

# Speaking Up About Safety

Perspectives of people with disability on personal safety at home, in the community and in disability services

#### **Acknowledgements**

National Disability Services (NDS) would like to thank people with disability from across Australia for sharing their experiences and ideas through participation in focus groups. We'd also like to acknowledge the eleven disability advocacy organisations that arranged and conducted the focus groups on behalf of NDS. We are also grateful to Dr Sally Robinson from the Centre for Children and Young People at Southern Cross University for her support and guidance in this process. We acknowledge your commitment to ensuring the voices of people with disability are heard strongly in the *Zero Tolerance* initiative.

#### 1. Introduction

NDS is leading *Zero Tolerance*, a national initiative to build the capacity of service providers so people with disability can exercise choice and control whilst remaining safe from risk of abuse, exploitation and neglect. A range of collaborative and consultative activities have been used to develop a practical framework with tools and resources for building the capacity of disability services providers to better prevent and respond to abuse and neglect of people with disability.

The first round of information was collected through a series of state and territory consultation forums with the disability sector in late 2013. Recognising public forums might present risks to people who have experienced abuse or neglect and who might need professional trauma supports, it was decided to arrange a separate process for incorporating the views of people with disability into the *Zero Tolerance* initiative.

This report provides a summary of responses from 11 focus groups for people with disability held in March and April 2014 on the topic of personal safety. Feedback has been grouped into themes to support the identification of implications for service providers and inform the development of the *Zero Tolerance* framework and resources.

## 1.1 Focus Group Approach

Drawing on expertise of members of the *Zero Tolerance* Project Reference Group, a series of small focus groups was proposed as the most appropriate way to capture the views of people with disability. It was also recommended that the groups focus discussion on concepts of personal safety rather than abuse to further reduce risk of personal trauma for victims.

Recognising the need for participants to speak freely NDS approached disability advocacy organisations that had participated in the *Zero Tolerance* forums to coordinate and facilitate focus groups in each state and territory. Three non-jurisdictional focus groups were also run to seek feedback specific to women with disability, people with disability from rural and remote indigenous communities and people with complex communication support needs.

Organisations were asked to invite people actively using disability services to participate in focus groups, to help inform practice improvements amongst service providers. To ensure active participation in each group, it was suggested that numbers be capped at eight.

A set of standardised questions was provided to each focus group. Organisations were given freedom to facilitate the groups in the way that best met participants' needs. This included use of any existing meetings or groups where people might be familiar with each other and/or consultation processes. Two jurisdictions were unable to conduct group sessions and conducted individual private interviews.

Focus group sessions typically lasted two-three hours, with two facilitators in each group. All participants were given a \$50 retail voucher to acknowledge their time and contribution. Catering and attendant care was provided where requested. Facilitating organisations were not paid for their time.

Participants were asked non-identifying demographic questions. Some participants chose not to respond. Feedback to questions was de-identified and provided to NDS using a template.

The feedback was coded and analysed according to themes identified in the data. With a few exceptions – notably a strong emphasis on gendered aspects of service provision from the focus group for women with disabilities – themes were notably similar across all groups.

#### 1.2 Focus Group Facilitators and Dates

11 focus groups were held in total, one in each state and territory plus three non-jurisdictional groups. Facilitating organisations, dates and number of participants are provided in **Table 1**:

Group	Facilitating Organisation	Date	Participants
ACT	Advocacy for Inclusion	17 March	4
NSW	NSW Council for Intellectual Disability	14 March	5
NT	Darwin Community Legal Service	10 March	6*
QLD	Queenslanders with Disability Network	6 March	8
SA	JFA Purple Orange	7 March	4
TAS	Speak Out	12 March	6
VIC	VALID	25 March	5
WA	People with Disability (PWD) WA	4 April	5
Women with disabilities	Women with Disabilities Victoria	13 March	7
Indigenous communities	Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Women's Council	14 March	6*
Complex communication	Scope Communication Resource Centre	19 March	3
TOTAL			58

<sup>\*</sup> NPY and Darwin Community Legal Service discussions were undertaken individually and not in groups due to availability of participants.

# 1.3 Who Participated?

Table 2 below provides an overview of participant representation across all focus groups. There were 58 participants in total, across 11 different sites. Percentages are a reflection of the full cohort of participants.

There was a good balance in representation of **gender** (almost 50% spilt across all groups), age (with 36-55 years most represented) and **primary disability**, with physical (31%) and intellectual disability (36%) the most identified. Although communication was not recorded as a primary disability, several participants are understood to have had communication support needs.

There was strong **indigenous representation** (19%), aided by but not limited to the creation of a specific focus group for people from indigenous communities. However representation of people from **cultural and linguistically diverse** (CALD) backgrounds was very low. Facilitators could not identify any specific factors that might have contributed to this under-representation.

Table 2: Focus group participant demographic data

		TOTALS	%
Gender	Female	28	48.3%
	Male	30	51.7%
Age	18 – 25 years	5	8.6%
	26 – 35	10	17.2%
	36 – 45	18	31.0%
	46 – 55	18	31.0%
	55+	7	12.1%
Culture	Indigenous	11	19.0%
	CALD	2	3.4%
Primary disability	Cognitive/intellectual	21	36.2%
	Sensory	4	6.9%
	Physical	18	31.0%
	Communication	0	0.0%
	Psychosocial	1	1.7%
	Did Not State	4	6.9%
	Multiple	10	17.2%
Current housing	Social housing	18	31.0%
	Community housing	11	19.0%
	Boarding house/hostel	0	0.0%
	Group home	6	10.3%
	Private own/rental	12	20.7%
	Family home	11	19.0%
Housemates	Live alone	21	36.2%
	Share with others not of your choice	7	12.1%
	Share with other of your choice	8	13.8%
	Live with family	21	36.2%
	Others	1	1.7%
Day Activities	Supported employment	6	10.3%
	Open employment	10	17.2%
	NGO funded day activities	20	34.5%
	Volunteer	11	19.0%
	None	11	19.0%

Participants were not asked to identify what specific services they used when responding to questions. However, limited data collected shows that participants were representative of a range of **housing options**. Living alone or with family were the joint-equal most common arrangements (36.2% each), though over 25% shared housing with others.

A majority (34.5%) accessed NGO-provided **day activities**, and more than a quarter of participants were in either supported or open employment. Facilitators noted that people with no day activities either chose not to do anything or were limited by a lack of options in their local area.

While the data does not indicate what support people get from service providers, the focus group discussions suggest they are referring to day services, residential services and individualised support services provided by an NGO or government service provider.

Although representative across a number of domains, the facilitators were agreed that participants were not wholly representative of the disability sector because of their **relatively strong connections with independent advocacy**. Over a third also lived with family. It was noted that this is not the case for many people with disability, who might have no contact with people outside of the staff paid to support them. This was reflected on by some focus groups, where several participants noted how their current situations were much improved from previous circumstances when they had felt considerably more isolated.

The facilitators noted that many of the same issues raised by the focus groups were almost certain to apply to people living more isolated lives, although the solutions may be harder to achieve without support.

#### 2 Questions and Responses

Evidence from other work on personal safety for people with intellectual disability highlights how concepts of safety vary considerably. Questions for the focus groups were therefore designed to allow some broad exploration of concepts of safety.

Questions focussed on safety in different areas of people's lives including at home and in the community. Participants were asked to reflect on actions by service providers that make them feel valued, as well as to propose actions that providers can or could do to make people feel safer. One question sought to explore how people might respond to situations where they felt unsafe, and who they might tell.

The final questions provided to facilitating groups were:

- 1. What things does your service provider do that make you feel like you/your decisions matter?
- 2. What things help you feel/ stay safe at home?
- 3. What things make you feel safe when you are out in the community?
- 4. What you would do if you didn't feel safe? Is there someone you could tell?
- 5. What things could your service provider do better to help you stay safe?

Some of the facilitating groups chose to commence sessions with a discussion about safety, harm and types of abuse. Relevant comments from those discussions are also reflected in the analysis of feedback provided below.

<sup>&</sup>lt;sup>1</sup> Safe at Home: factors influencing the safety strategies used by people with intellectual disability, Robinson 2013

# 2.1 What things does your service provider do that make you feel like you and your decisions matter?

In responding to this question participants chose to highlight actions that are undertaken by service providers *and* suggested areas for improvement. Both are reflected below. Experiences ranged greatly from the positive ("99% of them are good. Staff I hire do things to my instruction") to the poor ("they hardly ever make me feel like I matter.")

A common response across all groups was **listening**. Participants who felt valued said their providers took an interest in what they were saying ("listens to my concerns, even though he is the Director") and followed up on any issues. ("I know the people that listen. If I have something important to say I go to them. Trust them… especially to speak up about something.") This was not the case for many; some whom perceived support workers to be either too busy ("they should listen. If they can't hear they should come back to you

at a different time") or disinterested ("half the time people listen"). Informal and formal listening opportunities were highlighted with one group noting "having a chance to give feedback is important. It needs to feel safe to give that feedback. The provider needs to be approachable."

Listening was directly related to providers **showing respect for choices and decisions**, with emphasis on support workers who "respond to my ideas and concerns" and on "making my ideas happen." Participants distinguished between 'performing tasks' and actively supporting people in their choices ("promises need to be

"If I want to go somewhere they always worry if it's OK with the office. I want to go to Bunnings but they say it's too far. They should try to find a way to meet me half way instead of saying no."

delivered ... showing an interest in the individual, not just meeting a need.") Some spoke highly of their providers ("I had to change my hours and they were great, working with me not against me... treating me as equals, not even like a client.") Others felt less valued when they weren't asked their opinion ("They should talk to you first before making a decision" and "maybe [they] feel that I can't do it but I just like to be asked."). Having decisions questioned ("they have to acknowledge that it's OK to make different decisions") was also frustrating, people preferring when "they guide you, not tell you what to do." Insufficient time to act on choices also made people feel less valued.

The importance of **relating with people as individuals** was raised in discussions about courtesy and respect, with one participant noting "them knowing how I'm feeling makes me feel like I matter." One group stressed the importance of 'an approach that upholds a relationship as the platform upon which support work occurs.' Humour was valued by many people, with having a joke mentioned several times. Simple acts like using a person's name or addressing people directly were also identified ("when they are genuinely interested they make eye contact. Treat me like an equal.") For some this was rare ("they switch off on you, ignoring you, doing their crossword. If I say anything I might not get anyone to work with me.")

For several groups the organisations that demonstrated their value of people did so through active **involvement in service decisions.** Whilst not the case for everyone, some people shared stories of involvement in many service decisions including interviewing and selecting support workers, developing rosters and sitting on organisation advisory committees. One participant noted that despite it being quicker to do things for them their workers will ask "what do you need me to do so you can do it."

**Providing good staff** was seen as a mark of respect, with several respondents noting a difference between the organisation and its staff ("service provider does not make me feel like I matter, support workers make me feel like I matter.") Staff continuity was seen as significant both in practical terms (getting to know someone and develop trust) and feeling valued ("they always take away the good staff. They get yanked away. They were really helpful, they are the ones that helped me have a say. I'm comfortable with the person I've got instead of swapping and changing all the time.")

Several participants spoke about the value of **respect for privacy**, especially at home. This included common courtesy such as knowing and waiting to be let in, as well as respect for personal space and property ("if you have a gift ... and you don't want anyone to open it and they open it that's not respect.")

Other day to day interactions were important to different groups. Participants in rural and remote areas strongly valued **assistance with everyday needs** from providers, including arranging for household repairs, driving people to shops and appointments, organising family outings and providing arts materials. Support that helped their family unit was very important to this group. Others felt less respected when basic decisions were not explained "our rent went up and I don't know why. It makes me feel angry. I'd like them to explain a bit better in those situations."

With regard to feeling valued, one participant presented an alternative perspective: "Some workers don't seem to feel good about doing their job. I think services should value their workers more, they might feel better about doing their job."

#### 2.2 What things help you feel/ stay safe at home?

This question asks about safety at 'home'. As Table 2 indicates, the participants of the focus groups lived in a range of places they called 'home'; social housing, group homes, private rental and family homes. It also indicated they share these homes with a range of people. Data about the relationships with these people is not available, but could include partners, friends or co-tenants. This information provides some context to the following responses as some people refer to the people who are 'in their homes' and relationships they have with them; support staff, family and co-residents. It also reminds us that the meaning of 'home' is broad and for many people with a disability 'home' is very different than the homes of others in the community, being sometimes a workplace for paid staff, temporary and/or not of their choosing.

The most common response in answer to this question was **staff actions and attitudes**. Staff that took the time to get to know people properly made participants feel more comfortable.

Relationships with support workers were identified as critical for safety in the home, one group noting "people with disabilities want someone they know, trust and hopefully like." On this point, introducing new staff was acknowledged as a challenge ("it's always hard for new staff. It makes it hard for both of us if I can't really tell them what I want ... after a while they get to know you.") One participant advocated always meeting new workers before their first shift as a way to mitigate this. In another case a provider has

compiled a book of written instructions about service users for new starters, but does not support the residents to provide content ("I can't put anything [it in]. It's only for staff talking to each other.")

People stressed the value of 'being asked' in terms of both seeking opinions ("it's important they ask me what I want") and clarification ("communication about what they don't know. They should ask me, not decide themselves.") Listening was again seen as critical ("they don't listen to me, it makes me feel upset. I just go in my bedroom and cry"), including respecting people's preferences ("[they should] take no for an answer, even if they want to help.") Not listening was also seen as potentially dangerous. One participant spoke of a worker who 'did not take care when putting the sling on for a lifter which resulted in pain ... she had not listened and had not followed instructions.'

"I feel safe at home with my worker but I have in my mind 'this is my home.' I don't want you to go in my bedroom because it's my personal space. I don't want you to go in my cupboard. She may not ask if it's OK to go in my fridge. They get so comfortable that they might overstep that worker relationship and it's important they don't do that"

**Staff being competent in meeting basic needs** was raised by others as a factor in feeling safe ("they should take care not to make you feel at risk – for example [not] feel like you are drowning when they bathe you" and "I need to know they know what they are doing.") Small seemingly innocuous actions also had an impact on participants ("we don't feel safe when the worker is not appropriately dressed or has no worker ID.") Acts such as respecting a person's home and helping to keep it tidy also helped people feel safer with a worker.

Collaborative approaches were preferred ("engage with us and show us we can do things together") but without forgetting who is in charge ("they will put forward their ideas but we've got the control as the

*employer.*") Having similar **shared values** was seen as useful in this regard, with some people feeling disrespected and unsafe when workers voiced values contrary to their own in their homes.

When values matched, people felt safer. One participant spoke highly of a staff member for being respectful of his relationship with his visiting father; 'knowing when to step back, be present, but not interfere with the normal family relationship.' Some appreciated staff doing things beyond what was required of them ("making my bed. They are just meant to do personal care [but] it helps my mum.")

"You get scared that everything could be taken cause you know when I'm on the toilet or something people could be going in there and taking stuff. I do have a safe now, but it's not about that. I mean, you can't lock every valuable you've got."

One participant praised their staff for supporting them to 'get rid of a bad staff member' by keeping evidence. Conversely, another group took care to stress that "nobody's perfect; we're all allowed to make mistakes, we are all human and fallible."

Participants in all groups had had negative experiences with support workers. "I had one support worker who was totally useless. He spent more time on the phone." Some reported workers who actually created danger ("we had a fire and [worker] goes to sleep and he doesn't wake up. I had to bang on his door.") However, all groups noted that having choice about who supports you was a positive way to manage such situations and had led to improvements. This included being able to choose between male and female staff which was important to many. Some participants had been involved in staff recruitment processes previously but very few were currently involved in recruitment.

"Sometimes I don't feel safe because of other people I live with... who slam the door and are noisy and yelling and that. That scares me. Respect for privacy was universally viewed as important. People valued having their own space ("I've lived in an institution so my space and my stuff's important to me") and wanted that respected ("knock before they come into my room, knowing that my room is private. They don't always knock"). For many this issue was more challenging if they had concerns about co-residents, and in particular those who people had no choice about living with ("some other people in the house can make you not feel safe. Being made to live with someone I don't want to live with makes me feel angry and not safe.") This was echoed by several participants in different

groups ("they should ask first if someone else could move in. We should have a say in who moves in; it's our house.") One woman spoke about a friend who felt unsafe due to men in her accommodation. She felt no effort was made to change the men's behaviour or move them and finding alternative housing for her friend was a very long process. Strangers were also highlighted as a concern, particularly those associated with co-residents. People described having no control or say over who came into their house, or any power to control the behaviour of guests.

Contact with and support from outside the service was important for most participants, and in particular contact family and friends. This included living at home, telephone contact with family ("my brother will

ring me at home if he's out with the family"), family being able to visit or stay over, or being able to stay over with friends ("staying with a family member or friend at home makes me feel safe").

Formal and informal support networks helped people feel safe, including personal safety alarm systems, community registers for vulnerable people, after hours help lines and neighbours dropping by. People spoke quite positively about experiences with the police, again noting improvements over time. Most felt confident the police would come and deal with any significant issues.

People also spoke about common approaches to **day-to-day safety and security concerns** including being able to lock doors, have security doors and cameras and leave lights on if going out. Pets made some people feel safe, providing reassuring company, although one participant noted that their provider did not allow residents to have pets. In the absence of pets, people valued their own **routines**. Being able to watch TV, listen to the radio or meditate all helped people feel more relaxed in their homes. People also reinforced their right to feel comfortable in their own home ("that fact that I am in my own home makes me feel safe. It is locked up, and I have back up batteries, so I don't let myself feel unsafe. It is about attitude; I don't let myself become overly fearful.")

#### 2.3 What things make you feel safe when you are out in the community?

In responding to this question people strongly appreciated **support from service providers**, with many feeling unsafe in the community without their support workers. A common reason was having someone to help in case of an incident ("someone being close in case I have a seizure" and "if my wheelchair broke down they'd be there to push me"). Others felt reassured by company ("I like to be with someone at night" and "I like to be with someone on public transport") and felt their support worker was watching out for them ([for example] "so your drink does not get spiked" in a night club). Even with a support worker some people felt anxious ("I do feel insecure sometimes if my support worker needs to go to the toilet and I am waiting in the shopping centre or in the park and I see people eyeing me for what they can steal.") Despite this some groups reinforced the need for dignity, wanting support workers not to wear identifying badges or clothing that drew unnecessary attention to them in the community.

Going out with **friends and family** helped many feel safe in the community. This was flagged as especially important to people in the Northern Territory ("everyone in the community is my family and friends. Whenever I go out I am among familiar faces and that makes me feel safe.") Support dogs were also seen as giving confidence. **Familiarity** with people, including neighbours, shop keepers, cafe and bar owners and, in particular, taxi drivers all contributed to people feeling confident in the community ("knowing lots of people in the community means they are more likely to help you if you are in trouble.")

Many participants spoke about the need to be aware of risks and advocated **avoiding potentially dangerous situations.** For many this meant not going out alone after dark ("*I don't usually go out late at night unless I know the area* [or] *people there and I know how to get help.*") It was noticeable that nobody challenged this as unfair, with most seemingly resigned to not going out after dark.

Whilst **increasing familiarly** with certain 'danger spots' through frequent visits was encouraged people strongly advocated **planning ahead.** This included regular charging and services for wheelchairs, organising transport well in advance and giving service providers notice so staff can be on hand.

Use of **technology** also helped people feel safe, with mobile phones seen as an important tool for anyone out in the community. People expressed mixed views about contacting the police in case of an incident. Some were confident that police would act and intervene, whilst others had already experienced poor police responses ("I got assaulted and the police did nothing, like the time they didn't follow up when my home got broken in to.")

Some people spoke about avoiding confrontations ("I keep to myself on public transport") or areas with large noisy crowds whilst others took the opposite view, advocating **positive attitudes** ("Positivity [and]

confidence! I have a good light system on my wheelchair and I have a voice. I live in a small town so people see me! I'm visible!!") Viewing safety for people with disability as different to safety for non-disabled people was also challenged ("we're just like other people. I don't really see how we're any different.") by more than one group ("people treat us like 3 year olds or don't treat us like everyone else. We don't want sympathy but understanding.")

Other feedback included the need for more public education about disability and the importance of public access to transport, buildings and public facilities through availability of ramps, railings, traffic lights, levels crossing and unbroken pavements. Where access was poor people felt increasingly vulnerable.

#### 2.4 What would you do if you didn't feel safe? Is there someone you could tell?

Responses to this question acknowledged the difference between **service providers and support workers**. People make a distinction between talking to their support worker, or taking an issue to the provider if it involved a member of staff ("I'd speak to management or the boss at work").

One group explored the benefits of reporting ("I need to tell someone so I can get it off my mind, get it out, and get rid of it. Then you feel more safe") but acknowledged challenges in reporting a member of staff. People felt the member of staff might intimidate them and ask "why did you do this?" Comments included "you feel like you would have to get your facts right" but people recognised "the person could get in serious trouble but you would feel you have done the right thing and feel better making the complaint."

People generally felt comfortable approaching management to complain ("I'd call John, the boss of my service provider") or using organisation complaints services, though one group had low expectations about organisational responses ("it's hard to get any disability services to help when you're not safe. There is an afterhours carers line that helped me once. Mostly it's only friends that come through.")

Family and friends were again seen as primary allies for people to contact if there is a problem ("I tell my nanna and my sister if I don't feel safe at home"), with many participants saying they would contact family before their provider ("[I need] someone I can trust. I ended up ringing a friend because someone kept texting me and threatening me. They made sure I was OK then helped me go to the police.") Circles of Support were also identified as being trustworthy, and people stressed the need for unpaid people outside of your service provider that you could talk to if there was a problem.

"For people with intellectual disability the support service information looks daunting, with small print and 20 services. How would I know where to start? If you just call one they tell you you've called the wrong one."

People expressed mixed confidence in the **police**. Some felt categorical that they would call the police ("*if I was out in the community I'd call the cops*"), whilst others felt people with disability were a low priority,

especially for incidents like theft ("you feel more comfortable going to the agency over the police [as] they might have bigger kidnappings or things like that. When you go to the police it's big and scary."

Several people understood they could turn to **advocacy organisations** ("I might be able to sort a problem out on my own but I might need an advocate to support that.") People had mixed views about Official / Community Visitor schemes with many seemingly unaware of their role. The focus group for women also highlighted the valuable role of external contacts and **specialist services** such as Centres Against Sexual Assault (CASAs) and family violence centres. However the group noted "if you are closed in an SRS [accommodation service] you will never hear about [them]. You wouldn't know where to start."

**Technology** was seen as an important enabler to report problems, both in terms of immediacy and anonymity. People with complex communication needs spoke highly of being able to report independently using technology ("doesn't have to be face to face and reliant on others").

Whilst considering this question, participants also spoke about credibility ("important not to be the client who cried wolf. Creating little dramas about nothing may cause problems in the future when a big issue may arise. They might not be taken seriously because of their past complaints"). Another group felt that service providers were unlikely to provide education on rights because "services are frightened if we have our rights we may talk up more. They might be frightened that someone like me might take it to court."

## 2.5 What things could your service provider do better to help you stay safe?

Consistency of feedback from across the country was notable in responses to this question, with many of the same issues and solutions revisited. Many participants were happy with their service ("there is nothing anyone can do more. In general everything is good") and reported improvements compared to the previous experiences ("I think my provider does as much as he can to make me feel safe.") However, even where people felt they personally were enjoying a good service, they advocated for general improvements.

**Listening** ranked highly again as a way for people to feel safer and more confident, with emphasis on active listening ("not just listening but listening so they believe you") and being taken seriously. People acknowledged that service providers can sometime be limited in what they can do, but this shouldn't excuse not listening and trying ("my new service was prepared to listen to me and meet me half way. They at least acknowledged what was important to me.") Several groups emphasised the need to listen to the person and not default to family members ("I'm sick of not being heard. They ask my family or case worker.

They don't listen to me.")

"It is important when they take me seriously. When they treat me like an intelligent person with views that matter." Participants wanted to see listening translated into action through meaningful **input into processes** ("be more involved than just dots on paper.")This included participating roles in staff recruitment processes, having a say in who provides supports, opportunities to provide feedback about staff ("ask us if we think staff are honest and if we trust them") and general catch up meetings with client input. One group suggested people with disability could be supported to become trainers so they could train staff about safety from a service

user perspective ("we know more about living with a disability than anyone else.")

This was reflected in comments on the need for **better training for support workers.** This included training on human rights; gender, parenting and sexuality specific training. Other ideas included "providing training for staff so they know what it is like to receive support" and the need to explicitly "train workers not to harm people or threaten people." One group felt support workers understood physical disability better then cognitive disabilities ("services need to learn how to assess support needs for these 'invisible' disabilities").

People were clear that service providers have a responsibility to **ensure quality of staff.** This included an expectation that providers "don't hire the wrong staff" and "undertake regular police checks." "Employing trustworthy and honest staff" was advocated, with one group suggesting providers 'ask questions at interview to test whether or not people have a mature outlook' noting that maturity did not refer to age. Responsibility was seen to go further than recruitment with one participant commenting "management need to have training in how to train their staff." Service limitations were identified, as people sought "More staff. More time. Not rushed [so they can] stop and listen." People also wanted to see regular "staff reviews to keep an eye on standards slipping, make sure they know what they're doing and happy in their job so we are happy." Ultimately people wanted to know that when things go wrong providers will act decisively: "move the staff that don't make us feel safe" and "if workers break the rules they need to be sacked."

Feedback suggested that **leadership from management** was important in setting the expectations about safety ("they always take the services [support workers] side. They should listen and believe what we say.") Participants alluded to the need for better **complaints management processes**. One group in particular spent a great deal of time exploring people's reluctance to complain and speak up if a staff member 'crossed the line.' The group displayed a keen awareness of 'the rules' but a sense that the process does

not work equally well for the service user and the staff member involved. Commenting on the group's discussion, the facilitator reported participants had difficulty understanding that threats and assaults by a support worker were significant and serious. In the same group one participant considered it reasonable that a support worker who had assaulted a client would be merely spoken to by the boss but then allowed back on shifts, noting "they are higher than you, so they have more rights."

"This is the guarantee I want: 'Our services can guarantee your safety and when that guarantee is broken we guarantee we will act immediately to restore safety."

The theme from this conversation reflects responses from other groups however it was differently expressed emphasising the need to provide **information and training for service users** about abuse ("talk to us about safety") and rights ("they need to let people know their rights and how to complain. If clients complain services shouldn't threaten them or punish them.") For many this included information about and **access to support services**, including independent advocacy, sexual assault support services, self advocacy and peer support. As people became more empowered, there was an expectation that services would **respect their choices** ("I need respect, control and choice. This is fundamental to feeling safe and to be safe.")

Having **consistent staff** was again raised as a factor in people feeling safe, both in terms of familiarity ("I feel my privacy is violated each time a new person comes. I had 13 support people in [three months])" and staff having sufficient time to understand people's specific requirements ("keep staff over a long period of time so they build up skills.") For parents with disability this poses additional risks ("the service expected me to leave my children with strangers. The service sends strangers to my door. Stranger after stranger. That's not safe for my children.")

**Language** was raised as an important skill, with some participants reporting staff with little to no comprehension of English. In addition to general communication difficulties, this had led to people feeling unsafe as their instructions were ignored or misunderstood ("it's a problem, because I can say, "Oh, you need to move to my left shoulder, or to the right," and they will say "But what's a shoulder?" And that makes me unsafe in my transfers, in my home, in everything."). People also valued staff that were diligent in performing **basic support needs** tasks. Good timekeeping, cleanliness and support to maintain equipment were seen as indicators of trustworthiness.

More broadly the groups identified challenges in **changing the culture of accommodation services**. Several participants had lived in institutions or group homes and noted the emphasis on routine as a precursor to people being abused. ("In there your whole life is controlled and hurried. Eat breakfast now. Leave the house now. Shower now. There aren't choices about anything and there should be.")

Other suggestions focussed on the need for **better responses from mainstream services**, including mental health services and the police. Community education and training to improve understanding of disability rights and issues were viewed positively.

#### 3. Summary and conclusion

This consultation aimed to hear directly from people with a disability about perspectives on safety in their lives; safety in services, in the community and within a range of service based relationships.

The focus groups involved a broad range of people; ages ranged from 18 years to 55 years+, and there was a diverse representation of primary disability. Participants lived in a range of housing types and used residential, day support and individualised support services.

While a broad discussion of safety has been provided, some common themes are summarised below.

- Mirroring the nature of the focus group questions, participants expressed many ordinary or commonplace perspectives on the question of personal safety. This helps to consider harm in its different contexts, highlighting a range of potential sources of abuse and identifying factors that may influence or contribute to the problem.
- The feedback confirms the importance of individual level safeguards that support people's independence within the parameters of reasonable risk. Specific safeguards may be ordinary in nature (e.g. familiar people, avoiding 'danger spots', use of mobile phones) or particular to the person's disability (specialist equipment, accessible environments). People also spoke about the importance of people from outside the 'service world' as confidants, advocates and supports including family, friends and advocates.
- The feedback supports the notion that policy and procedure have a role to play but that people who use services are overwhelmingly focused on the issue of service cultures. Failure to listen was the most common theme. Being overly familiar or disrespectful of a person's home and possessions; failure to elicit opinions or decisions; undue focus on routines; and 'doing for' behaviours also represent areas of poor practice that require an early intervention response on the part of service providers.
- Unequal power relationships between service users and staff and a fear of consequences mean
  people are discouraged from speaking up about quality of service and issues of concern. These
  cultures should be addressed, along with recognition of the limitations of traditional methods for eliciting
  feedback on service delivery. Increased and regular engagement with friends and supporters of the
  person with disability will also assist to unearth any potential areas of concern.
- The feedback suggests that **client strengthening and empowerment is needed**, with an obvious role for service providers to increase awareness of rights and complaints processes.
- The feedback suggests that provision of truly individualised approaches and in some cases expression
  of people's rights can be impinged in the operation of some accommodation environments. There
  is a need for greater flexibility around daily routines and increased choice about who people living in
  shared supported accommodation interact with on a daily basis, including staff and other service users.
- There is a clear expectation that providers should be responsible for ensuring the quality of their workforce underlining the importance of diligent recruitment practice, training, performance management and other workforce development activities.
- Gendered aspects of service delivery are not always fully recognised, and more work is required to
  ensure service providers understand and support the safety requirements of women. This appears to
  particularly significant with regard to accommodation services, with choice about gender of staff,
  response to concerns about male co-residents and links to specialist services raised.

#### 4. Feedback and Comments

Following publication of the report in 2014, NDS sought feedback from people with disability; parents and carers; and disability advocacy organisations to consider:

- any comments in response to focus group themes; and
- other actions that service providers can do to maximise the safety of people with disability using their services.

Feedback was then incorporated into the final Zero Tolerance framework and tools and resources.

NDS believes the responses provided in the focus groups offer an important insight into the experiences of people with disability who use services and what must be done in response. We encourage providers to share these stories and talk about safety within their organisations, as well as with the people who use your services, their families and carers.

You can call or write to us and tell us what you think about the report. Any other feedback you might like to share is also welcome. Contact James Bannister via james.bannister@NDS.org.au.

#### 5. About the Zero Tolerance initiative

Zero Tolerance is a response for the sector, led by NDS in partnership with the sector, to existing and emerging challenges to ensuring people with disability can exercise choice and control whilst remaining safe from risk of abuse, exploitation and neglect.

It builds on a range of existing approaches and resources that help staff identify factors that create vulnerability for people with disability, and support better responses to cases of abuse.

The emerging approach to safeguarding under the NDIS is also being monitored to ensure the practical framework that is developed is complementary to the changing funding and service delivery environment.

For more information please visit the Zero Tolerance project page on the NDS website:

https://www.nds.org.au/resources/zero-tolerance

