

Department of Communities and Justice – Ageing and Disability Commissioner Act Review Focus Groups

Summary Report

Lead Facilitator:

Jonathon Kelleher, Inclusions Projects Officer

Overseeing the project:

Tracey Lloyd, Inclusion Services Manager

Participants:

6 participants with intellectual disability engaged with this project.

Background

Setting

2 focus groups were held in a hybrid model of online and in person attendance. 4 people in total attended online and 2 people participated in-person.

Participants

10 people with intellectual disability were engaged for the project. 6 participants in total successfully engaged in the focus groups. 4 people were unable to participate and due to late notice, we were unable to recruit replacements.

Considerations

Due to the specific support needs of the participants in the focus group with regards to focus and level of cognition, the facilitator used discretion in selecting and omitting questions in order to elicit responses within the session. PowerPoint slides containing Easy Read wording and photos were used to aid comprehension of the content. The Easy Read discussion paper about the review of the Act was used as a basis for the discussions.

Interview introduction

For both focus groups participants were supported to become familiar with the topic and purpose of the project. This included a discussion regarding the meaning of 'laws' and 'abuse'.

Participants indicated they understood that a law is a rule people must follow. Majority of participants indicated they had not heard of the Ageing and Disability Commissioner Act, with one stating "I knew there was a law but I wasn't aware of this law." Another participant stated "A lot of people with disability don't know about laws. They don't tell you because they don't know how to." Participants in both groups queried why the law is being reviewed now, and why it has not been reviewed earlier. One participant stated "it has taken too long", with another stating "I think they should do it more regularly".

Participants expressed their understanding of the different types of abuse people with disability can suffer, including financial and physical abuse. One participant

stated that people with disability also get abused by other people with disability a lot. This participant expressed that often people with disability “are scared because they don’t know right from wrong” and that “they need to be able to understand what is and isn’t abuse, and what is wrong”. Another participant stated that “for some people with intellectual disability they don’t know they’re getting abused” and that “the law should help people better understand what abuse means.”

The right to stop the discussion at any stage was confirmed for all participants. Participants were all confirmed as feeling comfortable and consented to the focus group. Participants were made aware that their personal information would not be shared and that all feedback would be de-identified.

Sections

The following information looks at the responses and themes of the participants involved.

The document is split into 4 sections:

- Section 1: The Ageing and Disability Commission
- Section 2: The ADC Commissioner
- Section 3: Official Community Visitors and reporting
- Section 4: The effectiveness of the Act

Section 1: The Ageing and Disability Commission

Participants were asked the discussion questions about their opinions on the rights in the Act, and whether there are any further rights people with disability need protected.

Participants indicated they agree with the rights in the Act and that people need the right to be safe from abuse, as well as the right to privacy and to make decisions. Participants agreed with people's right to be safe from physical and emotional abuse. One participant stated "I think the rights are good, but it's very difficult for people to talk about to people". This participant stated that some people with disability are scared that if they speak up about abuse "they'll miss out on services and getting support". Participants stated the right to complain is important, and that people need to be informed and assured that they will get support if they make a complaint.

Participants emphasised that there are further rights people with disability need under the Act. One participant stated that the law should protect parents with intellectual disability "so they don't get their rights stripped" as they "deserve their rights and to be heard". This participant expressed they had felt abused in the way they had been treated by the government about their parenting rights.

One participant stated the Act "doesn't address abuse behind closed doors" and does not refer to the abuse that happens in group homes. Another participant stated that people with disability need the right to interpreters so they can "speak to someone in their own language who understands their background". This participant also stated that Aboriginal people with disability need their rights protected.

Participants in both groups expressed the importance of government workers understanding the rights of people with disability, with one participant stating "All of the government should learn about who we are". Participants agreed that disability awareness training should be delivered "across all the government" to ensure people with disability can get their rights.

2: The ADC Commissioner

Participants were asked the discussion questions about the process of selecting the Commissioner, and length of time the Commissioner can be in the role.

Majority of participants indicated they did not know who the Commissioner is or what his experience or qualifications are. All participants agreed the Commissioner who is chosen should have qualifications and experience working with people with disability. One participant stated it is essential that the Commissioner has experience in “how to communicate with a person with disability to understand their needs.” Another participant stated the Commissioner should have leadership skills and “be able to say what types of reforms they want.”

Participants queried why one person is responsible for choosing the Commissioner, with many agreeing that an independent group of people should be responsible for making this decision. One participant stated “the Commissioner should be chosen independently of all government departments” to avoid government bureaucracy. Another participant stated that the group of people who make the decision should include people with disability and government board members. This participant stated each area of NSW should be represented in this group to represent the different people with disabilities across NSW, and that “People who know best how to treat people with disabilities are people with disabilities.” One participant queried the Governor’s knowledge and understanding of disability, and stated “It is important that the person choosing the Commissioner knows about disabilities.”

There was a variety of opinions regarding the length of time the Commissioner can perform the role. One participant stated 5 years is an appropriate time, and that “After 5 years it should then be someone else”. One participant stated that 5 years is too long and that 3 years would be an appropriate time. Another participant stated that 10 years would be an appropriate time.

One participant stated the length of time the Commissioner can perform the role “depends on how good they are at the job and how well they understand disability and the different needs of people with disability.” Another participant stated that the Commissioner’s role should be reviewed when a change of government occurs, “to see what he has done and make sure that he has made changes”.

Participants were asked the discussion questions about whether the Act helps the Commissioner keep people safe, and whether the Commissioner should have a choice to tell other organizations when a person has been abused.

Participants had difficulty responding to whether the Commissioner keeps people safe from abuse, with one participant stating “It’s hard to answer the questions because it’s hard to know if someone’s safe”. Another participant indicated it is difficult to answer as they do not know the outcome of each person who is helped by the Commissioner. One person did however indicate that they believe the Act help the Commissioner keep people safe from abuse.

One also queried how the Commissioner finds out about the abuse, the process of selecting people to help, and whether people are able to complain “if the Commissioner doesn’t make it better for them.” This participant expressed concern about whether the Commissioner is able to help people in the long-term, as if the abuse is occurring in their home the person “could be waiting years to move” and this could mean they are not kept safe from further abuse.

When asked whether the Commissioner should have the choice to tell other organisations when a person has been abused, all participants strongly emphasized that before the Commissioner speaks to any other organisations he should talk to the person with disability first, with one participant stating “They should speak to the person with disability and ask what they want to keep them safe”, and another stating “The Commissioner should have to ask the person before the information goes to other organisations.”

Participants agreed that the Commissioner should have the choice to tell other organisations, with one participant stating “Yes he should have a choice for every single one of us who is abused from everywhere”. One participant suggested these other organisations may be housing providers, the Justice department and the Police.

Participants were asked the discussion question about when the Commissioner should be able to help an individual who has not consented. One participant stated the Commissioner should be able to help if a person has been badly abused and they are “not able to talk about it” or if they “are not ready to say yes but the Commissioner can see.” This participant also stated that if there is proof of abuse but

the person denies it, or if they cannot make their own decisions, the Commissioner “should look into it to make them safe.” Other participants also expressed that the Commissioner should be able to help people who may not be able to speak for themselves, or feel comfortable to say yes. One participant stated that “Every case should be individualized.” Participants agreed that it is important the person understands what ‘yes’ and ‘no’ mean as some people may not know this. Participants stated the person should be supported to understand the meaning and consequences of giving, or not giving, consent.

Participants were asked the discussion question about whether the Commissioner should be able to share the person’s info with other services. Participants agreed that the person should firstly be informed if the Commissioner is going to share any of their information. One participant shared of an experience of their information being shared with another service without their knowledge, and stated this caused them stress and anxiety. This participant stated “The person needs to be told and updated if the Commissioner decides to lock into something.” One participant stated that the other services the Commissioner may share information with will depend on each person’s situation, suggesting this may be health professionals or psychologists. Participants consistently emphasized that the person should firstly be informed before any of their information is shared.

Participants were asked the discussion questions about their opinion on the specialized responsibilities of the Commissioner, and whether these will help them perform their role. Participants agreed that these are “good things” however many stated that the Commissioner needs to be more directly involved in talking to people with disability. One participant stated “I think they can do a bit better” and that the Commissioner should “try to get more in the disability community and understand more about how people communicate”. This participant stated if the Commissioner speaks to more people with disability they will “know more about what they can do for us to keep us safe.”

Some participants expressed concern at the Commissioner’s ability to get information about the person from their home. One participant stated “I don’t like the person going to the people’s homes.” with another stating “It may make things worse if they go into a group home.” Another participant stated that sometimes the person may want the Commissioner to have the information, “but the service provider may

not want to give you information.” Participants agreed that for these reasons the Commissioner should talk to the person and ask their permission before going into their home, with one participant stating “The person should be able to have a say about giving the information, or give the information themselves.” One participant felt positively about the Commissioner’s ability to get information from the person’s home, stating “I reckon it’s pretty good they can go to the house and get information to help out.”

Of the Commissioner’s ability to arrange a meeting about the person, one participant stated it is essential the Commissioner recruits the appropriate people for the meeting. This participant stated that the meeting should “have family members to give different perspectives, not just medical people.” Regarding the Commissioner’s ability to make public inquiries, one participant responded positively to this, stating “I think it’s pretty good that they can do a public inquiry and see if they find out if it’s the same for lots of people.” Other participants expressed concern about the idea of people’s private information being shared publicly in an enquiry, with one participant stating “People’s stories are private and should be kept private.” A participant suggested that any inquiry made by the Commissioner should be limited to the people involved, and not open to the whole public, in order to protect the privacy and safety of the harmed person. Another participant stated that if a person’s information is shared, the person should be reassured that they have “done the right thing” as “they’re going to be terrified that the information is going to be used against them.”

Section 3: Official Community Visitors and Reporting

Participants were asked the discussion questions about whether Official Community Visitors (OCVs) should be able to share group home information, and whether there should be volunteer OCVs in NSW.

All participants agreed that OCVs should be able to share information about group homes with other organisations, with one participant stating “If they find something has happened in the group home and they have to share it, that’s fine.” One participant noted that if information is shared it should be specific to the individual, stating “I think they should share certain information, but don’t make it look like everyone in the group home is the same”. Participants stated it is important for other

organisations to know the types of issues that exist in group homes so these organisations are able to help resolve these issues.

Participants expressed a variety of opinions regarding whether there should be volunteer OCVs in NSW. One participant stated that there should not be volunteer OCVs in NSW as it is “very important work” and OCVs “should be paid for their time”. Another participant stated there should be both paid and volunteer OCVs in NSW. One participant stated there should be volunteer OCVs as the person “may feel more comfortable speaking to someone who looks similar to them.” This participant stated it would be helpful to have OCVs with lived experience of living in group homes, as these OCVs would have a good understanding of the policies and procedures of group homes and be able to better help the person. One person stated “I reckon if they had a volunteer there they would find out more stuff.” No participants had ever received help from an OCV. One participant stated that OCVs should be available to more people with disability as “they can help us to raise our voice.”

Participants were asked the discussion question about whether the Commissioner needs to report to the government the outcome of people who were referred to other services for help. All participants agreed that the Commissioner needs to do this. One participant stated that the Commissioner should include in their report the reasons they could not help the person, the service they are referring the person to and the reasons for choosing this service.

Section 4: The effectiveness of the Act

Participants were asked the discussion question regarding whether they think the Act helps keep people who have been abused safe. Participants expressed that this was a difficult question to answer, as they had not previously heard of the Act or the Commissioner. One participant stated “How would we be able to answer that question if we don’t see results”. This participant stated the fact they had not heard of the Act or Commissioner before indicates that the Act is not helping and that it “needs to do more”. Another participant stated “They’re trying to find quick solutions and it takes time to heal wounds.”

Participants were asked the discussion question about whether any part of the Act needs to be changed. One participant stated that “The whole thing needs to be

changed” so that more people with disability know about the Act and how it can help them. This participant stated “It’s not doing enough” and said the Act should be changed to specifically include the different types of abuse it protects people from.

One participant stated that the Act needs to ensure that the person receives the right support and follow-up after they have received help, stating “You need to go beyond and make sure that this person is not affected” so they feel as safe and comfortable as possible “once the issue is out.” This participant stated the Act should ensure the abuse does not happen again to the person. One participant stated that there are no parts of the Act that needs to be changed.