Building safe and respectful cultures

in disability services for people with disability

Executive Summary in
Large Print

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Disability
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Commissioner

Prepared by

Sally Robinson

Peter Oakes

Melissa Murphy

Peta Ferguson

Francesca Lee

William Ward-Boas
Marianna Codognotto

Jodie Nicks

Dina Theodoropoulos

For the Disability Services Commissioner

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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.

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

Facilitators

- Relationships based on trust and familiarity
- Feeling heard
- Having multiple ways to express views and feelings

Constraints

- 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 lacking in depth
- The passivity of the 'participant' role
- Impact of the wider world on young people's relationships in services

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

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

Facilitators

- Relationships that recognise positive qualities and attributes in others

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

Constraints

- 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 the rights of staff

- Fragility in staff sense of security and safety in role

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

Facilitators

- 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

- 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 preventive 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 the rights of staff
- Difficult balance between compliance, risk and rights discourses

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

Facilitators

- Increasing knowledge of human rights
- Pride in role, strong values base

Constraints

- Activation of rights
- Risk of support relationships fracturing
- NDIS dominating practice and structure

Complexities

- Many – outside the remit of this research (e.g. poverty, exclusion, social isolation, discrimination, community attitudes)

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.

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

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For further information:

Disability Services Commissioner,
1300 728 187
contact@odsc.vic.gov.au