listened to, understood and heard, and having a response to their voiced opinions, feeling this was protective for their family member. Some did not feel a need to know detailed information:

I've never had a problem. I don't necessarily know what the rules are, or the policies and procedures are, but I'm assuming that they're very similar, in many ways, as to the DHS policies and procedures. That's what I'm assuming.

(Helen, family member)

## Choice and decision-making

Most people with disability indicated they were able to make choices about the activities and programs comprising their daily routines. They were generally pleased about this. Some people said they knew what to do if they had a problem, and these people mainly talked about seeking help from senior staff at their service.

They said they felt confident most of the time in asking for help and felt that they were listened to. Two people mentioned practising having a say through client meetings and advocacy groups, and a third talked about building confidence to have more of a say over time. People with disability generally spoke about having a say about activities in the service, and not about their involvement in decision making about relationships or wider quality of life issues.

Several people said that it is hard to speak up at times. This was for a range of reasons: feeling shy; because it was hard to speak up to staff when they said no; when a trusted member of staff was not available to speak to; because of the effects of pain and fatigue associated with their disability; and when there was conflict with other people with disability who also used the service. Two people talked about how they used joking and teasing to try to talk to staff when they felt uncomfortable or worried.

Sometimes I don't say anything and sometimes I try to say something to the boss over there. Harriet and another boss, too. Two of them. I always give cheek to them.

(Cassandra, person with disability)

Transitions were difficult for a small group of people with disability, and it took time for people to get used to new services and to compromising in ways they had not had to before. Some people had previous negative experiences, which affected their views about how they could manage their current service provision and relationships. This included loss and grief, trauma, abuse, having private information shared without consent, lack of choice, and lack of communication on significant issues. These experiences affected their confidence, willingness and capacity to speak up.

All staff described encouraging people with disability to make choices about daily activities, from basic daily decisions about food choices through to collaborative program development. One staff member raised appropriate communication as fundamental to supporting decision making. They had recently assisted a young woman to update her communication toolkit to better reflect her age and circumstances with positive impact for her, staff and family members.

We have communication aids for them as well, so, for the guys who are non-verbal. I know one of them, she had a really outdated communication folder, so I've redone the whole entire folder so she has now an updated communication aid. … Oh, she did it herself. We did it together. And I got the family involved to send in new photographs, so gave them input as well. Yeah, everything, she's changed. She really likes it. It updated to her age group, she's only in her 20s. (the last one was) when she was in early high school.

(Angela, staff member)

Some staff stressed the importance of looking for signs that people with disability were either satisfied or unhappy and being proactive in approaching them to resolve any emerging issues before they became problems.

Definitely being able to recognise when someone is not happy is a massive skill. To be able to learn the participant's facial expressions, hand gestures … For you to be able to recognise when someone is asking for help, to be able to then be spoken to about what the issue is. You know, if they're not feeling safe.

(Warren, staff member)

In most of the service contexts, staff were supportive of the rights of people with disability to talk with them about concerns. However, they did not necessarily equip people with the tools to do so, or recognise barriers to speaking up for people with disability. People with disability spoke about needing to wait in their busy services for staff to be free from other duties. Families mentioned that they had overheard private conversations and had felt uncomfortable about having conversations with staff about their own family member in front of other people who used the service.

Family members generally felt that the services were responsive to requests to change program activities, and in some cases were proactive in offering options where people with disability indicated they were not fully engaged. Several felt an informal 'open-door' approach to service feedback by managers and senior staff encouraged their family members and other service users to feel comfortable in speaking up.

Some family members actively encouraged and promoted supported decision making, and those people described more extensive community connections and richer inclusion experiences.

Tom has this saying, "It's my say now". And we've taught him to do that. "It's my say now," and I think we are very, very conscious always of any changes in our life, that we listen to Tom …
A great support worker just left last week, Mark. And … they had a farewell for Mark out there. He came home and said, "I did a speech" and … that's really important for him, that his voice is heard on those occasions. So I suppose having a say is just listening and respecting.

(Sandra, family member)

Others conveyed a position more in keeping with substitute decision making, having more reliance on the service system to take responsibility for taking care of family members, as well as lower expectations of their self-determination and agency in decision making. In the absence of other informal supporters, people without close family involvement, or a history of institutionalisation seemed to rely more heavily on their disability service provider for support with decision making.

… [T]here used to be a client meeting, I'm allowed to do that, and I said to them, I said, "What about us clients having a say about what we want to say?" and understand it's just not for the parents, I said, "What about if the parents say this and that," and I said, "What about us?" It should be about us not them, it's about us, we're human beings like you all.

(Penny, person with disability)

## Problem solving

People with disability said that staff were available to assist with solving problems, but also that it was hard to approach staff sometimes. Some people talked about how it took time to build confidence, and that they were more comfortable speaking with staff they knew well or had known for a long time. Some people also talked about feeling safe if they could call on staff if they had a problem and that they knew how to contact emergency services if needed.

When you've got problems I think, talk to the people [is] what you do. Talk to them. If you know them, that is.

(Cassandra, person with disability)

One person said they would go to staff for a big problem, but their busyness put her off going to them for less critical issues. Conflict and discord between people with disability appeared an ongoing feature in some people's lives and was both a continuing frustration and source of distress.

Some staff expressed the view that while it is part of their job role, their core duties were to help people fulfil daily living activities, and sometimes they needed to prioritise this over individual problem solving and people needed to wait. Other staff spoke about scaffolding opportunities for building confidence in problem solving into daily activities. For example, one staff member related watching to see whether and how people are enjoying themselves and creating the conditions for them to discuss how they are feeling and whether they would like a change if they seem unhappy.

People with disability, families and staff members all spoke about the importance of being able to choose who they can approach with a problem. Some people with disability felt it was important to speak to known and trusted people, and others were pleased to have access to senior staff. Family members thought it was important that they and their family members had ready access to managers and staff who knew their family member well. Staff emphasised the importance of good rapport and a personal connection, but also the need for all staff to be able to communicate effectively with all participants to minimise the impact of staff turnover and absence.

Families provided several examples of times when the services had helped their family members with problems. These were about both resolving problems with satisfaction with the service (for example, when people did not enjoy an activity) and more complex interpersonal issues (for example, conflict between people using the service). Families did not raise issues lightly:

You have to be sure of your facts before you say something. You can't just accuse. You have to know what you're talking about before you say, now, hang on, this is not right. I've learnt that over the years.

(Helen, family member)

Where families felt services responded well to problems about the program or activities, the services had done several things: responded promptly to ensure everyone was safe; cared for the (sometimes competing) needs of each person; listened carefully to the people involved; contacted family members quickly; worked collaboratively together to minimise the chances of the problem recurring; and followed up.

[Tom] came out [at the end of the day] and he was crying, this young man was having a go at him, as he said, "They spoke to him, he mustn't do that". I thought, isn't that good? It wasn't just, "Yeah, yeah, that was yesterday, don't worry about it".

(Sandra, family member)

# Facilitators and constraints to safety and respect for people with disability in the services they used

This section of the results explores factors that influence the cultures of safety and respect in the services. It uses the social ecological framework to shape this discussion, focusing first on the identity of people with disability and their interactions with other people in the service context; then on the relationships of support which staff, families and managers sustain to support people in the services. The role of organisations in building safe and respectful cultures follows, and finally, the effect of wider social and cultural factors on the practices and relationships in the services is considered. This approach aims to highlight both the layers in which safe and respectful cultures are in play, and the interactions and intersections between the domains. As well as those things that help and hinder in creating safe and respectful cultures, we have also highlighted issues which are difficult to resolve. It is these tensions, difficulties, silences and discords which continue to trouble, and which are often un-named. In a project of our size and scope, we cannot pretend to resolve these complex issues. We can at least name them. Implications for action arising from analysis of these results follow, focusing on practical strategies to promote change.

| | Facilitators | Constraints | Complexities |
|---|---|---|---|
| **Personal and intrapersonal factors affecting safety and respect for people with disability** | • Relationships based on trust and familiarity<br>• Feeling heard<br>• Having multiple ways to express views and feelings | • Not being taken seriously<br>• Feeling unable to speak up<br>• Peer-to-peer harm<br>• Disrespect<br>• Lower standards applied to people with disability<br>• Limited agency and power | • Speaking up is hard to do<br>• Problem-solving strategies might not help you become safer<br>• Safety strategies can be lacking in depth<br>• The passivity of the 'participant' role<br>• Impact of the wider world on young people's relationships in services |
| **The effects of relationships of support in building safe and respectful cultures** | • Relationships that recognise positive qualities and attributes in others<br>• Using multiple ways to support people in difficult times / with sensitive issues | • Impact of challenging behaviour and interpersonal conflict<br>• Misuse of power by staff<br>• Staff not seeing relational support as a priority<br>• Gratitude and hesitancy to 'make a fuss' by families | • The little things are the big things<br>• Balancing competing needs and preferences<br>• Difficult for some staff and families to see the perspectives of people with disability<br>• Stress and a sense that other people don't understand<br>• Unresolved conflicts / tensions between the rights of people with disability and the rights of staff<br>• Fragility in staff sense of security and safety in role |

| | Facilitators | Constraints | Complexities |
|---|---|---|---|
| **The role of organisations and systems in building safe and respectful cultures** | • Well-organised environments<br>• Policies, procedures and guidelines developed for the service context<br>• Practical strategies in services that bring policies to life for people with disability<br>• Trained and supported staff<br>• Education and opportunities to practice safety-making for people with disability | • Impact of resource and time constraints on capacity to support people with disability and staff<br>• Resource constraints impeding effective responses to problems<br>• Staff who are under-skilled or ill-equipped to provide preventive support<br>• Lack of support, supervision, career planning for staff and managers | • Differing levels of knowledge about policies, procedures and implementation<br>• Role clarity and boundary setting for staff<br>• Tension between rights of people with disability and the rights of staff<br>• Difficult balance between compliance, risk and rights discourses |
| **The effect of wider social and cultural factors on the services used by people with disability** | • Increasing knowledge of human rights<br>• Pride in role, strong values base | • Activation of rights<br>• Risk of support relationships fracturing<br>• NDIS dominating practice and structure | • Many – outside the remit of this research (e.g. poverty, exclusion, social isolation, discrimination, community attitudes) |

Table 3: Facilitators, constraints and complexities to safety and respect for people with disability in the services they used

| | Implications |
|---|---|
| **Personal and intrapersonal factors affecting safety and respect for people with disability** | • Develop and tailor strategies that assist people with disability to make and sustain relationships of greater depth<br><br>• Provide opportunities and multiple ways for people with disability to have a say<br><br>• Develop practical education and strategies to support people to see results from practicing having a say |
| **The effects of relationships of support in building safe and respectful cultures** | • Work to develop positive and equal relationships where each party to the relationship can influence the other is the core task across the sector<br><br>• Building skill in staff to recognise and respond to the safety strategies that people with disability use when they feel worried or unsafe<br><br>• Prioritise action on issues raised with staff and management<br><br>• Blurring of boundaries can cause confusion and introduce dilemmas<br><br>• Look for opportunities for people with disabilities, staff, families, managers and the wider community to train and work together |

| | Implications |
|---|---|
| **The role of organisations and systems in building safe and respectful cultures** | • Consult with people involved in any change before it takes place<br><br>• Increase the use of accessible information and ensure it is systematised<br><br>• Make time available within rosters and staffing allocations to build and maintain relationships<br><br>• Provide staff with supervision that builds a supportive and accountable relationship<br><br>• Offer staff training that is regular, evidence-based, and responsive to issues that they face in their daily work<br><br>• Review complaints processes<br><br>• Review the extent to which organisational administrative and domestic demands keep staff away from the core task of interacting with people with disability<br><br>• Build on the positive practice at the senior manager level across organisations to establish and sustain a collaborative interagency community of practice focused on safe and respectful cultures<br><br>• Work collaboratively across organisations to make inroads into 'wicked' problems |
| **The effect of wider social and cultural factors on the services used by people with disability** | • Relationships need to be prioritised in planning and funding mechanisms<br><br>• More streamlined and less confusing NDIS planning and funding<br><br>• The NDIS needs a policy and funding framework for prevention work<br><br>• Access to independent advocacy for people with disability and families is needed |

**Table 4: Implications for practice**

## Personal and intrapersonal factors affecting safety and respect for people with disability

This section focuses on how people with disability felt about their safety and relationships in the services they used, and how their relationships enhance or diminish feelings of safety and respect more broadly.

Intrapersonal factors consider the self-perceptions, attitudes and skills that people draw on to work through situations (such as self-esteem, open-mindedness, self-confidence). These are intimately bound up in personal identity. Personal and intrapersonal factors and influences are engaged in the person's immediate context, such as their family, friends, services and other domains where they spend time in activities and interactions.
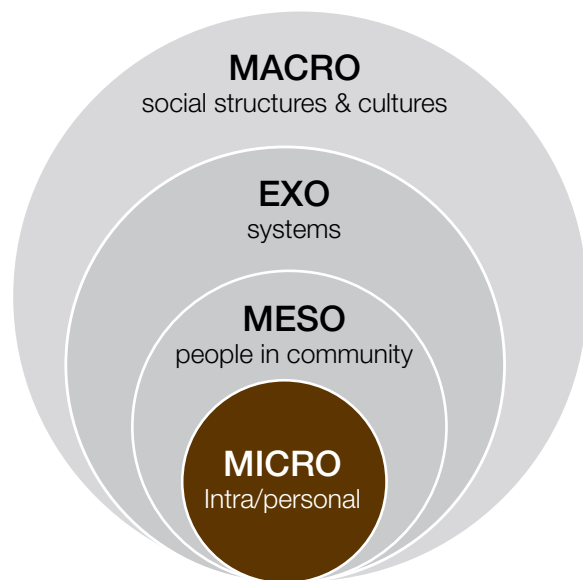


MACRO
social structures & cultures

EXO
systems

MESO
people in community

MICRO
Intra/personal

The key points in this section are:

## Facilitators of safe and respectful cultures

- Relationships based on trust and familiarity

- Feeling heard

- Having multiple ways to express views and feelings

## Constraints of safe and respectful cultures

- Not being taken seriously

- Feeling unable to speak up

- Peer-to-peer harm

- Disrespect

- Lower standards applied to people with disability

- Limited agency and power

## Complexities

- Speaking up is hard to do

- Problem-solving strategies might not help you become safer

- Safety strategies can be promising but lacking in depth

- The passivity of the 'participant' role

- Impact of the wider world on young people's relationships in services

## Facilitators of safe and respectful cultures

### Relationships based on trust and familiarity

Having someone you felt you could trust and could talk to was of central importance to people with disability. People based their judgement of the trustworthiness of others (particularly staff) on their experience of them, and most people felt that it takes time to build trust.

Having your preferences and priorities known and respected was an indicator to people with disability that they themselves were known and valued as individuals. For example, two people mentioned that if staff members checked to see if they were okay after someone else had an outburst, it helped to build trust and a feeling of safety. For some people, being able to maintain friendships over time was an important way to feel safe, as they looked to their friends to give and receive emotional support and practical help.

To have someone there to understand you and know not to say to anyone else. And trust them to say, hey it's just me or you, not everyone else.

(Penny, person with disability)

## Feeling heard

Feeling listened to was raised by most people with disability in the research. When people felt listened to, the examples they provided were about feeling more secure, more confident and more satisfied with speaking up about problems. For this to happen, people also needed to have a sense that the person they spoke to would act if it was needed, in consultation with the person.

For some people, an important element to feeling heard was having the time and opportunity to both form their views and express them:

Yeah … as it was not rushed we were all given the opportunity to contribute, we were all given an opportunity to say. As … when, when … if the staff were not approachable, then we won't have our own, and then we won't feel very safe or won't feel confident speaking.

(Max, music interview participant)
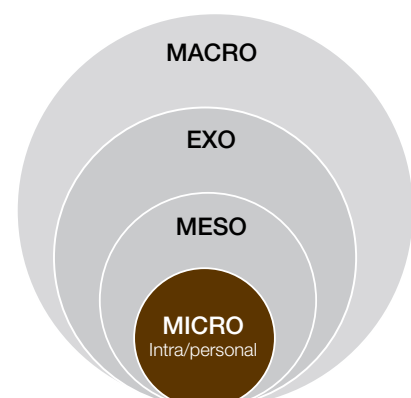
### Having multiple ways to express views and feelings

Several people with disability talked about the significance of finding different ways to express feelings that were not about responding to direct questions but allowed them to share thoughts and ideas. This included music and art, but also some rituals, such as birthdays, greeting others and being warmly greeted in the mornings, and farewells for staff. The music workshops were very popular with people with disability as a way to express feelings, as well as for the musical experience.

A developmental approach to having a say also opened possibilities for people with disability to build their capabilities, learning new ways to express views and feelings and having opportunities to practice in various contexts. People were enthusiastic about their plans to continue with a range of activities and initiatives that built on their capacity to express their views – either building on successes from their own or their family's advocacy, or things they had learned through this project. Staff also saw the value of this:

I would say that the biggest thing would be Jo's increase in communication [through the music workshops]. Because we know that by increasing his communication, it decreases his behaviours of concern and it also increases his ability to tell us what is going on for him.

(Reba, support worker).

# Constraints to safe and respectful cultures

## Not being taken seriously

People with disability talked about times when other people didn't listen to them. Sometimes this was annoying. But sometimes, when they wanted to talk about important things, it was a big problem.

People talk to me but people don't listen to me and it's really annoying … I hate when people don't listen, it just annoys me … If people don't listen to you, they're not interested

(Grace, person with disability).

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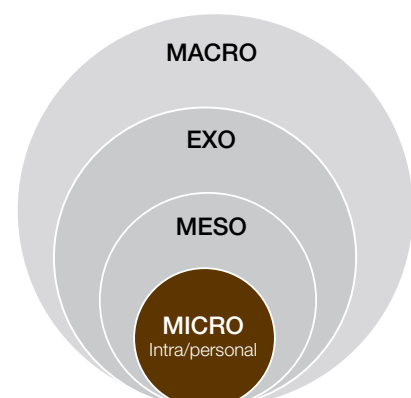
On some occasions when people had raised problems, they had no recollection of receiving feedback about the outcome even when staff and managers responded with, 'We'll sort it'. In some cases, their view was that nothing had changed. In other cases, people felt that speaking up changed some things, but did not result in any change to the situation that was causing the problem.

I feel safe where I am but living with one of the residents is hard. It's like when she came out and swore at me one morning, I was ready to say a few words back to her but shut my bedroom door. The staff sort of just spoke to her. And then this morning I got an apology from her. But yeah, it's just sort of frustrating and hard sometimes being in the house with the others …

(Fern, person with disability)

Some people talked about the emotional impacts of change, particularly of feelings of loss and grief. Movement of people in and out of people's lives was recognised through some rituals such as farewells for staff leaving one of the services, but several people with disability talked about much more significant loss and grief, such as leaving the family home before they felt ready, losing custody of children and deaths of family members. From their perspectives, they were not adequately supported in managing these feelings and situations.

## Feeling unable to speak up

Some people felt unable to raise issues of concern, and others felt that at times they were unable to speak with staff or family members about worries or concerns. There were several reasons behind people's concern about raising issues:

- they felt scared or nervous about speaking up

- workers sometimes seemed like they were too rushed to listen

- workers sometimes seemed like they were not in a good mood and people were concerned about further upsetting them

- sometimes workers and family members did not think that people's ideas were important.

## Peer-to-peer harm

Many of the people with disability in this research were troubled by peer-to-peer violence and conflict. In their experience, services responded poorly to this because they continued to be exposed to it. They were often unable to remove themselves from the cause of the violence, which was mostly from people with complex behaviour support needs using the same services. They talked about the distress and fear that this caused them.

Some people understood the difficult situation of the people who have complex behaviour support needs, but at the same time worried for their own safety and felt that there was inadequate acknowledgement of the interpersonal violence against them.

I always go outside for lunch. Sometimes, when it's a nice day, like sunny day. I stay me own self, to go outside because I don't like fights and other things, and when they get really mad. … And then this other boy, he comes out and goes mad. I get sick and tired of it. He can't help it, he just gets really sad or something.

(Cassandra, person with disability)

## Disrespect

In some instances, disrespect of people with disability was evident. A staff member referred to adults as being childlike; another spoke to a person's family members about a sensitive incident in front of the person and other people; the honesty of a person was questioned; and 'joking' nicknames with a critical undertone were discussed.

Senior managers pointed to the messages that are sent to people with disability when they are faced with a lack of stimulating activities in their daily programs and planning that fails to build on their strengths and interests. Such practices and attitudes contribute to a climate in which people using the services are disrespected. Treating people as less worthy of a fulfilling and engaging life opens a space where they are disregarded and ignored.

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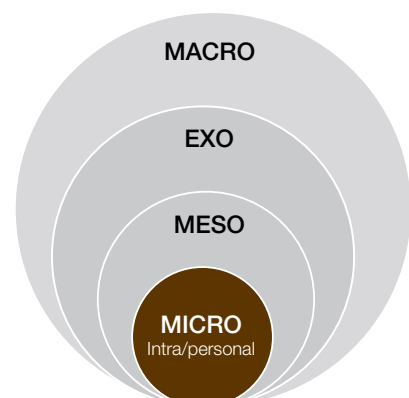
### Lower standards applied to people with disability

Standards applied to some of the people with disability were quite different to those applied to other community members, and these were internalised by people with disability. The ways that some people spoke about the patterns and routines of their service use indicated that they were resigned to a less than 'ordinary' life. Some examples provided included one person who said they were not allowed to speak to staff at certain times; another who talked about having to wait until the afternoon for a shower if they did not have an appointment that day; and others who spoke about changes of work activity with no notice or information. One interview took place a few days after one person had an item very significant to them either lost or taken. They related being unable to receive assistance from staff in either locating it or attempting to replace it and were in considerable distress.

Have you been able to check in again with the staff?
**I've searched everywhere.**

Would the staff be able to help you with that?
**I'm going to have to talk to them.**

When did it disappear?
**It was some time Saturday.**

Yeah, it's Monday, so …
**It has been written down.**

(Lee, person with disability)

Some people with disability spoke about violence in ways that indicated it had become a normalised part of their lives. Routines in some parts of the services functioned to minimise conflict, but also isolated people from one another and reduced opportunities for positive social life. For example, people spent their time in their own rooms or watching separate televisions, were 'put to bed' early, or did not eat in social settings.

## Limited agency and power

People with disability depended on staff to organise key elements of a safe and respectful culture. These include activities and the program, as well as organising the physical space to enable people to find somewhere private and quiet when they needed it. This was regarded as largely positive by staff and families. However, the need to rely on someone to help with problems was conflicting and at times difficult for some people with disability.

There seemed to be a disconnect between words and actions. While people with disability were generally aware (and told by staff) that they could have a say, they thought that there were a limited range of issues about which they could have a say and had limited practical opportunities to put their preferences into practice. People talked more about routines, schedules, activities; and families and staff focused more about the quality of these things.

While there was not deliberate exclusion of people with disability, there was in some cases an absence of active promotion of choice making and capacity building. It did not appear that people with disability were expected to contribute to more significant decisions. Staff did not talk about building decision-making capacity as a part of daily support. A view was expressed in some families and staff that it was not possible for some people with disability to make choices. Some people with disability had a sense of resignation about situations that they found unsatisfactory, describing strategies for coping with the status quo:

## You get over it the best way you can.

(Vance, person with disability)
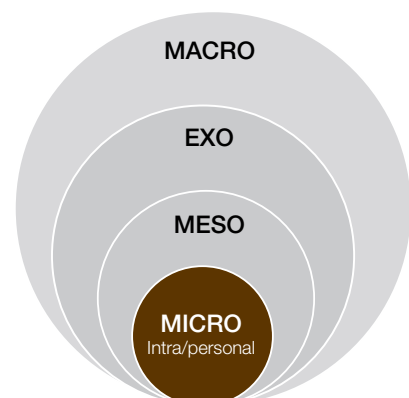
# Complexities

### Speaking up is hard to do

Speaking up about worries and concerns was difficult for most people with disability we spoke to. They talked about feeling scared, needing to be brave, feeling stressed, worrying about being blamed and how hard it was to speak up.

Some people also said they felt relieved once they did speak up and that their perspectives were well received. To feel more confident that they would be well received by others, people said they spoke first to trusted people for advice (mainly family and friends), and only spoke to staff who were in the 'right' mood.

… [A] worker didn't like me, one worker didn't like me one day, and I was so scared to tell Mum … But then I had to, because I was so stressed out about it. It's really bad … Mum rang Olive [manager] and got it sorted out then. Once you say something about it, you'll feel much better, trust me, you don't want to be stressed out like I was. I was so stressed.

(Grace, person with disability)

## Problem-solving strategies might not help you become safer

Several people with disability provided more detailed responses about how they dealt with conflict, and their advice to others about ways to deal with problems. They said that it was good to talk with people you trust, naming family, friends and staff. They also gave examples of times when they had done these things. Talking with family members had helped to resolve problems, both by sharing worries and getting advice and emotional support, and in getting practical assistance (for example, family members going to talk with service managers to resolve problems). Talking with friends provided emotional support but was a less concrete strategy for resolving problems. One person pointed out that they wanted more friends to be able to have access to this kind of emotional support. Talking with staff was mentioned by people as a way to solve problems.

Many of the people with disability interviewed used a strategy of withdrawing, either from conflict or to deal with distress. While this kept them safe from escalating conflict and peer-to-peer violence, it also left some on their own with feelings of stress and distress. Some people commented that they would like staff to check in with them about how they were feeling, both after being involved in conflict and after witnessing incidents.

The examples that people with disability provided were mixed in their success in resolving problems. Several different examples were given where people had raised their concerns with staff, but no changes or no meaningful changes happened. These were often about ongoing interpersonal conflict, and staff responses included getting the other person to apologise or encouraging the person to withdraw from the situation, but not addressing the underlying problems arising from unwanted co-location.

This raises a question for services about whether staff have the skills and resources in busy and sometimes volatile situations to recognise what is going on for quieter people or those who withdraw, to be able to respond at early points to prevent situations escalating, and to seek people out and check on them following disagreements, conflict or incidents.

## Safety strategies can be promising but lacking in depth

Some of the strategies for resolving problems that people with disability talked about were fragile. These included relying on a strong relationship with an individual worker, or problem-solving ideas that had promise but lacked substance. These promising ideas would benefit from further strengthening to extend the benefits to other people using the services, for example by broadening and deepening the participatory mechanisms, documenting the processes or ensuring enough resources are available.

In one service people valued the opportunity to have a say at a large regular meeting, but this meeting only lasted around 15 minutes. In another service, two people described separately how it helped them to know that a worker was looking out for their safety when they were distressed and left the room after witnessing peer-to-peer violence – the worker checked in later, talked with them and reassured them, and followed up on their concerns. They felt this was due to the qualities of that individual worker, rather than service practice as they had not experienced this with other staff.

## The passivity of the 'participant' role

No people with disability felt that anything had changed for them in the three months between the two rounds of interviews. When it emerged in conversation that some things had changed in their circumstances, this was generally not due to action on their part, because speaking up about a problem had not resulted in change. People were often very passive about the activities in their lives and seemed resigned about the (lack of) control they had over what happened, both in the way that routines and activities were established and maintained, and in how problems were resolved. Few people expressed or demonstrated a strong sense of personal agency or believed their actions would or could effect a change in their circumstances. The locus of control for resolving problems sat much more closely with staff or families.

People with disability did express their goals differently to staff, and in ways that showed that they saw themselves as more than service recipients. Several people had goals related to learning to drive, careers working with children and in the café and restaurant industry. However, some people also talked about how their families did not feel that they were capable of the things they aspired to. In several cases people's activities were far more modest, focused more around programmed learning and leisure activities available within the services.

Others spoke about their goals in ways much more aligned to other community members, but staff tended to express goals through a service-user lens. For example, some young people involved in the music workshops talked about their desire to learn a musical instrument or join a music group to pursue their interest in music following the workshops. Workers spoke about this with a similar level of enthusiasm, but about a goal for more music therapy sessions.

## Impact of the wider world on young people's relationships in services

Relationships outside of services, particularly on social media, were influential for many of the people with disability in the research, for better or worse. Social media was a source of connection and access to information about friends and shared interests which was important currency in friendships. However, young people talked about online conflict interfering with the relationships during the day and causing difficulties and tensions.

We've had a bit of conflict, we've got like a bit of a clique-y group and there's a bit of bullying and conflict going on between them that we've tried to tackle, but unfortunately social media comes into it quite a lot, and that's something that we can't control at all because you know, it's [out] of hours. It's on personal devices, you know, so that's really hard.

(Rachel, staff member)

## Implications for action

- **Develop and tailor strategies that assist people with disability to make and sustain relationships of greater depth, including:**

  > ways of having greater control over who supports them
  > recognising the significance of family, geography and culture
  > ways to explore friendship
  > making space and opportunity to grieve when relationships are broken or lost.

- **Provide opportunities and multiple ways for people with disability to have a say** – about positive, neutral and complaints-related issues; and about the small indignities that are important to them and that grow into larger concerns if they are not addressed.

- **Develop practical education and strategies to support people to see results from practising** having a say, speaking up, and enacting their rights.

# The effects of relationships of support in building safe and respectful cultures

This section explores relationships between the people who supported people with disability in the project: staff, managers and families. It looks at the effects of these relationships on facilitating and constraining a sense of safety and respect for people with disability in the services. Understanding the relationships among and between these groups is important for this research because people have multiple relationships.
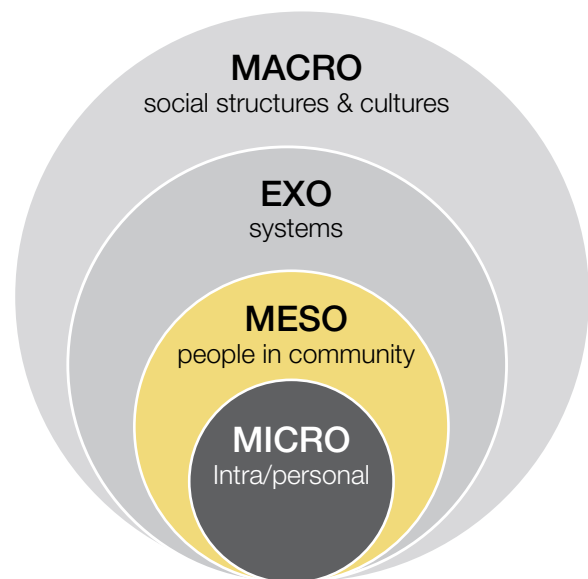


MACRO
social structures & cultures

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systems

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Intra/personal

The key points in this section are:

## Facilitators of safe and respectful cultures

- Relationships which recognise positive qualities and attributes in others

- Using multiple ways to support people in difficult times / with sensitive issues

## Constraints to safe and respectful cultures

- Impact of challenging behaviour and interpersonal conflict

- Misuse of power by staff

- Staff not seeing relational support as a priority

- Gratitude and hesitancy to 'make a fuss' by families

## Complexities

- The little things are the big things

- Balancing competing needs and preferences

- Difficult for some staff and families to see the perspectives of people with disability

- Stress and a sense that other people don't understand

- Unresolved conflicts / tensions between the rights of people with disability and staff

- Fragility in staff sense of security and lack of safety in role

## Facilitators of safe and respectful cultures

### Relationships – recognising positive qualities and attributes of others

An emphasis on trust and care about one another in relationships in all three groups was evident in the results. Shared relational values were about trust, respect, rapport, power, control and boundaries. This involves group, team and family relationships including the interplay between the three. It was clear that in this study, people cared considerably about each other at all levels.

The centrality of trust in relationships was shared across the three groups. Having someone to talk to and being able to choose that person was part of this. The issue of communication was also very important and included the value of communication for all groups and the importance of sensitivity where people find verbal communication difficult.

There were also some differing emphases for each of the groups. Most staff commented on positive qualities in the people they supported, promoting their resilience, determination and good humour. They emphasised the importance of building rapport and using relational connection to work effectively with people, particularly when they were elevated or distressed. This was a mutual experience, with some staff talking about the energy and fortitude they drew from working with people with disability they admired and respected.

Being respectful is one key that sets the tone for anything. If you're respectful, if I'm respectful to you, you feel safe to go on to the next word of a conversation, you are safe to ask me for what I need. Even though that's your right, but you're safe to ask me that question. Respect is key to me.

(Dennis, staff member)

For families, feeling able to communicate easily with staff about ideas or concerns regarding their family member was important. Some family members involved in the research reported a change in their perspectives between interviews, recounting that their involvement in the early indicators of concern workshops had increased their confidence in putting their ideas forward and their capacity to listen to other people's perspectives (especially people with disability).

However, neither people with disability nor staff reported a change in their expectations and agency.

### Using multiple ways to support people in difficult times / with sensitive issues

Drawing from a mix of proactive and reactive strategies to support people who were either harder to support or going through a difficult time helped both the individual and created a safer and more respectful culture. Staff described setting a warm and welcoming tone for each day, watching for shifts in mood or behaviour or signs that people were disengaged or not enjoying activities or interactions, and using incidental opportunities to check in with people. They spoke about checking in with people if they were distressed, recognising the stress caused to people who raised significant issues, and the importance of following up and reporting back to the person.

Some family members valued an approach used in two of the services that saw the person as embedded in their community, and where the service and staff extended warmth and support to family members who were also having difficulty with health or mental health. They saw this as supportive for the whole family, including the person using the service.

From what I can see because I drop Tom off each morning, with the meeting and greeting, and then it seems to be a very well-oiled machine where there's no sort of sitting around, there's no, "Hurry up!" We've witnessed over the years, "Hurry up," and "Get in there!" It's very, very respectful. Yes. I just think, I feel, you know, when you walk into the centre or you're collecting the adults, the young adults, or clients, they're cheery, as in, interacting with each other, "Bye Tom," "See ya Tom," "Hi Sandra," you know, "Are you Tom's mum?"

(Sandra, family member)

# Constraints to safe and respectful cultures

## Impact of challenging behaviour and interpersonal conflict on everyone

In some of the services there were high levels of behaviours of concern. These had significant impact for everyone - for the person using the behaviour; for other people with disability and staff who were distressed and traumatised; for some staff who were under-skilled in responding and understanding these complex situations; for managers who sometimes felt underequipped to support and respond; and for families who felt guilty and stressed.

As discussed previously people with disability talked about interpersonal conflict and the significant negative effects of it on them. Staff and families did not raise this issue to the same degree, although this may be because they framed it as behaviours of concern or did not place the same priority on peer relationships.

## Misuse of power by staff

While in the main people were treated with respect, in some instances staff misused the power they have in their relationship with people with disability. This did not appear to be due to malevolent intent, but more unthinking disregard of the person as an individual. For example, one person who used a wheelchair was mid-interview. A staff member entered the room and without conversation with the person, began to back him out of the room in his chair, appearing to do what he would usually do. Managers pointed to the impact of what they termed a 'maternal care model' in some staff, which led to staff assuming they knew best, making decisions on behalf of people with disability, lacking transparency in their practice, and not following through where needed. The impact of these actions was compounded by lack of agency of people with disability to act on their own behalf in many instances.

## Staff not seeing relational support as a priority

In the interviews and observations, staff talked about staff shortages, time pressures, and the volume of tasks they had to complete creating a pressured work environment where tasks were a priority and relational support had become less urgent. This was also reported in the comments of two members of staff using the staff stress survey. In exploring reasons why staff were not involved in the music workshops, one researcher was told by a coordinator, 'But they're busy. They can't always be here.'

Senior managers viewed this lack of priority on relationships as a signal of poor organisational and individual health. They saw signs of it in disengaged and disconnected staff, poor-quality relationships, lack of skills in staff, and lack of effective supervision (addressed in the following section).

## Gratitude and hesitancy to 'make a fuss' in families

Some families expressed some hesitations and concerns, but wanted to emphasise that they did not know what happened 'behind the scenes'. No-one wanted to make a fuss. They noticed the lack of rapport with some staff and their family member, but felt this was common to any interaction in a group of people. They worried that their family member sometimes had to wait some time for assistance, but were grateful that they received support from the service at all.

Lack of communication about changes to activities and programs was an issue for several family members at times. A small number of families were actively involved in the services through governance and management support roles and other informal support activities. There was reluctance expressed in most families to overstep boundaries, with people not wanting to trespass on the private business of other people with disability or their families.

I've observed different things where one of the residents had a concern … It happened to be in the staff room. They're both talking outside [with] the people, I thought, oh, I'm not going to walk through that. So I went out to the street.

(Olive, family member)

# Complexities

## The little things are the big things

Recognition by staff and managers of the significance of issues raised by people with disability and families helped them to feel respected. When staff saw the significance of an issue from the perspective of the person, they responded more openly to requests for change. Where this was not the case, families talked about continuing struggles to have their issue recognised:

> I carry a spare shaver and face cloth and tissues and everything like that in the boot now, because sometimes I come out and I look and he hasn't been properly shaved, you know? … But that's not, that's not a big issue. It's just probably our standard more than anybody's concern but ... [he has] a shaver you use with water, a wet shave and a dry shave. I think some people don't know how to do it, how to keep the battery charged. They certainly don't give him a wet shave as I would.
>
> (Allan, family member)

Some of these 'little things' are evident in the small moments that make up the fabric of the day. The subtle communication between staff and people with disability that often goes unreported sets a tone and flavour. In the observations and interviews, good practice included courtesies and interactions between staff and people with disability such as chatting warmly while setting the table together, quiet encouragement while feeding someone their meal, and using the daily shower routine for a singing session:

She and I have the same taste in music and so when she showers me, we sing in the shower. You can hear. It is quite loud isn't it?

(Kim, participant in music workshop focus group)

When this interpersonal warmth and responsiveness was not present, people with disability spoke about feeling ignored and minimised. They waited for support and their requests for help to resolve problems were rebuffed.

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## Balancing competing needs and preferences

Tensions in managing competing needs and preferences were raised in several contexts – between the preferences of families and people with disability; between the routines of services and the preferences of individuals; and between the needs and preferences of people using the services.

Some staff said it was hard to balance the needs of everyone in a group setting so that everyone had a say. At times, families were disappointed to see their family member waiting for attention from staff or having limited options from which to choose. Some families felt that it was difficult to have influence over some issues in services, for example when staff standards of personal care did not match their expectations. Other issues were points of tension, when family members were not satisfied about quality of an interaction, but did not feel able to provide feedback, or that the matter met a threshold of poor practice enough to warrant them making a complaint.

## Difficult for some staff and families to see the perspectives of people with disability

Some families and staff members found it difficult to reflect on their own experiences in the context of the person's lived experience. This suggests that people in these groups are relying on judging situations from an external position rather than from the perspective of the person. This might reinforce fundamental difference rather than shared humanity. Examples included missing the significance of personal events like the loss of a treasured possession, using children as a reference point for decisions or well-meaning but essentially disrespectful language.

An inherent tension was evident in that some people with disability did not want to rely on others for help with problems, preferring to be more self-determining. However, some staff and families preferred that the person with disability was assisted, and some families did not work in a way where they were used to their family member having a say. Some staff who were supporting people were genuinely surprised by the experiences people were describing. This was especially the case when thinking about safety and feeling safe.

## Stress, and a sense that other people do not understand

There were high levels of stress among all the groups, and a sense among many participating in the research that other people do not understand what their situation is like.

People with disability were not confident that others understood their risk from the behaviour of peers, the level of interpersonal conflict they were exposed to, and the lack of control they faced over their physical and emotional safety.

Family members were not sure that services acknowledged the long-term role and deep understanding they had of their adult family members and what they might need. They felt sensitive to the idea of being seen as too protective.

Staff were in a state of constant stress and busyness, and some felt that their managers were not fully aware of the pressures of daily service provision.

Managers were stressed about the level of responsibility they hold for operations and safeguarding, and particularly about the NDIS and external factors that could mean failure of services.

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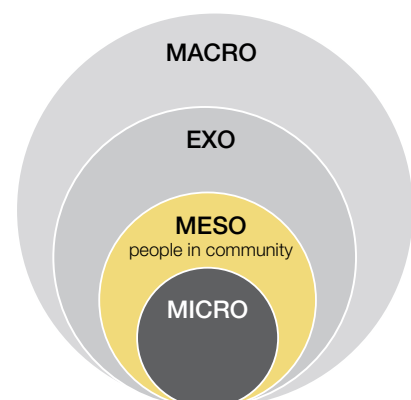
## Unresolved conflicts and tensions between the rights of people with disability and staff

In some examples shared with the researchers, staff were put in a position of having to support people with disability in situations which put them in conflicts of interest and worse, in direct opposition to their right to a safe workplace. Staff provided examples of times when they had supported people at a cost to themselves, such as assisting a person with disability to make a complaint about the service that named the staff member. Staff in these cases spoke respectfully about the rights of people with disability, but also about their concerns about how they can come into conflict with staff rights to be safe at work and the tensions in putting themselves in the direct line of criticism.

These examples highlight the importance of collaborative relationships between disability service providers and independent advocacy services.

When it came back to me, my name was also called for investigation and they asked me, "So who helped him fill the form?"
I said, "I did." [The investigators said,] "So, did you feel bad about your name being there?" I said, "Why should I? That's his opinion. I respect that."
It made me feel good that my job was giving me the right to give someone the empowerment to do something, and we follow the same with everybody.

(Denise, staff member).

## Fragility in staff sense of security and lack of safety in role

Some staff talked about times where they felt unsafe in their work, both physically and emotionally. Experiences of being threatened with malicious complaints about their work performance, feeling unsupported by colleagues and working in difficult circumstances left some workers feeling that their safety or lack thereof was poorly recognised. While senior managers held relatively positive views about staff perceptions of and attitudes to their work, staff felt a little less optimistic. In the stress survey, while the overall responses were neutral about attitudes and job satisfaction, staff reported some ambivalence about pay and conditions, and a lack of certainty about what was expected of them in their roles. The importance of support from team members and encouragement from managers to address problems and seek advice and support was clear.

Some staff felt unsupported in their work and that rapport between them and their clients was poor. Some experienced racism from some people with disability they worked with, and felt it was poorly addressed. They felt that peer relationships with their colleagues were not positive, and this affected their job satisfaction. Others talked about building mutual respect and a strong work ethic with staff colleagues, which one staff member said helped their team to feel confident in taking any issues to management.

Staff talked about emotional safety in terms of managing anxiety and feelings about their work and discomfort in challenging work situations. Finally, they discussed how the rapport and relationship they had with colleagues contributed to a sense of psychological safety as a professional in the field, and that when this was absent they were at risk of feeling depressed and discouraged.
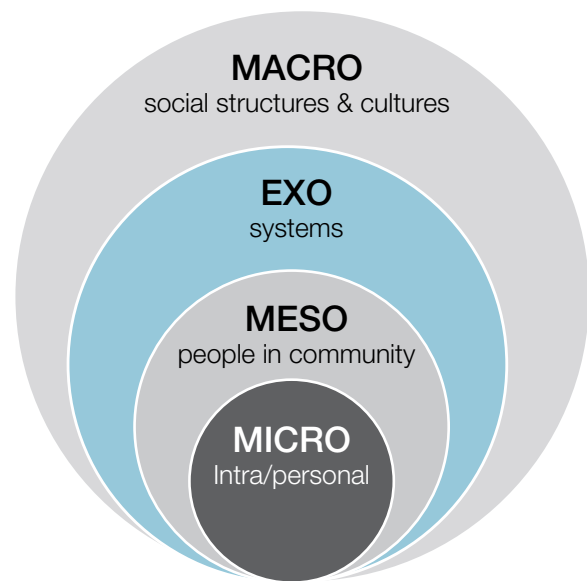
## Implications for action:

- **Working to develop positive and equal relationships where each party to the relationship can influence the other is the core task across the sector.** Relationships are at the heart of developing safe and respectful cultures.

- **Building skill in staff to recognise and respond to the safety strategies that people with disability use when they feel worried or unsafe** builds capacity and agency in people with disability and supports a sense of safety and respect in the services they use.

- **Prioritise action on issues raised with staff and management.** Increasing feedback loops and accessible reporting back on action taken will build confidence in people with disability and families to raise issues of concern and ideas for improvement.

- **Blurring of boundaries can cause confusion and introduce dilemmas.** Articulating and working through roles may help reconcile some of the tacit boundary confusions that lead to tensions around safety and respect.

- **Look for opportunities for people with disability, staff, families, managers and the wider community to train and work together** in ways that build trust and rapport. Using creative approaches (such as art and music) may assist in approaching issues about communication and power in ways that build capacity, including for people who do not use words. It is important to balance these with initiatives that encourage and hold the voices of the people with disability carefully and respectfully.

# The role of organisations and systems in building safe and respectful cultures

This section discusses the systemic contexts, and the important influence of management and operating systems on the experiences of people with disability. These are not the relationships and direct practices that people experience (addressed in the previous section), but the policies, procedures and operational standards which guide their actions.

In this section we also consider the ways that management or governance approaches set the conditions for safe and respectful cultures, and the opportunities and constraints created by resourcing and staffing approaches.

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The key points in this section are:

**Facilitators of safe and respectful cultures**

- Well organised environments

- Policies, procedures and guidelines developed for the service context

- Practical strategies in services that bring policies to life for people with disability

- Trained and supported staff

- Education and opportunities to practice safety-making for people with disability

**Constraints to safe and respectful cultures**

- Impact of resource and time constraints on capacity to support people with disability and staff

- Resource constraints impeding effective responses to problems

- Staff who are under-skilled or ill-equipped to provide preventative support

- Lack of support, supervision, career planning for staff and managers

**Complexities**

- Differing levels of knowledge about policies, procedures and implementation

- Role clarity and boundary setting for staff

- Tension between rights of people with disability and staff

- Difficult balance between compliance, risk and rights discourses
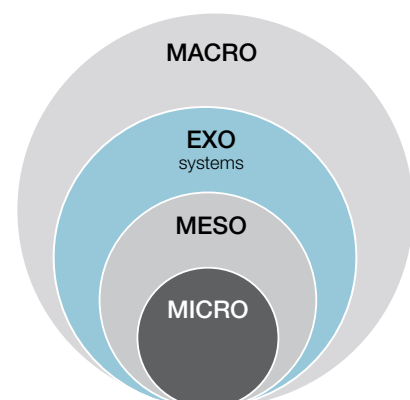
# Facilitators of safe and respectful cultures

## Well-organised environments

Important elements of maintaining a well-organised environment from the perspective of people with disability focused on the feelings created by staff in the services. For example, in observations at one service it was clear that staff worked hard to create an inviting atmosphere with lots of different activities, plenty of spaces for people to move around in, and warm personal greetings as people arrived in the morning. People with disability and families also stressed in interviews that it was important to them that staff ensured that they did not have to spend time in groups with people that they did not get along with, or where there was conflict and discord.

Staff discussed strategies and systems that underpinned their work in providing a person-centred program of activity, daily living tasks and experience that was reliably and respectfully implemented. These included ensuring a range of activities enjoyed by people were on offer, physical environments were well planned and appropriate (for example, the need

for privacy, a safe space was available, and people were not too crowded together), and variety in the program was maximised. Some staff also spoke about the importance of gathering and responding to feedback in improving the environment in which people received services.

Managers emphasised the climate of change in their organisations in the action learning sets. It was commonly recognised that in the past, organisational cultures had not always been safe or respectful. Most managers felt that their organisations were in a transitional space, and were making significant steps in improving accountability, reporting systems and building trust with stakeholders.
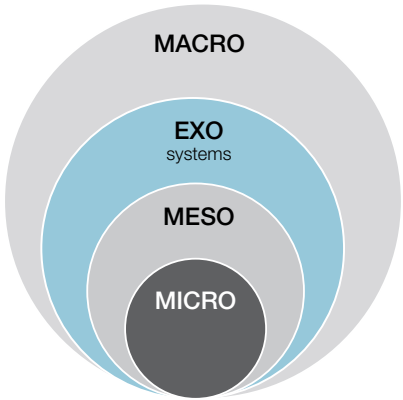
## Policies, procedures and guidelines developed for the service context

Most staff and managers interviewed expressed the view that policies, procedures and guidelines were important in shaping and guiding their work. Those who felt their organisations implemented robust policy and procedures to manage and monitor safety, harm and risk talked in a more engaged way about policy acting as a framework to guide practice, rather than a static set of documents. A number of staff mentioned the NDS Zero Tolerance resources, indicating an awareness of bringing wider influences and guidelines into practice.

Senior managers had a critical mindset about how to make better use of policy. They collectively identified the need to create space to further develop reflective practice at all levels of an organisation to ensure a critical learning model to activate policy and practice.

Family members had varying levels of knowledge about policies and procedures about safety, abuse and related issues. Some felt that policies and rules would be in place, but they did not know what they were. They did not express a need to know, trusting that 'actions speak louder than words' and positive service cultures worked to keep their family members safe, and that they would be able to identify any potential safety concerns of their family member.

Other family members had a much deeper level of knowledge about service policy, either through their roles in service governance or because of previous experiences of harm to their family member. After incidents, family members said they were aware of policies and procedures and felt confident that services followed them and kept them informed about complaints and investigations. One family member was involved in policy development through their role on a management committee. In this role, she was aware of processes for managing risk in employing and screening staff.

Gaps in policies were identified by one member of each of the groups. A person with disability felt that it was important that people using services had more information about rules to build understanding, treat everyone the way you want to be treated and wait your turn to speak – to treat each other with more respect. A family member wanted to see a policy around stranger danger and developing the capability of people with disability if approached by someone they did not know in public places. A A staff member felt that existing policies could be stronger in making sure that people with disability knew that in the event of a problem they have options in having someone they can talk to, a choice of people if needed, and support from management.

## Practical strategies in services that bring policies to life for people with disability

There were organisational strategies to increase the effectiveness of policies and procedures in some of the services. These could be seen in initiatives that were offered to help people with disability manage their own safety proactively as well as responses to concerns in the service. For example, managers in two of the services had an 'open-door' policy for informally raising issues of concern. Both people with disability and family members independently raised this approach as one they felt positive about and had effectively used.

Petria's got sort of like an open-door policy and Bonnie knows if she gets really, really distressed, she can go and speak to Petria, and has done a few times.

(Lisa, family member)
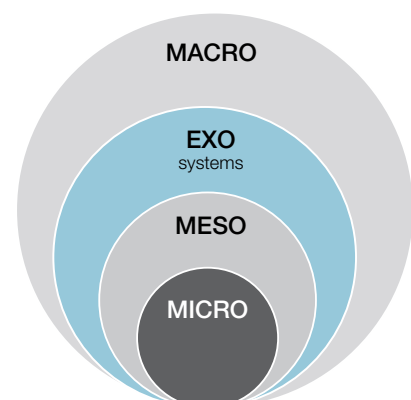
Other strategies developed by the services included the installation of a quiet space for people who needed to rest or be away from noise and activity, and a facilitated friendship circle to respond to increasing tension between peers which was caused by social media outside of the service.

A small number of staff spoke about how they followed core policies and procedures and adapted them to make things work for people and help them feel safe – both applying them to their contexts (such as individual funding and support) and to manage interpersonal conflicts more effectively. Several raised the importance of reinforcement and encouragement.

We do tell them often if they're having a disagreement with someone or if someone's hurt them in anyway, we go through what our policies are, it's OK to speak up, it's OK to point them in the right direction, that they can go and make a complaint, it's OK to complain. Like, we do follow that and we really reinforce that with our guys on a repetitive basis because they tend to forget a lot of the time what their rights are entirely and then we say, you can come and talk to us and then point me in the right direction.

(Angela, staff member)

### Trained and supported staff

Although many staff conveyed concerns in survey responses and workshops about the effectiveness of the supervision available to them, some staff provided detail in interviews of support that they found helpful. Staff who provided collegial support to each other said that this built morale in their teams and improved their work satisfaction.

Stability and consistency in staff teams also helped some staff, both by allowing people to build relationships and by removing the stress associated with change, lack of staffing, and use of casual and short-term staff. This consistency was seen by staff to be helpful to the organisations, as staff built up organisational knowledge and a deeper level of understanding of people using the service, relevant policies and procedures, and the knowledge and networks that underpin facilitation of social inclusion.

Senior staff talked about the importance of regular and available support for staff, particularly those new to the field who need assistance in developing programs,

managing their responses to incidents, and debriefing. It was becoming increasingly difficult to provide this. It is important to note that only a small proportion of staff felt that they received training that they considered effective and adequate: regular, evidence-based, and responsive to issues that they faced in their daily work.

Some families also commented on the importance of systems in keeping people safe, particularly the things that affected the quality of staff. It was important to some families to know that staff had completed training at induction to ensure they were able to uphold professional standards. This included training and experience in confidentiality, behaviour management, boundaries, and ensuring the appropriate Police and Working With Children Checks were conducted at recruitment. However, some families had seemingly little concern about policies and procedures, and placed a high level of trust in their 'gut' feeling about the services based on their personal experiences.
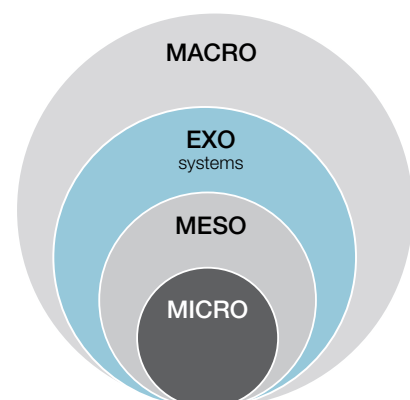
### Education and opportunities to practise safety-making for people with disability

Establishing and maintaining a culture in which people with disability felt confident that their views would be well received was described by some staff in the services as a continuing activity, needing a range of learning strategies and ongoing reinforcement. A small number of staff and managers discussed the need to build the skills and confidence of people with disability so that they would feel more able to act if something affected their sense of safety. In one service, the manager described using different formats to target people with different learning styles and preferences, including materials from White Ribbon Australia, the organisation's code of conduct and a pictorial booklet about abuse. She said:

We need to reinforce that pretty consistently so that people know that we're always there to support them and they're always welcome to come talk to us, and that we're very, very conscious of making sure that people do feel safe and that they feel comfortable talking about it if they don't.

(Rachel, manager)

# Constraints to safe and respectful cultures

## Impact of resource and time constraints on capacity to support people with disability and staff

Staff spoke in interviews about a lack of time for sharing necessary information with their team members. They felt this had worsened since the NDIS implementation, and non-participant time had become more constrained. Staff worried about the potential impact on quality of support for people with disability when information was not shared in a timely way, due to cuts in frequency of regular staff meetings. In one case, the NDIS had led to a change in the model of support. Where people previously had 'key workers', under the new more general support system workers said they felt 'less connected to people' and that they had fewer opportunities for prompt discussion of issues or concerns they may have or to develop in-depth knowledge of people's likes and preferences.

Staff and managers also felt that other resource constraints such as staff shortages, difficulties with staff retention, and movement of staff within organisations affected clear communication channels. These communication gaps, staff shortages and time to get to know people's preferences for support have significant implications for effective safeguarding.

Managers discussed resource constraints, and the effect this has on their organisations. Since the implementation of the NDIS, these constraints have led service provider organisations to reduce training, staffing, transport, human resources and recruitment services, IT and systems support, and policy development. This had a significant impact on their ability to operate their services without pressure on staff and performance.

Managers also spoke about working in time-constrained environments, where neither they nor staff had adequate time for regular supervision. Managers were acutely aware that services were not funded for staff supervision under the NDIS, and although some of the services found ways to continue some supervision of staff, this was difficult. Supervision had become less frequent, irregular (or absent for some shift workers), less focused on reflective practice, and more task focused.

## Resource constraints impeding effective response to problems

Most of the staff noted that it is easy for people to be overlooked in the busyness of disability services. They all identified that their own work pressure was a barrier to responding quickly and thoroughly to problems people with disability brought to them to discuss and resolve, and worried about this. While all staff were supportive of the right of people with disability to make decisions, limits to this were also evident, often because of resource constraints. For example, people had to wait for staff to be available to assist them, and staff said it is very easy for someone to be missed in a busy service. Some staff mentioned strategies for mitigating the risk of forgetting to come back to people, such as writing notes to themselves. Others felt that it helped to ensure that everyone had more than one 'go-to' staff member, and that managers have an 'open-door' policy.

At an organisational level, there were several examples of responses to complaints that did not resolve the underlying problem. This included working to help people resolve their fear and hurt feelings, but not separating people permanently when they really do not get on; or not changing the time that people have to be assisted to bed when they are unhappy about the hour. These indicate the lack of control that staff and managers had over the resources available for use in the programs, as well as the lack of power of people with disability and families to make meaningful change to their circumstances by raising issues of concern. There were also instances where financial resources were not required to address underlying problems, but still resolution remained out of reach, including meaningful apologies for harm incurred and responding in a timely way to requests and complaints.

I guess that's what we're concerned about. The night-time stuff. If Vance's had a busy day, OK, he's tired but we don't want it to happen that, OK, it comes after tea and there's nothing else so is it boredom? ... Yeah, I think that happens because there's nothing else and even at that stage through the night, well of course, with the hoisting, yeah, we're grateful for [the service] but we sort of think, well, what else is there?

(Olive, family member)

## Staff who are under-skilled or ill-equipped to provide preventive support

A small number of staff directly expressed the view that they did not have the skills they felt they needed to fulfil their roles effectively. These were higher-order skills in positive behaviour support, planning and supporting people with relationships. More common were gaps in staff skills in these areas not named by staff but observed by the research team, which resulted in people with disability being under-supported in the prevention of behavioural incidents, of relationship conflict, and of boredom and frustration.

Two things are important to note. The first is that we do not seek to lay responsibility for prevention of these complex features with individual staff members. For example, some support workers in the research were actively seeking new ways of working but lacked access to available training. The second is the limitations of the pilot study, and our acknowledgement that there may be elements of the support we were not privy to.

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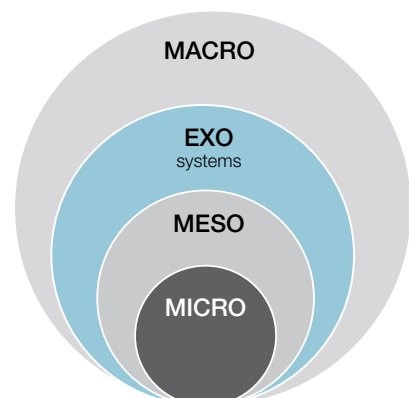
## Lack of support, supervision, career planning for staff and managers

Staff reported varying levels of satisfaction with their employment conditions. In the survey responses overall, staff did not report a strong commitment to their organisations, nor perceive that their organisations were strongly committed to them. Connected to this, staff also expected that their job would change in the future. This lack of security in their roles was undermining of confidence and capacity to make the most of their current opportunities.

Staff indicated in interviews and survey responses that they felt current approaches to supervision were of limited value. Staff working shift work and short-term and new staff appeared to receive less structured supervision than long-term employees. Some staff talked about changes to the model of supervision in their organisation, away from a reflective practice approach towards one that was more task-focused with fewer regular meetings with their supervisor. It was notable that almost half of the respondents to the staff stress survey had experienced significant life events that they felt impacted their work life in the six months prior to completing the survey. They were concerned that important issues were not discussed, and that their professional development was under-considered in these approaches.

Staff indicated in interviews and the staff stress survey that they would value more information and involvement in decision-making about key developments in their organisations. Some staff said they were unsure of what their managers expected of them in their roles, which made it difficult for them to feel they fulfilled the requirements of their positions. Some staff indicated a desire for more structured supervision:

where you can develop and [that] matches opportunities for training and development to your gaps.

(survey respondent)

Managers also recognised limitations in supervision. While some of the services recognised the importance of reflective practice, they also reported challenges in providing staff with appropriate mentoring and supervision with limited resources. Some managers also indicated that lack of career planning and progression opportunities was a barrier to keeping staff in long-term employment. They felt that staff often see the support worker role as a stepping stone to something else, rather than a career in itself.

The impact of these views in staff and managers was striking. Both staff and managers expressed views that they did not feel able to initiate change and lacked agency in their roles.



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# Complexities

## Differing levels of knowledge about policy, procedures and implementation

People had very different levels of understanding about policies and procedures for making services safe and respectful, and widely ranging ways of thinking about whether policies were rules or suggestions about how services should work. Staff spoke about familiarising themselves with written policies and procedures on starting their jobs. Some felt it would be valuable to brush up on their knowledge, especially after dealing with issues of safety.

Many policies are not written in the house. So it makes it difficult. Even to be sure if it exists or not. Another situation of that is, it means such rules are not rigid. And rules about safety need to be rigid. So if I need any more information, I can only ask colleagues who are working in the house longer than I've worked. And if I am telling you this, as a permanent worker, you can imagine how most casuals would be in such circumstances.

(Dennis, staff member)

Some staff approached policy as an operational guidebook, seeking to follow a set of rules. For example, one person nominated equipment maintenance as a gap in policy in their service, feeling under-equipped to know how to respond in a systematic way to equipment maintenance as a safety issue. Others looked for more general principles-driven guidance to direct their practice, naming policies such as positive behaviour support and support for decision making as examples. This is an important issue, pointing to the need for increasing knowledge and understanding for staff about policy purpose and the different ways that it can be implemented.

Some staff felt that people with disability using the services were not necessarily aware of policies and procedures, but they were of the view that they had a growing awareness of their rights, and when their rights were and were not being met. They felt this was important because policies and procedures were written from a rights perspective, and so an understanding of rights would help people with disability to know whether staff actions (in keeping with policy and procedures) were fair or not.

People with disability interviewed had a very limited knowledge of policies and procedures guiding the services they used. Their knowledge was mainly focused on the rules shaping interpersonal relationships between service users – no swearing, wait your turn before speaking, treat other people the way you would like to be treated. For example, Cassandra talked about rights, but as her comments show, there were critical gaps between knowing about rights and having them upheld:

Do you think there are rules about keeping people safe?

**Nup, not really.**
**Oh, when people hit you.**

So no one's allowed to hit you?

**No, they're not supposed to.**

Does that ever happen?

**Sometimes they do, I think.**

(Cassandra, person with disability)

## Role clarity and boundary setting for staff

Staff discussed a wide range of professional approaches, different understandings of professional/personal boundaries and levels of clarity about their roles. Staff managed boundary issues in different ways. Some set limits on the advice they would give, and others spoke about having predetermined levels at which they would seek advice from senior staff (for example, they would give advice but refer on to a manager if someone wanted to make a complaint). Others spoke about being clear about the amounts of personal information they shared (such as connections outside of work). While at an individual level, these variations were often managed in ways that staff felt confident and comfortable about, at a service level, wide variation in understandings of roles can be both confusing for people with disability and inconsistent with policy.
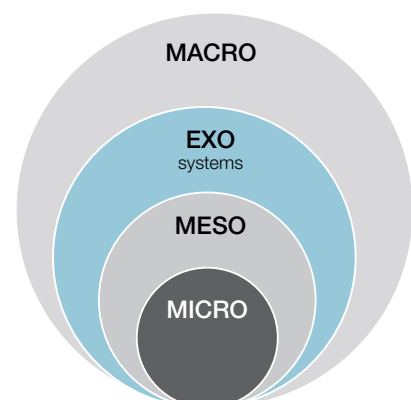
## Tension between rights of people with disability and the rights of staff

Several interviewees commented on a 'clash' between the rights of people with disability and the rights of staff that is rarely discussed in disability services, providing examples illustrating how the two sets of rights were not working in alliance. This highlights the complexity of relationships and the difficulty for everyone involved to continue without support when safety or respectful cultures are breached in significant ways.

From the perspective of people with disability, this appeared as a silencing of people's perspectives about the entrenched difficulties they had in dealing with interpersonal conflict, loss, grief and sadness, and low expectations.

Some staff spoke about times when they supported people with disability at a cost to themselves, either personally or professionally, including physical assault and supporting people to make external complaints that named the staff member.

For example, a staff member described a recent traumatic experience with a person they supported, naming it assault. While quick to acknowledge the rights of the person and the complexity of their support needs, they also reflected on the complex and intersecting needs for safety that were raised, but not resolved, by this incident. It highlighted for them how little safety there was for staff in crisis situations – no duress buttons, no security, no backup, and it was not

considered appropriate to involve police due to the nature of the support needs of the person. The incident was also very frightening for other people with disability and staff who witnessed it, and there could be further significant consequences for the person involved and their family. Exclusion of the person from the service or the people who may have been affected, either directly or indirectly, was likely to have negative consequences for them and their family. This staff member also described intense time pressures and inadequate recording mechanisms to document escalation over time, complex behaviour and patterns of incidents and assault that are common to other services, and make it very hard to develop a picture of what is happening and a proactive response to keep the person and others safe.

Suggestions were made about how people might be made safer. At an organisational level, this included increasing the ways that people with disability can contribute to choice and decision making about directions for their own lives and the service (through direct communication with management, confidential surveys or interviews). Further, 'open-door' approaches to hearing complaints and feedback should include a process for logging information and feeding back actions taken to those who raise issues.

## Difficult balance between compliance, risk and rights discourses

In environments where support was provided in groups, processes of continual balancing were in play between the rights, needs and preferences of people with disability, professional roles and needs of staff and the requirements of the services. A series of tensions were evident between the compliance requirements of the services, risk discourses, and the impact on the rights of people with disability.

To manage compliance requirements, some managers and staff focused closely on systems, discussing how they protected the safety of people with disability by being diligent with employee checks when recruiting, ensuring visitors signed the visitor's book, and ensuring that the physical environment in which services were provided were safe, such as addressing trip hazards and minimising physical risks.

They were also concerned about systems and structures that made it hard to minimise risks, such as times when they had to rely too heavily on casual staff due to illness or absence of regular staff, or low resources that meant groups could not split up if they needed to. This resulted in less choice and control for people with disability, for example not being able to choose the gender of staff who provided personal care or being able to leave a group activity if one participant is having behaviour problems that made people feel unsafe.

We have both male and female customers in the house and sometimes when we have casual staff who they are not familiar with, they may request not to be showered by the opposite gender. Especially from the females, if we had a male casual, she says, "Oh I don't want to be showered by that person" … she wasn't too comfortable with me giving her a shower and assisting her dressing and all of that.

(Andrew, staff member)

Some staff were concerned that people with disability had inadequate time to participate in existing strategies to support people to exercise their rights, and that they were not well suited to all people. For example, strategies such as client advocacy meetings did not suit those people who have delays in processing, who lack confidence to speak in a group setting, who are easily led to agree, or who cannot remember an issue for several days or weeks. In one service, an independent advocacy organisation came in to conduct education with people with disability on a regular basis.

Even those with verbal skills may not be able to express to you, "I'm feeling sad, I'm feeling annoyed, I'm feeling happy." but you can tell by what they are doing and how they are interacting with stuff too. They need that additional support to get their message across. But if they had more opportunity to do that, and actually did it with the whole lot of the participants at the centre, I think that would be advantageous as well.

(Jane, staff member interviewee, music workshops)

## Implications for action

- **Consult with people involved in any change before it takes place** and consider the potential impact of change on the lives and relationships of people with disability, staff and families.

- **Increase the use of accessible information and ensure it is systematised,** so that all key information about safety and respect in services is available to people in alternative formats.

- **Make time available within rosters and staffing allocations to build and maintain relationships.** For example by

  > establishing and including a range of relationship-based activities for people with disability to choose
  > minimising disruption to staff allocations
  > ensuring adequate time for sharing necessary information
  > responding to requests for preferred worker–client pairings.

- **Provide staff with supervision that builds a supportive and accountable relationship.** As part of this, support staff to reflect on the place of relationships and relationship-based practice, taking a prevention approach to support, and where and how they can prioritise this in their daily practice.

- **Offer staff training that is regular, evidence based and responds to issues they face in their daily work.**

- **Review complaints processes:**

  > Ensure that internal and external complaints systems are or can be used by people with disabilities themselves.
  > Consider ways of differentiating between levels of concern in reports of incidents and complaints to recognise patterns over time.

- **Review the extent to which organisational administrative and domestic demands keep staff away from the core task of interacting with people with disability.**

- **Build on the positive practice at the senior manager level across organisations to establish and sustain a collaborative interagency community of practice focused on safe and respectful cultures.**

- **Work collaboratively across organisations to make inroads into 'wicked' problems such as:**

    > raising expectations for people with disability – improving measures of safety, respect, and what constitutes a 'good' life

    > addressing client-caused injuries to staff, as well as working conditions and occupational health, safety and respect, and wider employer responsibilities

    > developing indicators for leadership in planning and support that focus on prevention of isolation and minimising risk of harm, and maximising opportunities for choice and control.

## The effect of wider social and cultural factors on the services used by people with disability

Wider social and cultural factors were not directly in the remit of the research, and as such, do not feature as strongly in the results. Nonetheless, the wider factors such as rights, participation, inclusion and exclusion were influential on the experiences of people within the services. There are many complexities at the structural level, but they are outside the remit of this research, and so not addressed in this report (for example, the impacts of poverty, exclusion, social isolation, discrimination, community attitudes and so on).

The key points in this section are:

### Facilitators of safe and respectful cultures

- Increasing knowledge of human rights

- Pride in role, strong values base

### Constraints to safe and respectful cultures

- Activation of rights

- Risk of support relationships fracturing

- NDIS dominating practice and structure

# Facilitators of safe and respectful cultures

### Increasing knowledge of human rights

Throughout the research, people demonstrated a basic knowledge of the fundamental human rights of people with disability. Some people with disability were able to articulate their rights to safety and to make choices and decisions. Families, staff and managers were in many cases aware of the basic rights of people with disability to safety, respect, choice and decision making. Policies and codes of conduct in many cases were grounded in human rights frameworks.

### Pride in role, strong values base

Overall, a picture emerged in this study of a workforce that took pride in the work they were doing, and which was underpinned by a shared view that their roles were valuable and valued. Notwithstanding the desire for improvements to supervision and to contribute more to decision-making in the organisation, staff talked at length in interviews about motivations for their work that were embedded in a values base in which they sought to contribute to improving the quality of life of people with disability. For some staff, this was articulated through a rights framework, and for others it was expressed more through a care lens. Managers spoke about recruitment and retention of staff being informed by the values base of their organisations.
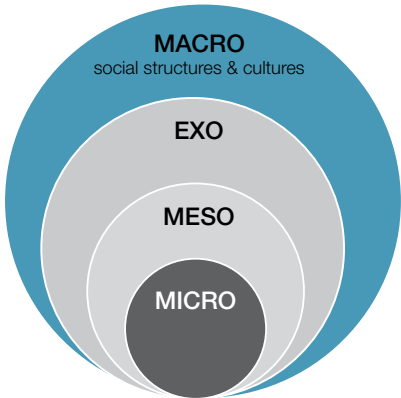
# Constraints to safe and respectful cultures

## Activation of rights

While people discussed an awareness of the existence of rights, there is still a considerable distance to go before all people are fully enacting their rights to choice and decision making, freedom from violence and abuse, and community inclusion. While some people were well-satisfied with their services and levels of participation, results in this study showed that collective expectations for people with disability remained lower than for other community members. In particular around important indicators such as the experience of violence and interpersonal conflict, choice of residence and choice to spend time with other people. Few people in this study had independent advocacy, an important link to rights access.

## Risk of support relationships fracturing

This study took place in the early implementation phase of the NDIS. The NDIS had a very strong external influence on the ways in which services were being reframed, and significant operational, social and relational impacts.

With the NDIS, new models of support replace previous block or group-based arrangements with individualised funding and support. While for many people this was viewed as positive and progressive, concerns were also expressed about the potential for individualisation to lead to a fragmenting of support if not carefully coordinated. The need for consistent, reliable support over time was a consistent theme in all levels of the study. Managers stressed the risk to these relationships in funding and support models that may act to fracture relationships by focusing unduly on transactional costs of support. They emphasised the need for concerted attention to safeguarding in new and continuing support models, highlighting risks in an increasingly casualised and 'gig' support economy.

## NDIS dominating practice and structure

Changes to people's circumstances between the phases of the research were primarily driven by NDIS policy requirements. Little change was directed or influenced by the preferences or goals of people with disability or their families, or by staff or managers. While the NDIS is structured according to principles of choice and control, in its implementation in these services, there was little evidence of people with disability exercising new levels of control over their lives.

Managers described the NDIS as a dominating discourse, causing substantial operational disruption as well as personal and interpersonal stress. It was seen to affect relationships at both operational and individual levels. For services, managers felt that the NDIS affected the capacity to be known as a disability service provider as the sector shifted to new models and the market changed. For people with disability, they felt there was a risk in being less well-known within the service as people used it less, and patterns of staffing became less stable. The influence of the NDIS on the sector more widely was discussed by managers, in terms of its effects on stability and strong external influence on change to the structure of the disability service sector.

There was a shared view that smaller providers are rapidly becoming financially unviable and need to merge with large service providers. This change to the climate of the sector was seen to have important implications for cultures of safety and respect, making it more difficult for people to maintain personal relationships in large organisations.

## Implications for action

- **Relationships need to be prioritised in planning and funding mechanisms** to maximise possibilities for new and more progressive approaches to community inclusion for people with disability.

- **More streamlined and less confusing NDIS planning and funding** is needed to help people make more innovative choices.

- **The NDIS needs a policy and funding framework for prevention work.** Many prevention activities are broad scale and work at the societal level. They are currently not funded.

- **Access to independent advocacy for people with disability and families is needed,** especially people who do not have family or other natural supports who are engaged with their care.
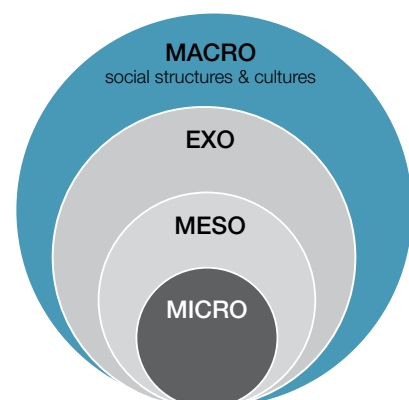
# Effectiveness of the project and implications for future research

Part of the learning from the project was about the effectiveness of the research approach and implications for future research and action. While there were multiple limitations to the pilot, the processes and data collection have led to rich results.

## Effectiveness of the project

Input from the PAG influenced the framing and conduct of the project. Recruitment to the project was challenging. The main reasons mitigating against involvement for organisations appeared to be busyness and the level of sensitivity of the topic.

The involvement of community researchers brought great value to the data collection and analysis processes. Their involvement promoted authentic connections with participants, and they were particularly tuned in to rehearsed responses and favourable presentations. Their contributions to knowledge exchange have been important in sharing results in accessible ways.

Ethical requirements for participants were addressed at the outset of the project, but the effects on researchers of hearing stories of trauma meant that the team needed to ensure additional support was provided through process and analysis phases.

Learning as a community/community of practice as part of the indicator workshop was a novel experience for all the services, and one many people liked. People particularly enjoyed the opportunity to learn from the perspectives of other participants and the spirit of collaboration. Using the indicators was helpful for participants, providing a practical framework that they could apply in their own contexts.

Music therapy promoted communication. Some staff members observed how the workshops allowed each person to be given a voice, including people who do not use words. Staff members and people with disability noted how this was achieved by not being rushed and the non-verbal nature of shared playing and listening to music. There was one example where a previously unknown song preference of a participant was established in the workshops and was later shared between that person and their support worker to defuse a situation

where they were becoming distressed. Some people were able to enjoy songs that were personal to them and enabled them to express individuality and the workshops were overwhelmingly seen as fun and positive. Challenges remain in encouraging stronger participation of families and staff.

The method of repeat interviewing proved worthwhile, as several people spoke in more detail about change and about more complex safety situations in their second interviews. Pairing the community of practice approach with social ecological approaches was effective for analysis. Asking people about their experiences separately and working together to identify issues and build capacity was a useful approach to identifying and addressing sensitive issues.

The collection of quantitative data proved challenging. The reasons for this were not systematically analysed. It is possible that the extent of demand for paper-based responses in the sector may have been a factor, along with the number and range of options presented to the services.

## Implications for action:
## for future research

- The results emerging from the analysis reflect value in combining mixed methods research with a community of practice capacity-building approach. The pilot results suggest that a more extensive research project which extends and deepens this approach has merit.

- Music workshops and music therapy brought a valuable participatory method to the project that supported the participation of people who would otherwise have been excluded from the research. Future research could focus on evaluating the impact of arts workshops using different approaches to include the voices and perspectives of people who communicate without words.

- A co-production approach that included community researchers in design, fieldwork, analysis and knowledge exchange phases added significant value to the research. Future research could build on this learning by ensuring adequate time and resources for fieldwork preparation and accessible report preparation.

# Discussion and conclusion

**This section highlights the complex nature of these issues and of the roles played by every person in these services. In emphasising action, we aim to promote collaborative activity directed towards positive change.**

This is particularly important in four key areas that emerged from the results, and which cut across the domains. These are:

- the feelings expressed by people at all levels of the research that it was very difficult for them to make change

- the need to bring multiple sets of rights into view, and into intersection, to promote safety and wellbeing in disability services

- the increasing pressures on resources and efficiency in service delivery and ways this increased risks to safe and respectful cultures

- the practice approaches that stand out as strategies to actively build safe and respectful cultures.

# Difficult to make change

At all levels, many people felt that they had little personal capacity to change their circumstances or to make change to improve the lives of people with disability. People with disability felt personally disempowered and unable to influence change. Families were often hesitant about 'rocking the boat' and reluctant to raise issues unless the need became urgent. Staff felt unable to influence change outside of minor issues. Managers focused on the external factors that make it difficult for organisations at every level, such as resource constraints and compliance requirements.

Most people involved in this research were in a state of vigilance. Almost everyone was stressed and conveyed a sense that other people do not understand what it is like to be in their situation. People with disability expressed fear and worry about their safety from the behaviour of other people using the service and from interpersonal conflict, and worried about the lack of control that they had over their own physical safety. Some families felt that the long-term relationship and level of knowledge that they have about their family member was under-acknowledged and under-respected, and that they were at times viewed as over-protective. Staff were in a state of constant busyness and stress, and many felt that managers did not understand the realities of their daily work. Managers were stressed about the impacts of the NDIS and external factors on the viability of services, and their safeguarding responsibilities.

The community of practice approach used in the indicators workshops was highly valued by people who participated. Feedback indicated that the activities drew out a sense of equality and community and helped participants from all the groups to hear perspectives from others more clearly. Learning about and using the early indicators of concern was a way to practically identify and act on concerns. Training and community-building activities that include participants from all groups across the community of disability service providers (people with disability, families, staff and managers) may help in addressing the feelings of misunderstanding expressed in the study.

# Bringing multiple sets of rights into view

The need to raise expectations for people with disability is particularly evident regarding choice, decision making, safety and relationships.

The choices offered to people are constrained by lack of agency, but also by lack of vision about potential alternatives – for example, if people were not feeling safe in their activity in two of the services, they could choose to be in another room, and sometimes even in another activity or group for the day. However, it did not appear that people were provided with support to think about choices and decisions that might take them outside of the traditional disability services system. For the NDIS to be transformative for people with disability, meaningful choices, time, advocacy and support for decision-making needs to be available to allow people to make decisions about significant matters in their lives, including where and how they spend their time.

Prioritising relationships for people with disability involves support for building and sustaining friendships between people with disability; articulating and navigating working relationships between people using services and people providing them; and providing clear frameworks for relationship-driven support within services.

Similarly, for people to feel and be safe in the services they use, their priorities and perspectives need to carry weight. In no other community is it considered acceptable to continue to spend time with people you fear or from whom you have experienced violence, abuse and neglect.

Most of the time, people with disability and workers described relationships based on mutual regard and trust. However, at important times, the rights of one or both groups to safety, decision making, participation and privacy were tested. These have been discussed at length in this report.

In a few difficult cases, the rights of both groups were tested at the same time. These times were about the right to be safe, the right to be supported, and the right to be treated with respect. These examples highlighted the difficulties that disability service providers have in responding to the intersecting rights of people with disability in complex situations where instigators of violence, victims, and witnesses hold different positions and responsibilities in the organisation.

# Fewer resources and pressure to deliver efficient services make it harder to create safe and respectful cultures

All the services taking part in the study described a context in which they were under pressure to reduce resources and increase efficiency in service delivery. While some of the changes were welcome improvements (such as increased opportunities for individual support), time and resource constraints imposed changes to previous ways of working that staff and managers felt affected safe and respectful cultures.

Decreased time to share necessary information between colleagues, no longer having a key worker model, and increasing the use of casual and agency staff all contributed to concerns about constraints to safe and respectful cultures.

Staff described applying policy to their work environments in ways that required them to apply rights unevenly – for example, having to make decisions about how to negotiate competing demands for support or manage interpersonal violence in group settings. This included decisions about their own workplace rights. This meant they were often making the best of a difficult situation in the context of resource constraints.

Demands on the resources of services in the current NDIS climate affected the willingness of providers to participate in the project in the first place, as well as staff stress and availability, and the willingness of managers to engage in supervision. At a personal level, it affected the feelings of people with disability about how ready staff and managers were to listen, and the ability of families to find people they can talk to and have the confidence to bring up issues.

Intersections between different levels of policy may exacerbate this problem. For example, costing and funding constraints that mean that in group settings, inadequate choice or support for people may lead to boredom, frustration and interpersonal tensions – and breaches of

the right to safety of people with disability and staff. It is not possible for people with disability, individual workers, families, and managers to resolve this at the origin of the problem, and they are all trying to alleviate the pressures as best they can.

These increasing pressures point to potential risks of losing sight of the benefits of individualisation policy goals in the administrative thicket of implementation.

These themes point to a particular tension between the ways that relationships are enacted, and the ways that resources are increasingly being prioritised. As the NDIS matures, and particularly as the NDIS Quality and Safeguards Commission Regulatory Framework is implemented across Australian states and territories, the reconciling of these tensions will require concerted attention. The willingness of people involved in this research to work together as communities of practice within and across their organisations sends a positive signal of the sector's openness to working towards this.

# Practice approaches to actively build safe and respectful cultures

Participants in this study were strongly in favour of relationship-focused support. Across all groups, they wanted more relationally focused support and stronger attention to building positive practice and raising expectations.

Three practice approaches stand out as strategies to actively build safe and respectful cultures.

## 1. Relationship-based practice

Mutually rewarding relationships were fundamentally important to building safe and respectful cultures in this study. They were foundational for a sense of safety and respect for people with disability and supported both their identity development (for example, as a person of worth and value) and growth in confidence to speak up about issues concerning their service provision. For staff, strong working relationships with people with disability reinforced respect for the people they supported and pride in their role. For families, rapport in relationships with staff and managers and indications that their input was valued mattered in building confidence to raise issues when needed and to build trust. Relationships between staff, and between staff and managers, supported reflective practice and built team morale.

Where relationships were not reciprocal, or were lacking in depth and opportunity to engage, or were institutionally impeded, the impacts were evident. People with disability had far fewer opportunities to speak up and much less confidence to talk about issues worrying them. Families were reluctant to raise issues unless they were critical problems. Staff felt less satisfied in their work and less informed about the organisational direction and how they could contribute.

## 2. Embedding a prevention approach into support

Some staff described the ways that they worked in the short-term to prevent problems from escalating into bigger concerns about safety and wellbeing. They actively looked for early warning signs that people were feeling out of sorts or uncomfortable, or for subtle signs that things 'just weren't right' and attempted to remedy the causes. While focused on individuals, they also shared information in appropriate and timely ways to the person's benefit.

In the longer term, approaches to prevention included using planning to minimise the likelihood of harm occurring (for example, by increasing one-to-one support, or managing the movement of people within the centre differently to avoid congestion) and maximising control, choice and safety for people with disability.

At its most effective, a prevention approach to support work brings these long-term and shorter-term approaches together to work with the person to build a safer life where their safety is assured, their control is maximised, and the focus can turn to growing their good life. A key tension in the NDIS lies in the fact that prevention work is not costed or funded.

## 3. Reflective practice and supervision

Supporting staff in their work emerged as a critical issue in this research. It is important to view this in alignment with initiatives to promote and implement the rights of people with disability.

Recent moves away from reflective practice may have affected staff satisfaction and capacity to complete important elements of their job, including reflecting on difficult conversations and interactions and progressing towards professional development goals. For staff to work effectively as partners in relationship-focused support and in prevention approaches, they need opportunities for mentoring and reflective practice to be guided in sometimes difficult ethical and practice territory by more experienced managers.

# Conclusion

This project highlighted the complex cultures of three disability services, and analysed some of the features of those cultures that facilitated feelings of mutual respect and safety, and the converse. As a pilot project it was modest in scope, aiming to better understand culture, identify potentially useful and practical strategies, and establish the potential for wider research in this area. The timing of the study is particularly resonant, and we hope that it contributes in some small way to the dialogue about the importance of culture in preventing violence, abuse and neglect of people with disability.

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# Appendix 1: Social-ecological approach

Social-ecological approaches consider individuals as active agents who both shape and are shaped by their environments (Lounsbury & Mitchell, 2009). Originating with Bronfenbrenner's social-ecological model of child development (Bronfenbrenner, 1986; Bronfenbrenner & Evans, 2000), more recent social ecological approaches also draw from constructs applied in disability abuse research (Sobsey, 1994; Hollomotz, 2009; Robinson, 2010, 2012; and Fitzsimons, 2009). These approaches all share a focus on the person at the centre of their wider socio-ecological context, made up of a number of interacting domains or spheres of influence (Robinson et al., 2018).

The four interacting domains of the social-ecological framework are used in this research:

**Micro: (intra/personal)** – interactions between personal and intrapersonal factors and influences in the person's immediate context such as their family, service, friends and other domains where the person spends time engaging in activities and interactions (for example, the way people with disability feel about their safety in their disability support service, home, peer group).

**Meso: (people in community)** – the interrelationships among the multiple microsystems in which people spend their time (for example, interactions and relationships with family, friends and others in community, including interactions in places of work, services, and other public and private spaces and places). Because people spend time in more than one microsystem, it is important to understand the relationships among and between these systems.

**Exo: (systems)** – systemic contexts that have important influences on the person's lived experience – policies, protocols, techniques, social institutions, accepted standards and practices relating to safety or abuse (for example, medical services; policies relating to working with people with disabilities).

**Macro: (structures and cultures)** – encompasses remaining systems, structural and societal factors, such as poverty and homelessness, and broader cultural concepts like inclusion and exclusion, rights, participation, and discrimination.
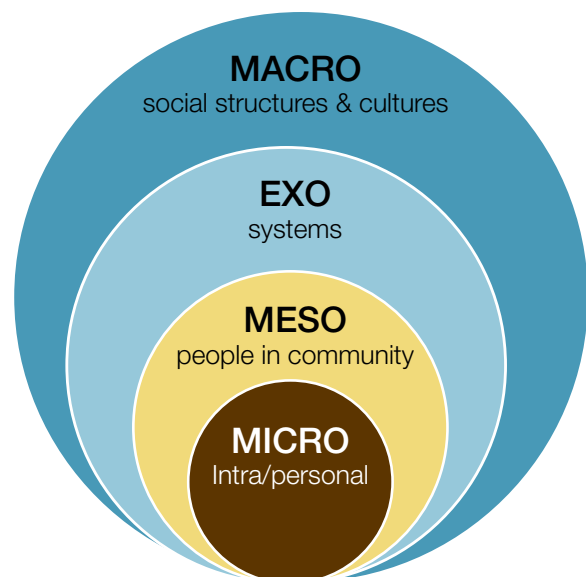


**Figure 4: Social ecological model**

# Appendix 2: Early indicators of concern

## Introduction

This guide has been developed following detailed research into known cases where abuse took place in residential support services for people with learning disabilities. Analysis of these cases produced a series of indicators of concern and found that these indicators fell into six distinct areas. Abuse or neglect was found to be associated with situations where practitioners had identified a number of indicators of concern, spread over a range of these six areas. The findings from this project suggest that we should be most concerned when such a spread or range of indicators is identified.

This guide presents the six areas of concern and gives some of the commonly occurring examples reported by practitioners during the research. There is then a further sheet that can be used to collect information and reflect on the risks that might be present in a service. You can access detailed accounts of the areas of concern and the research using the following web link: http://www2.hull.ac.uk/fass/care/safeguardingadults.aspx

The guide can be used in one of three ways. An individual can use the sheets to record and structure concerns. A group of people, including families and professionals can use the sheets to collect concerns about a service from different sources. A team from a service can use the sheets to review and reflect on their own service. We suggest a simple but essential process:

Record

Reflect

Talk to Someone

Act

**Important notes:**

1. A pattern of concerns is not proof of abuse and abuse can happen when concerns are not apparent. This is a guide to help people to record, reflect, talk to someone and Act. It is based on evidence and experience from examples where abuse did occur and these indicators were present but not acted upon.

2. The original research focused on residential services, however this pilot found it applicable across a range of service settings.

3. The use of this guide does not replace listening directly to people in services. On the contrary, it gives an important reason to listen more closely before and after concerns are raised.

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# Early indicators of concern

## Concerns about management and leadership

- The manager can't or won't make decisions or take responsibility for the service

- The manager doesn't ensure that staff are doing their job properly

- The manager is often not available

- There is a high turnover of staff or staff shortages

- The manager does not inform social services that they are unable to meet the needs of specific service users

## Concerns about the way services are planned and delivered

- Residents' needs are not being met as agreed and identified in care plans

- Agreed staffing levels are not being provided

- Staff do not carry out actions recommended by external professionals

- The service is unsuitable for some residents but no better option is available

- The resident group appears to be incompatible

- The diversity of support needs of the group is very great

**Concerns about staff skills, knowledge and practice**

- Staff appear to lack knowledge / understanding of what it means to have a learning disability
- Members of staff appear to lack skills in communicating with individuals and interpreting their interactions
- Members of staff use judgemental language about the people they support
- Members of staff are controlling and offer few choices
- Communication across the staff team is poor
- Abusive behaviours between residents are not acknowledged or addressed

**Concerns about residents' behaviours and wellbeing**

- Residents' behaviours change – perhaps becoming withdrawn or anxious
- Residents' communications and interactions change – increasing or stopping for example
- Residents' needs appear to change
- Residents' skills change – self care or continence management for example
- Residents behave very differently with different staff or in different environments e.g. day centre

**Concerns about the service resisting the involvement of external people and isolating individuals**

- There is little input from outsiders/ professionals
- Individuals have little contact with family or other people who are not staff
- Appointments are repeatedly cancelled
- Members of staff do not maintain links between individuals and people outside of the service e.g. family, friends.
- Management and/or staff demonstrate hostile or negative attitudes to visitors, questions and criticisms
- It is difficult to meet residents privately

**Concerns about the quality of basic care and the environment**

- There is a lack of care of personal possessions
- Support for residents to maintain personal hygiene is poor
- Essential records are not kept effectively
- The environment is dirty/smelly
- There are few activities or things to do
- Residents' dignity is not being promoted and supported

# Appendix 3: Results of the occupational stress survey

Full sets of data were received from all three organisations although two of the organisations returned a greater number of questionnaires than the third. This was not a difficulty as this report deals with overall figures across the whole project. Surveys were returned by a total of 35 staff. The results averaged across all three organisations were as follows. The headings reflect the key survey domains in the ASSET model.

| Perceptions of your job | Score (1–6)<br><br>1 = Strong positive perception<br><br>6 = Strong negative perception |
|---|---|
| Work relationships | 2.03 |
| Overload | 2.675 |
| Work-Life Balance | 2.08 |
| Job Security | 2.72 |
| Control | 2.76 |
| Resources and Communication | 2.76 |
| Pay and benefits | 2.83 |
| Table 5: Combined scores for how staff perceive the job they do | |

Any score between 1 and 3 is broadly positive and it is immediately clear that these results are largely neutral. People working across all three organisations are reporting a general level of satisfaction with their employment.

Those who completed the survey were generally positive about their relationships with colleagues, team work and the ability to maintain a good work life balance.

There is a trend towards negative views of pay and benefits, the extent to which they are involved in decision making and to which they were informed about what is happening in the organisation. The pattern is seen across the individual items although there are two particularly striking items: first, staff were not sure what their managers expect of them. The second item related to job security. Individuals were not concerned about losing a job, but they strongly expected their job to change in the future.

| Attitudes to your organisation | Score (1–6)<br><br>1 = Strong positive perception<br><br>6 = Strong negative perception |
|---|---|
| **Perceived commitment of organisation to employee** | 4.37 |
| **Commitment of employee to organisation** | 4.58 |
| Table 6: Combined scores for staff attitudes to the organisation | |

Staff did not have strong commitment to their organisation, nor perceive that their organisations were strongly committed to them.

Staff were also asked about their health and wellbeing.

| Health and wellbeing | Score (1–6)<br>1 = Strong positive perception<br>6 = Strong negative perception |
|---|---|
| Total physical health | 2.265 |
| Total psychological health | 1.93 |
| Table 7: The effects of stress: combined scores for health and wellbeing | |

Overall, staff reported that they suffer the ill-effects of stress either sometimes or rarely. This was borne out by individual questions and by other questions relating to the days off sick, visits to the doctor and experiencing significant life events. Here the only striking

finding was that 16 of the 35 participants had experienced significant life events in the six months prior to completing the survey. The Health and Well-Being data accurately reflect the broadly neutral scores for the perceptions of the job and demonstrates that the ASSET model of stress in the workplace is suitable for use in this sector.

The comments section attracted responses from just six people. Two comments reflected the results, one suggesting greater clarity about what is expected, right from the point of recruitment; and the other raising the issue of communication. Two written comments in the survey drew attention to the reality of working life in some settings, referring to physical assaults whilst the remaining two noted the pressure to cover times when staff are needed and a general sense of not being valued. It seems important to note these in as far as they represent the experience of people and add validity to some of the wider findings.

# Appendix 4: Results of direct observation of practice

Direct observation of practice follows a tradition of studying interaction in services for people with disabilities which records interactions between staff and people receiving services. The interactions are then coded according to whether they are either positive or negative and also the extent to which they are controlling of the person with a disability. It is also important to know just how much human interaction is available to people receiving services.

In this project all three services participated in planned observations of practice at the beginning of the project and then again at the end of the research period using the Quest Observational Profile. These were for a period of one hour and researchers observed each member of staff who was on duty during the observation period. Any interaction was recorded and coded according to

the following categories:

- helpful speaking – offering information or explanation to support choice and opportunity

- helpful listening – listening or asking questions to elicit choices and opinions

- positive prompting – offering guidance or instruction to do something positive

- negative controlling – stopping people doing something

- casual – any general conversation

- no talk – not interacting with the people in the service

In addition to recording and coding interactions; researchers also noted down any other observations or reflections.

At time one a total of 167 interactions were observed and coded. The figure for time two was 159.

| Category | Time one | Time two | Change T1 to T2 |
|---|---|---|---|
| Helpful speaking | 11% | 21% | **16** |
| Helpful listening | 13% | 7% | **-10** |
| Positive prompting | 17% | 12% | **-9** |
| Negative controlling | 3% | 1% | **-4** |
| Casual | 11% | 23% | **18** |
| Childish or put down | 4% | 0% | **-4** |
| No talk | 41% | 36% | **-5** |
| | 100% | 100% | |
| Table 8: Results of direct observation of practice | | | |

Observers were able to reflect on the experience of being in these settings and it is interesting to record some of the comments that were made. Some of these related to the overall sense of the settings – the climate of noisy business or homeliness, or how comfortable people appeared to be in each other's company. Reflections also captured the intonation in interactions, including examples of people being talked to in childlike ways and in gentle and supportive ways.

There are some interesting and positive findings here. It was clear that the day-to-day experience of interaction between staff and people with disability is worthy of a good deal more attention as services attempt to improve the social and emotional environment and address fundamental issues of power. The use of direct observation was an important aspect of this study and showed several positive trends. The increased levels of interaction and the suggestion that these were more positive is a promising early

finding for the project. The overall level of interaction was higher and there were no examples of childish or put down interactions at time 2. The other main change was an increase in the giving of information to support choice and the general casual conversation. However, there was a reduction in the use of questions and the amount of listening that was happening.

It is interesting to note that members of staff are spending between 36 per cent and 41 per cent of their time not interacting with the people they support. This is by no means unusual in studies of this type (Oakes, 2000) and raises a question about the optimum or appropriate level of interaction that might be expected for different people.