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Department of Communities and Justice – Restrictive practices framework Focus Group and consultations

Summary Report

Lead Facilitator:

Jonathon Kelleher, Inclusion Projects Officer

Overseeing the project:

Jemima Macdonald, Inclusion Services Manager

Participants:

5 participants with intellectual disability engaged with this project.

NSW Council for Intellectual Disability (CID) was engaged by the Department of Communities and Justice to facilitate this focus group and consultations.

The views expressed by the participants with intellectual disability are their own, and do not reflect the views of CID as an organisation.

Background

Setting

1 focus group was held in a hybrid model of online and in-person attendance. 3 people with intellectual disability attended online and 1 person with intellectual disability participated in-person. A representative from the Department of Communities and Justice also attended online in an observational capacity.

Following the focus group, further consultations were conducted with 2 of the participants who experienced difficulties in communicating when participating in the group online. These consultations were made in order to provide these participants a further opportunity to provide their responses on the questions discussed in the focus group.

An additional person with intellectual disability and complex communication needs who was scheduled to attend the focus group, but was unable to at short notice due to sickness, was also consulted via email following the focus group, as email is their preferred method of communication.

Participants

10 people with intellectual disability were approached for the project. 4 participants in total engaged in the focus group. An additional participant with complex communication needs engaged in the project via providing written email responses to the focus group questions. Of the 5 participants who successfully engaged in the project, 2 of these were female and 3 were male. Each participant disclosed at the time of approach that they had been subject to restrictive practices at one stage in their life. 1 participant stated they are currently subject to restrictive practices, as part of their Behaviour Support Plan.

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. As noted above, a number of participants who attended the focus group online experienced technical challenges which prevented them from being able to contribute fully and successfully. This at times disrupted the discussions within the focus group. Facilitators used strategies to attempt to mitigate this during the focus group, and ensured that the participants who experienced difficulties were provided further opportunity to contribute following the group.

Interview introduction

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 5 sections:

- Section 1: Introduction to restrictive practices
- Section 2: Using restrictive practices
- Section 3: Being part of a decision to use restrictive practices
- Section 4: The role of family and carers in making decision about restrictive practices
- Section 5: What to do if restrictive practices are hurting the person
- Section 6: Final thoughts and recommendations

Section 1: Introduction to restrictive practices

For the focus group and consultations, participants were supported to become familiar with the topic and purpose of the project. This included a discussion regarding the meaning of restrictive practices, and the types of restrictive practices used. Participants expressed an understanding of the different types of restrictive practices that can be used including chemical restraint, environmental restraint, physical restraint, seclusion and mechanical restraint. One participant stated they had been subject to financial restrictions which they considered a restrictive practice, stating "'I find money sensory, and I like to spend it on things I don't need. When I had restrictive practices, it actually helped me manage my money better."

Participants identified that restrictive practices occur in disability and health settings, with one participant answering "The NDIS" when asked what restrictive practices they have heard of, and another stating they had witnessed health staff physically restraining people in hospital. Another participant shared that they have seen chemical and physical restraints used in disability settings, stating "There was one client who was put in a room by himself at a day program. Sometimes staff can be violent when they shouldn't be." This participant stated they had also witnessed support workers giving Valium to people with disability in group homes "to make life easier [for the support workers]."

Some participants shared that they are currently, or have previously been, subject to restrictive practices. One participant stated they have experienced environmental and physical restraint, and chemical restraint while travelling on aeroplanes and having blood tests. This participant stated they had not experienced seclusion or mechanical restraint, stating "I don't think that a buckle guard is a mechanical restraint. It is an environmental restraint." This participant stated they have also been held down for health shots and tests.

Another participant stated they had experienced chemical and environmental restraints "a long time ago" before the NDIS was introduced. This participant stated the restrictive practices "…didn't work with me because I escaped. As soon as they tried them on me I told them the legislation. I told them I would call the police." This participant stated they have a current Behaviour Support Plan which allows restrictive practices to be used, however they have not needed to be used. This participant expressed dissatisfaction at restrictive practices being a part of their Behaviour Support Plan.

Section 2: Using restrictive practices

Participants were asked whether they think it is okay for restrictive practices to be used on people with disability. Participants had mixed views on whether restrictive practices are justified. Some acknowledged that, in certain situations, they may be necessary, while others opposed their use.

One participant stated that it is okay to use restrictive practices as some people need these restrictions because of their disability, and “every disability is different.” This participant stated “Physical restraint….Sometimes it is okay. When someone has a physical disability and getting too much, maybe they need restrictions to stop.” Another participant, who is currently subject to restrictive practices, stated it is okay to use restrictive practices to keep them and others safe. This participant said “It can be used when it is in my interest. When I am resistant to a new treatment like neurofeedback, it helps me to get used to it.” Another participant stated that restrictive practices may be appropriate to use for people with severe disability or severe mental health conditions. This participant also stated that it can also depend on the situation as to whether restrictive practices should be used, stating it may b okay to use restrictive practices “if they’re going to hurt someone. You have to work out the ABC’s.” This participant stated it is not okay to use restrictive practices for every-day life decisions, such as a family member deciding what the person with disability is eating for dinner, stating “No, it is the client’s choice.”

Participants agreed that better alternatives should be explored before using restrictive practices on people with disability. One participant stated it is not okay to use restrictive practices if the workers can “find better ways to support them.” Another participant stated that workers and services should “always look for other things to do first like moving the client to a place they like so they can calm down” before using restrictive practices. This participant stated that in group homes “they do things like chemical constraint because it’s easier for the workers.”

One participant in the focus group expressed that it is not okay to use restrictive practices because “It’s not feeling good.” In further consultations following the group, this participant stated it is only ever okay to use restrictive practices to keep the person with disability safe.

Participants were supported to understand some of the rules underpinning the proposed new framework for restrictive practices, following the Disability Royal Commission recommendations. It is important to note that the addition of a Senior Practitioner in the framework was not discussed within the focus group. Participants were asked for their thoughts and feedback on some of the rules in the proposed framework. Some participants responded positively, with one participant stating "I think it is okay." Another participant expressed concern that the new framework will not be followed, stating "They will just write the rules, but they will throw them out the window."

A small discussion occurred regarding the role of Behaviour Support Plans in restrictive practices, with majority of participants understanding the purpose of these plans. One participant stated "When you have a Behaviour Support Plan someone will sit down and try and help." Another participant stated "My first plan was like 70 pages long, but now it's less than 50-60 because I don't do a lot of those behaviours. Hopefully it will get down to zero." Participants generally recognised the role of Behaviour Support Plans in the use of restrictive practices.

Section 3: Being part of a decision to use restrictive practices

Participants were asked how they would like to be a part of a decision about if a restrictive practice will be used on them, and were provided the following choices:

- I want people to tell me why the restrictive practice will be used
- I want all the information
- I want to make the decision myself
- I want to tell people what I think
- I want to ask questions.

All participants in both the focus group and further consultations stated they would like to be a part of a decision in **all** of the above ways. One participant, who currently is subjected to restrictive practices, stated they would also "like to be able to decide to end it when I don't think I need it anymore."

Participants were asked if any of the choices for this question are most important to them. One participant stated the first option (‘I want people to tell me why the restrictive practice will be used’) is the most important so they can understand why any restrictive practice may be used on them, and have the opportunity to share how they feel about it. This participant stated “Maybe I can then say ‘Is there a better way of doing something?’ I am good at problem solving.”

Another participant agreed that it is very important they receive information about why the restrictive practice should be used, and to have someone “explain to me what it happening. Because I have a disability and sometimes I don’t understand, and people don’t explain things properly.”

Section 4: The role of family and carers in making decision about restrictive practices

Participants were asked how they would like their family and carers to be part of a decision about if a restrictive practice will be used on them, and were provided the following choices:

- I want them to say who I am and what I need
- I want them to stand up for me
- I want them to ask questions.

Two of the participants consulted following the focus group stated they want their family to be a part of the decision through all of the above ways. One of these participants stated “I want them to ensure that I am consulted through the development of the plan. I want to be able to use my keyboard (AAC device) to participate in the plan development.”

Participants in the focus groups agreed that family and carers can play an important role in decision-making for restrictive practices, with one participant stating “My family or my support workers are really important.” This participant stated that “Some people with disability just say yes all the time when they don’t know something” and that families and carers are important as they can support people with disability to understand. This participant stated it is also important that people and families from diverse cultural backgrounds receive information that they can understand.

One participant stated they feel it is most important for families and carers to say who they are and what they need. This participant shared that their family was involved when they were assigned a Financial Trustee, and this was helpful to them at the time. This participant stated they would want their family to be involved in any future decisions about restrictive practices.

One participant stated that some people with disability might not want their family involved in a decision about restrictive practices. This participant stated that “A lot of families don’t know what’s going on so they just say yes” and emphasised that the person with disability should be asked first what they want. This participant expressed that the role of family and carers in decision making depends on “the family member and how involved they are.” This participant stated that families should not have a role in making decisions about restrictive practices if they do not care about the needs and wants of the person with disability, but if the family will advocate for the person with disability “then it’s a different story.” This participant also stated that if the person with disability wants their information about restrictive practices kept private and confidential from their family, this should be respected.

Section 5: What to do if restrictive practices are hurting the person

Participants were asked what would help them if restrictive practices were hurting them, and were provided the following choices:

- Someone to talk to
- Information about how to make a complaint
- Support to make a complaint.

The majority of the participants indicated that all 3 options would help them if a restrictive practice was hurting them. One participated added that “My advocate should be checking in with me so I can lodge a complaint.” Some participants agreed that it would be most important to be able to speak to a counsellor or psychologist “if something happens to you” when receiving restrictive practices. A participant added that “If it’s going to trigger your mental health you should see a psychologist. If it’s physical you should go see a doctor.”

One participant stated that if a restrictive practice was used on them without permission they would “give them the legislation” or ask a supporter to look up the legislation. Another participant agreed with this, stating “Legislation was a good answer.” A participant stated that the help required can depend on the scenario, and that if the person with disability is able to, they can call for help, but if they are unable to they can “tell a trusted person to call 000.”

Section 6: Final thoughts and recommendations

The focus group concluded with participants sharing their final thoughts and recommendations about restrictive practices. Participants agreed that any information made about restrictive practices should be in accessible formats such as Easy Read and Plain English, with one participant stating “A lot of people don’t understand the rules because they’re too complicated.” Some participants expressed concern that the rules will not be followed if a new framework is implemented, stating “It is about actually implementing the rules that the government makes.” This participant stated that regulatory bodies such as the NDIS Commission need to act quickly if they receive reports of restrictive practices being misused or abused. One participant suggested that services could be fined if they do not follow the rules for restrictive practices.

A participant emphasised that restrictive practices need to be checked regularly if they are being used, stating the practices should be checked “every 3 months or shorter. 3 months is enough time to work with the participant around goals and change behaviours.”

One participant, with complex communication needs and a Behaviour Support Plan approving restrictive practices, provided the following recommendations, in their own words:

“I think advocacy including citizen’s advocacy, Guardianship and circle of support should be resourced. More access through inclusive practices will safeguard us.

The importance of education in positive support from early years will ensure negative behaviours are stemmed out before they become rooted.

Good support is important. Active support is good support.

When restrictive practices are in place, it is important to have a behaviour plan with a lot of positive strategies. To get a good support plan we need formal training for support workers and good behaviour support practitioners.”