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Staff perceptions following a training programme about reducing psychotropic medication use in adults with intellectual disability: The need for a realistic professional practice framework

~~Qualitative study of experiences of SPECTROM programme~~

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Abstract

Background

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Adults with intellectual disability are at higher risk of being administered psychotropic medications. The SPECTROM training programme educates disability support workers on psychotropic medications and alternatives to these medications.

Method

Interviews were conducted with 10 participants who took part in the pilot SPECTROM training programme to elicit their views on the programme and its appropriateness in an Australian context.

Results

The key theme was: 'Need for a psychotropic medication practice framework'. Four sub-themes were: Broad satisfaction with the SPECTROM training programme; Disability support workers acknowledging the limitations of their scope of practice; Empowering training through prescriptive and reflective methods and; Need for future mentoring from Multi-Disciplinary Team members in the application of new knowledge.

Conclusions

Participants felt that whilst they could improve their knowledge and attitudes surrounding psychotropic medication administration for behaviours of concern through SPECTROM training, a national practice framework is needed to execute its goals at scale.

Keywords

alternatives to medication
chemical restraint
disability support worker
education
non-randomised pilot study
nursing
training

1. INTRODUCTION

Up to 60% of adults with intellectual disability may display behaviours of concern (Deb, Unwin, et al., 2022). Despite the poor evidence for the effectiveness of psychotropic medications in managing behaviours of concern (Deb, Roy, & Limbu, 2022), they are used widely among adults with intellectual disability (49%–63%) and are often prescribed in the absence of a psychiatric diagnosis (Sheehan et al., 2015). Previous research demonstrates that 71%–78% of those receiving antipsychotics did not have a severe mental illness such as psychosis or the indication of their use was not recorded (de Kuijper et al., 2010; Sheehan et al., 2015). The use of psychotropic medications, in the absence of a psychiatric diagnosis to control or subdue a person, has been previously defined as chemical restraint (Donley et al., 2012). Between July 2020 and June 2021, over 585,000 instances of unauthorised chemical restraint were reported by Australian disability service providers (NDIS Quality and Safeguards Commission, 2021). In March 2022, the regulatory agencies for the Australian health,

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aged care and disability sectors released a joint statement about their support for collaborative action on the use of psychotropics without appropriate indications (NDIS Quality and Safeguards Commission, 2022). There is a critical need to shift the prescription and oversight of psychotropic medications in adults with intellectual disability, given the high rates of adverse side effects (Donley et al., 2012).

Changes in the delivery of care for adults with intellectual disability in Australia have meant that supportive care is provided predominantly by disability support workers (Iacono, 2010). Despite the increasing complexity of the people supported within the sector, there is a reported lack of support, knowledge and education available to disability support workers (Iacono, 2010). In Australia, disability support workers are expected to hold the equivalent of a 'trade' certificate, a short 6-month full-time certificate III course, however not all disability support workers hold such a qualification (Iacono, 2010; Moskos & Isherwood, 2019; TAFE NSW, 2022). Previously, many adults with intellectual disability had either oversight or direct care and support from registered nursing staff, who are regulated health professionals with professional qualifications to oversee the use of psychotropic medications (Donley et al., 2012). Contemporaneous to the shift in care delivery models, there is now a lack of clear legislative policy and regulation surrounding medication management and the education requirements for staff overseeing medication handling and administration in disability services (Duckworth & Wilson, 2022). Previous research suggests that disability support workers are aware of their limitations in this area of practice, and desire further knowledge (Donley et al., 2012). There are, however, several concerning factors relating to the Australian disability workforce, noted to be highly casualised, low paid, poorly trained and with high staff turnover (Baines et al., 2019; National Disability Services, 2018).

In the United Kingdom ~~(UK)~~, an online resource supported by face-to-face training workshops, called SPECTROM (Short-term PsychoEducation for Carers To Reduce Over Medication of people with intellectual disabilities) (<https://spectrom.wixsite.com/project>) was developed primarily for disability support workers as a tool to increase their knowledge surrounding psychotropic medications and non-pharmacological alternatives (Deb et al., 2020). SPECTROM's aim is to empower, inform and equip disability support workers with knowledge to understand the person they support, handle their own psychological responses to others behaviour, advocate on behalf of the person they care for and take the views of adults with intellectual disability fully into account. A UK pilot study of SPECTROM included interviews with 20 disability support workers which showed the training helped to (a) change staff attitude towards behaviours of concern and its management; (b) improve self-reflection; (c) improve knowledge; (d) improve the support provided to adults with intellectual disability; and (e) feel empowered (Deb et al., 2021). Nevertheless, unlike the United Kingdom, Australian disability support workers do not have access to and support from Community Intellectual Disability Teams that comprise clinical psychologists, community intellectual disability nurses, psychiatrists, behaviour therapists, speech and language therapists, occupational therapists and social workers (Mafuba & Gates, 2015) to support their practice in such complex areas as reducing psychotropic medications. An Australian SPECTROM non-randomised pilot study was therefore completed in 2021, to gain insight into the appropriateness of this training for the Australian disability support workforce before developing the SPECTROM intervention further in the local context.

2. AIMS

1. Explore Australian disability support workers perceptions of the SPECTROM training, including the content, delivery and context.
2. Gain an insight into how Australian disability support workers perceived their role in this area of practice.

3. METHODS

3.1. Intervention

The SPECTROM training programme consisted of ~~eight~~ 8 hours of training, the first ~~four~~ 4 hours (Medication/STOMP Module One) focused on psychotropic medication and the second ~~four~~ 4 hours (Alternatives to Medication Module Two) focused on alternatives to medications for behaviours of concern. During the training, participants were also taken through the SPECTROM website to highlight where to locate a range of free and accessible resources to support them in their day-to-day work. The goal is that disability support workers should be able to use the new knowledge and resources to work as a key part of the multidisciplinary team to support the appropriate and safe reduction of psychotropic medication use in the adults they support.

Due to social isolation requirements at the time, the training was delivered virtually, across multiple days. Two trainers were present for each session delivered, as well as a technical assistant. Three of the trainers were registered nurses with expertise in supporting adults with intellectual disability and complex support needs, and the fourth was a registered psychologist with expertise in behaviours of concern.

3.2. Research ~~d~~Design

This non-randomised pilot study forms part of a larger mixed-methods evaluation of the appropriateness of the SPECTROM training programme in Australia. This involved using questionnaires to assess participants knowledge of psychotropic medication and attitudes towards the use of medication to address behaviours of concern in people with intellectual disability before and after SPECTROM training as well as interviewing several participants. This paper solely presents rich qualitative data from post-intervention interviews. Outcomes data is presented in a separate paper (Wilson et al., 2023). As this aspect of the study was exploratory in nature, a qualitative research design using individual interviews was utilised (Beail & Williams, 2014). The Consolidated criteria for Reporting Qualitative research (COREQ) checklist was used for quality control, see [Supplementary-Supporting Information File S1](#).

3.3. Sample and setting

The research team worked in conjunction with a large Australian disability service provider—Life Without Barriers—who provides community-based shared accommodation for adults with complex needs, commonly known as ‘group homes’ in Australia. Using a convenience sampling approach, six group homes across two Australian states (New South Wales and Victoria) were available to participate in the research project. Each group home averaged six full-time disability support worker positions, however, the actual number of staff who worked in each group home varied considerably due to the diverse mix of full-time, part-time, holiday cover, and casual staffing. For a group home to be included in the study, they needed to have at least

one adult currently living there that was on at least one short or long-term psychotropic medication. Invitations for staff to participate in the project and subsequent training programme were disseminated via work emails by senior staff at the service. Potential participants could then self-elect to take part in the study and training programme. There were no criteria for how long a participant had worked at one of the chosen group homes or the role that they had within the group home. Following the completion of the training programme, emails were sent out to participants who had selected in a pre-training survey that they would be interested in completing an interview.

3.4. Participants

~~33~~ Thirty-three participants completed the training. The majority of those that completed the training were female (76%), disability support workers (39%) or house managers (42%), and had been working in the disability sector for more than 5-years (94%). Of the 33 participants who completed the training, 17 consented to an interview prior to the training, with 10 agreeing to be interviewed post-training. All interviews were completed between December 2021 and January 2022. Table 1 provides a summary of the interview participants demographic data. All staff who agreed to be interviewed worked in management or supportive positions, with no front-line disability support workers participating in an interview.

3.5. Data collection

Participants selected the time and date of the interview; all interviews were semi-structured and were conducted virtually over Zoom. A set of questions as a topic guide was developed for the UK SPECTROM pilot study (Deb et al., 2021) and these questions were used as a guide, see Table 2 for a list of interview questions. Open questions and prompts were used by the interviewer, a registered nurse skilled in conducting interviews, but who was not one of the programme trainers. Interviews were recorded digitally and transcribed verbatim, with the shortest interview being 37 minutes and the longest 94 minutes.

3.6. Data analysis

The first author analysed the interview transcripts using the six-step thematic analysis process: (1) “data familiarisation and writing familiarisation notes; (2) systematic data coding; (3) generating initial themes from coded and collated data; (4) developing and reviewing themes; (5) refining, defining and naming themes; and (6) writing the report” (Braun & Clarke, 2021, pp. 331). The first and last authors familiarised themselves with the transcripts, writing notes on the topics discussed. Initial data coding was completed for direct participants' quotes and these initial codes were then collated under sub-themes. Using the sub-themes, four main themes were generated, which then formed an overarching main theme. A codebook was used during the data analysis for developing and documenting the analysis.

3.7. Trustworthiness and credibility

Three of the authors (M.B., M.J., N.W.) reviewed all verbatim interview transcripts and video recordings of the interviews. Two authors (M.B., N.W.), both registered nurses (one a paediatric nurse with no disability expertise, the second with extensive background in health and intellectual disability), collaborated on initial coding decisions and defining each initial theme. These initial themes were then presented to the other co-

authors from diverse backgrounds including psychology, psychiatry, allied health, and public health, who reviewed each step of the data analysis, offering insight into the coding decisions and creating the final theme and sub-themes. Credibility was ensured through the discussions and member checking by the co-authors, who also provided rich insights to the data analysis and generation of themes. The interviewer had no prior experience in the disability sector, which reduced bias during data collection. Resonance with other researchers and colleagues also occurred during a governance meeting, where the theme and subthemes were presented.

3.8. Ethical considerations

The research project was reviewed and approved by the Western Sydney University Research Ethics Committee, project number H14559. All participants provided written consent to be interviewed and gave verbal consent to record the interview. Pseudonyms were added to interview transcripts, prior to any data analysis. There were no adverse events reported during the conduct of the study and no participants withdrew.

4. FINDINGS

The thematic analysis led to four sub-themes and one overarching core theme (see Figure 1): *the need for a practice framework about psychotropic medication reduction to ensure best practice*. Participant confidentiality has been protected by using participant numbers and job titles in all quotes. Participant quotes are presented in *italic* and words in square brackets are added by the researchers to aid understanding and narrative flow.

4.1. Need for a psychotropic medication practice framework

Interview participants overwhelmingly discussed their lack of knowledge of psychotropic medications, in the context of practice inconsistencies in their workplaces surrounding psychotropic medication administration. Participants felt that whilst they could improve their knowledge and attitudes surrounding psychotropic medication administration through programmes like the SPECTROM programme, without a practice framework, consistent reduction in the use of psychotropic medication would be improbable. Participants felt that this framework needed to focus on the forms of education disability support workers had when working with adults with intellectual disability, as well as mandated changes to the structure of workplaces to ensure continual medication reviews for clients prescribed psychotropic medications. Some participants felt that changes need to occur first with legislation, changing the requirements for all disability clients on psychotropic medications to be supported by multi-disciplinary team members with the right scope of professional practice to offer this support, as participants felt burdened with the risks and safety of their clients on high-risk psychotropic medications:

“This [Severe medication side effects] is actually even a failure in our current NDIS legislation. There is no requirement for a person on psychotropic medications to be under the guise of a psychiatrist.” (P2, Practice Support Co-ordinator)

“But we can't just grab all that [SPECTROM resources] and put it into, because we're doubling up and tripling up ... It's all got to come together, and we create a whole new system, but taking the best of everything.” (P4, House Supervisor)

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The four sub-themes were: Disability support workers acknowledged the limitations of their scope of practice; Empowering training through prescriptive and reflective methods; Broad satisfaction with the SPECTROM programme, and; Need for future mentoring from Multi-Disciplinary Team members in the application of new knowledge, see Figure 1.

FIGURE 1: Thematic analysis of findings

4.2. Broad satisfaction with the SPECTROM training programme

Participants generally enjoyed the online training mode of the programme, with some preferring face-to-face training and others enjoying the ease of virtual spaces. Those who preferred face-to-face training felt that if the training was delivered at workplaces, the scenarios that could be discussed could be more reflective of what the disability support workers experienced in their day-to-day work. Participants overall enjoyed the group discussions in the training programme, the way it was delivered, except for some technical difficulties encountered by one group.

Due to the programme originating in the [United Kingdom](#), some participants felt that changes in the material to ensure it reflected Australian culture and standards would be appropriate. The programme referred to UK services, such as community-based specialist teams, and participants felt that discussing local Australian services, would assist in the application of new knowledge:

“Maybe unpacking the services that are available in Australia and Victoria, because sometimes they change from state to state as well, the services that are available-... Maybe making those services really individual to each state.” (P10, Manager)

Participants saw value in having video stories of adults with intellectual disability discuss their needs and experiences with reducing psychotropic medication during the training programme, as it offered a stark reminder of the importance of involving people in their own care and challenged the status quo. The resources provided by the SPECTROM team were viewed positively, with real value in having new resources for their practice, as well as when engaging with their colleagues, their clients and their client's family:

“... that's what I took away from your session, the documentation with the medication. Because I loved all of these [Medication resources].” (P4, House Supervisor)

“... using those kind of tools [SPECTROM resources] has definite value and it doesn't matter if it doesn't look like it makes a difference because it might be five years later when they [The client] suddenly surprise you what they've actually absorbed.” (P2, Practice Support Coordinator)

Nevertheless, although all of the participants appreciated the new resources offered, some were hesitant to apply them into workplaces given the existing administrative burden:

“... we just need to streamline it. We need to work out where we're going to fit this [SPECTROM resources] in ... we just need to have a systemic way of introducing this suite of documents.” (P4, House Supervisor)

4.3. Disability support workers acknowledged the limitations of their scope of practice

Participants self-disclosed a lack of confidence and competence in medication knowledge and administration. Some participants felt uncomfortable when it came to medication administration given the large

variety of medications they were exposed to in practice, with each medication having their own purpose and subsequent side effects.

They reminded the interviewer that disability support workers are not healthcare professionals, but continue to need to advocate, support and monitor clients with intellectual disability who have complex issues, as well as handle serious medications. Participants discussed that any clients on psychotropic medications needed to have regular medication review follow-ups with their General Practitioner, however, some participants felt that they did not have the required knowledge to be an active member of decision-making to reduce these medications:

“We're taking people to appointment medication reviews all the time, and it's just a standard practice. Oh, well what did the doctor say? He said, “Well just give him another six months. Come back in a year.” No one's questioned anything. No one's knowing the right questions to potentially ask.” (P3, Manager)

Outside their acknowledgement surrounding medication knowledge and application, participants also felt that disability support workers needed to understand their client's individual uniqueness and care needs. Participants felt that many disability support workers do not have sufficient knowledge of how to handle clients displaying behaviours of concern, and often felt that the behaviour of concern was personal, and acted accordingly:

“I have slowly ... educated them [Disability support workers] around the fact that it's not necessarily personal. It's just the clients ... sometimes things are frustrating them or irritating them or agitating them or something they can't change. And the only way they can convey that is by a reaction and that reaction then maybe will get what they wanted or needed in the first place where some things are very difficult to convey in simple language.” (P8, House Supervisor)

Participants discussed how their attempts to seek out support and education was further diminished due to time constraints and workloads. Each group home was unique and it often fell to the House Supervisors and Managers to ensure all staff had the ability to seek out support and knowledge.

“So it's a very unique environment to work in and the team has to be really clued in to themselves and the people that they're supporting and each other and really looking after each other.” (P9, Practice Support Coordinator)

“It's resources, it's skill, and it's leadership, and it's education. We're dealing with people. It's working with people who don't have a Certificate IV, that don't have a background in disability.” (P6, Behaviour Support Practitioner)

All of the participants interviewed gave examples of case studies in their past work experiences that described the state of the disability sector and the issues and difficulties they had faced in this area of practice. The case studies described the lack of confidence and knowledge felt by many disability support workers and the need for further education and training:

“... when I was in as a house supervisor and I came in for a shift and they [The client] were in their pyjamas at four o'clock in the afternoon. And they'd had their showers. And I said, “What, if they want to go for a walk or go down and have a coffee or do something? They're in their pyjamas.” “Oh, but they want to.” And I go, “Do they want to or is it that you've embedded it, that this is your expectation?” And what came out of it was I found out later that it was only when I was on shift, that she changed that behaviour. And I said to the other

staff ... Why [Not] say anything?" She said, "You're only there for six months." She said, "The minute you leave, it's going to go back." (P6, Behaviour Support Practitioner)

4.4. Empowering training through prescriptive and reflective methods

All participants enjoyed the training programme and found it an important subject area. They found the information delivered across the **eight 8 hours** was clearly needed for frontline workers. Four of the 10 participants interviewed discussed how new the information they were learning was:

"... if I learned one thing out of the course a day, I benefited, but I know that every session that we did and every follow session, there was something that came out of it [SPECTROM]." (P6, Behaviour Support Practitioner)

Participants discussed the new knowledge that the training programme gave them and reflected on how they could apply this new knowledge:

"... what it [The SPECTROM programme] would do ... increase my knowledge-base to ask questions like, "Okay, well, is this person's weight being monitored? Is their cholesterol being monitored?" ... It'll give me the knowledge to ask the right questions at those panels and get a full scope of what's happening and make recommendations about the kind of care that needs to be provided, if we're going to approve and authorise the use of chemical restraints." (P1, Manager)

Participants discussed that the training programme delivered basic information on a range of topics that were appropriate to the level of knowledge and capacity of a disability support worker, but they would have preferred to have more in-depth training of the important topics covered. Module One (psychotropic medication) filled a knowledge gap and taught participants to challenge the status quo of practice in medication management and administration, giving them more confidence when dealing with psychotropic medications:

"Building confidence. Building knowledge, so that people can have those conversations and ask those questions. "Well, I've never heard of this medication before, so what are the side effects? What should I be looking out for?" And also having the confidence to question, well, this person's being on this medication for 10 years. Do they really need to stay on it?" (P9, Practice Support Coordinator)

"I think the things that influenced me the most was the understanding of medications and those side effects ... something that the training made me realise is that I am not as across side effects and contraindications as I can be and should be." (P1, Manager)

Participants held opposing views over the benefit of Module Two (alternatives to medications for behaviours of concern). Some believed that it was important to discuss self-awareness and setting healthy habits, whereas other participants felt that Module Two was not new information. The participants who enjoyed Module Two found the scenarios and case studies discussed to be empowering and profound, allowing them to reflect on how they personally would handle difficult situations and their own self-awareness:

"That was a good module [Module 2]. Although a lot of those factors I'm faced with on a daily basis, where people don't actually look at their own actions and how they're setting ... it's confidence." (P6, Behaviour Support Practitioner)

Whilst some aspects of Module Two enabled them to reflect and relearn previous training, they felt that the Module focused a lot on the disability support worker's own self-awareness, which could make some disability support workers feel blamed for how they felt about caring for challenging clients:

“I just would be careful with that week three bit, because if a DSW [Disability Support Worker] saw that, they would think that it was their fault. That's how I kind of took that. It wasn't looking at it from a holistic perspective.” (P9, Practice Support Coordinator)

4.5. Need for future mentoring from multi-disciplinary team members in the application of new knowledge

Participants voiced the need for a practical component of the training programme within their workplaces to more easily convert the knowledge into viable skills and meaningful change. Although the usefulness of self-directed and online learning was noted, having a face-to-face component could assist to ensure accountability to disability support workers to attend the workshops and ensure allocated time and space is given for new learning. Participants also felt that the face-to-face element of the training programme would assist in taking the new knowledge gained from the training programme and applying it into real-life situations:

“... that [further SPECTROM training] would give the group home and everyone the supports and understanding. Not only do they know what they're doing, but there are people there who are around so they can ask questions, find out more information, understand what the plan is, understand what can be done if it doesn't go according to plan and the supports around and taking the responsibility off people getting anxious about change or what's going to happen if something goes wrong.” (P8, House Supervisor)

“... you could really reinforce it [SPECTROM] with a practical element. I mean, you could go in and just say, “Okay, we've got your house, you've got five participants in here, we focus on one participant, and we're going to apply everything that we talked about in the SPECTROM training, and we are going to discuss it ...” (P5, Behaviour Support Practitioner)

When discussing the after-effects of the training programme, participants also discussed in detail the issues they faced between themselves and members of a client's Multi-Disciplinary Team, especially surrounding psychotropic medication and behaviours of concern. Some participants felt that members of the Multi-Disciplinary Team needed to have more of a presence in their client's healthcare and take accountability for the management of psychotropic medication administration:

“I think involving a lot of people in the review, it takes responsibility off support staff, especially if the support staff don't have the knowledge or training in medications and health conditions.” (P8, House Supervisor)

When discussing their relationships with members of the Multi-Disciplinary Team, participants also felt that medication reviews should be more streamlined to protect the safety and well-being of their clients, as well as making all members of the client's care team more accountable for their own subject matter area of expertise:

“You can have a GP prescribing something as an interim measure until they see a psychiatrist and you would think you could trust the GP to go, “Well, this is not right. They should be seeing a psychiatrist...” ... but if they don't say that and the person doesn't have family looking out for them, they're vulnerable.” (P2, Practice Support Coordinator)

Other participants had previously had negative experiences when assisting clients to liaise with members of the Multi-Disciplinary Team and found that these experiences could have detrimental effects on their client's health and possible medication reduction

“Some of them [Health professionals] are really rude-... They're busy, they don't get it. They don't get disability. They hate it when our clients trash their office or aren't compliant with what they want to do. There's

very few psychiatrists and health professionals that really understand what's going on for most of our clients.”²²
(P9, Practice Support Coordinator)

There also needs to be clearer links and development of relationships between disability support workers and members of the Multi-Disciplinary Team, who participants felt would also benefit greatly from attending some form of a SPECTROM training programme:

“I'd like to build a really collaborative partnership with all of my allied health professionals, because we're here for the same reasons, and I'm a really big believer in picking somebody's brain, because it is, it's multidisciplinary team approach, but you can only have quality people.” (P4, House Supervisor)

“Doctors always say to you, Oh, these are the side effects, and they usually dissipate after a couple of weeks. But they don't talk about the behavioural side effects that occur with medication. They talk about things like, sleep, apnoea and nausea, all of those clinical things. Whereas they don't necessarily bring up the behavioural things.” (P10, Manager)

5. DISCUSSION

This study is the first to explore the appropriateness of a rigorously developed training programme to reduce the use of psychotropic medication in adults with intellectual disability in the Australian context, by empowering staff with the right knowledge and tools to develop the confidence to deal with the difficult issue of addressing behaviours of concern. As noted previously, the use of unauthorised chemical restraint is at an alarming level in Australia (NDIS Quality and Safeguards Commission, 2022) suggesting the need for urgent policy and practice attention, perhaps even wholesale reform, in the overall use of psychotropic medications. Further, ‘off-label’ prescription of psychotropic medications is not uncommon in vulnerable groups such as older persons, children and those with mental health conditions (Bell & Richards, 2021). The literature is clear that adults with intellectual disability remain at persistently high risk of being prescribed psychotropic medications as a form of chemical restraint and behavioural/symptom management, which is outside their intended indications (Song et al., 2020). Created in the [United Kingdom](#) using the Medical Research Council guidelines for the development of complex interventions (Craig et al., 2010), evaluating the appropriateness of SPECTROM in the Australian context is a vital step towards the goal of better supporting Australians with intellectual disability who are prescribed psychotropic medications using a fully controlled trial.

The findings of this qualitative study are similar to those found by Deb and colleagues (Deb, Limbu, et al., 2022) during their recent focus group interviews of support staff, house/service managers and positive behaviour support trainers in the [United Kingdom](#) where they discussed their perceptions and views on the use of psychotropic medications for behaviours of concern in people with intellectual disability. In this study, participants broadly enjoyed the training despite several noted barriers, such as time and work pressures, and felt empowered by gaining new knowledge, as they did in the UK pilot study (Deb et al., 2021). Nevertheless, the stand-out point specific to Australia relates to the question of scope of practice and what can, or should, be expected from disability support workers, who are non-health professionals and [do not](#)²³ have ready access to community-based multi-disciplinary teams as they do in the [United Kingdom](#) (Wilson et al., 2022). Although the interview participants were more senior disability support workers with greater experience than most, the findings of this study indicate an explicit need for the development of a practice framework that includes the

right members of the multi-disciplinary team to underpin achieving the ultimate outcomes of SPECTROM—a reduction in the use of psychotropic medications.

When considering issues of a practice framework for psychotropics, the crux of the matter rests, both legally and morally, on the appropriate scope of practice. With respect to supporting adults with intellectual disability who are prescribed psychotropic medications, gathering the right information, effective and appropriate decision-making, and clear/measurable actions are vital. Moreover, close monitoring of the person—incorporating physiological, social and behavioural symptoms—during any reduction in what are a very powerful class of medications, is also key. These areas of practice are covered by the SPECTROM training and resources. What the findings of this study show, however, is that disability support workers not only identify limitations to their scope of practice, but also the need for mentoring from a health professional with the right scope of practice to underpin this complex work. In Australia, the vocational Certificate III covers topics such as providing individualised support to meet personal care needs, providing help with domestic duties, helping clients navigate the NDIS landscape and gain access to other services, empowering clients to reach their independence and social inclusion goals, using discretion and judgement in a variety of circumstances, and working with a range of diverse clients using a strengths-based approach (TAFE NSW, 2022). Assuming that the disability support worker has a vocational Certificate III in disability support, and the data suggest that this is not the minimum standard for being a disability support worker (Baines et al., 2019; National Disability Services, 2018) the fact is that they will have attained zero theoretical or practical education about complex health problems, pharmacology, psychotropic medication, or complex behaviour support. As noted by Duckworth and Wilson (2022), the law around medication administration and management within Australian disability services is in a state of legislative limbo, where only Tasmania requires Certificate III trained disability support workers to have undertaken an elective unit in medication administration. Yet, even this elective unit does not cover pharmacological agents and their side effects, nor anything about pathophysiological pathways across various human body systems, which are all vital interrelated issues when reviewing someone's psychotropic medication for considering reduction.

In line with the need for new national legislation for medication administration in Australian disability services, regulations aligned with these laws must strike a balance between the scope of practice of the various workers who are employed in disability services, and the thresholds where medication complexity necessitates that registered nurses must oversee this complexity. For instance, this complexity could be defined by the number of underlying chronic illnesses, the complexity and invasiveness of administration, the risk of adverse side effects, as well as the use of psychotropic medications. Such regulations should be supported by professional associations, such as the Professional Association of Nurses in Developmental Disabilities, Australia (PANDDA), who should develop position statements around the scope of practice for registered nurses working in disability services with respect to medication oversight, delegation to unlicensed workers, and managing such complexity. Crucially, disability support workers are not regulated health professionals and in the Australian context although they have a national code of conduct that they are obliged to follow, this falls well short of the standards, regulation, and training benchmarks that health professionals must meet. Although there is no international gold standard for unlicensed workers administering medications to vulnerable adults, studies have suggested that targeted training, delegation and oversight by a registered nurse offers a model

suitable for community-based living (Spellbring & Ryan, 2003). That is, delegation as it is defined by the Nurses and Midwives Board of Australia (NMBA), and not a reallocation of the role of registered nurses to disability support workers (NMBA, 2020). We would argue that such a model would be limited to the straightforward administration of pre-packed oral medications, and not the more complex, and potentially harmful, types of medication dispensing and administration routes.

Reflecting upon the practice limitations noted by study participants raises the question of who does have the scope of practice to oversee this complex area. In the [United Kingdom](#), disability support workers have access to community-based and specialised intellectual disability teams, which are referred to during the SPECTROM training. Although a multidisciplinary team, most of the roles within these teams are filled by specialised intellectual disability nurses who are the only health professional with the biopsychosocial scope of practice to provide oversight and support to individuals with intellectual disability and the staff who support them in complex practice areas such as reducing psychotropic medication use (Wilson et al., 2022). That is, allied health professionals, such as occupational therapists or speech pathologists, have a scope of practice that is focused on either functional participation or a particular body system. There are approximately 19,000 UK nurses with specialised qualifications in intellectual disability nursing (Gates, 2011). Although referred to by Gates as a ‘compromised workforce’, from the Australian context this amount of expertise might be viewed upon with professional envy as few, if any, health-specific roles exist in Australia. The size and location of the wider nursing workforce that directly support adults with intellectual disability in Australia is also largely unknown (Lewis et al., 2020). A way forward may be to identify how the scope of practice of Australian nurses can be harnessed to offer the needed support and mentoring to disability support workers in this area of practice. Whilst Australia does not have a national framework for psychotropic use for adults with intellectual disability, there are existing international guidelines for prescribing (Deb et al., 2009). These guidelines for prescribing may support the development of an Australian-based national framework that goes beyond appropriate and responsible prescribing to encompass the broader issues of day-to-day management and oversight of this complex area of practice, in particular where the aim is to reduce the use of psychotropic medications.

To this end, the development of a practice framework for the reduction of psychotropic medications should include direct registered nursing funding to anyone with intellectual disability and behaviours of concern who is prescribed psychotropic medication. This funding would support access to specialised registered nurses who can tie together all of the holistic needs of the person and support them, and the disability support workers who have been trained using SPECTROM, to proactively attempt to reduce dosages and/or psychotropic medication use via expert communication with the prescriber. For instance, if a person with intellectual disability who was demonstrating behaviours of concern had ~~eight~~ 8 hours of access to a specialised registered nurse, they could offer two annual visits of ~~two~~ 2 hours each, plus ~~two~~ 2 hours of supplementary research and report writing, to mentor the disability support worker through the structured process provided in the SPECTROM resources and communicating with prescribers.

5.1. Implications for a future **SPECTROM** training programme

The next step is to modify and develop an Australian version of SPECTROM that has clear links, notwithstanding the current inadequacies, to a national practice framework. Study participants have highlighted

that making the content of the training more relevant to their practice context is important, as well as considering the ideal mode of delivery that can realistically be situated in the context where the disability support workers are employed. Naturally, such suggestions still require significant buy-in and commitment from the disability service to follow through on the initiative. For instance, if delivered via online platforms, widening access to disability support workers from multiple settings may limit the ability to have detailed and relevant discussions about particular scenarios that can be more helpful in one setting. Once completed, the revised version of the training needs to be piloted further across different service settings, such as different Australian states and the inclusion of rural contexts where access to mainstream services often differs, with sufficient disability support workers of varying skill, experience, and confidence levels. As one part of such a study, qualitative data should then be incorporated into a rigorous appropriateness evaluation framework that covers domains such as the intervention experience, relevance, benefits, social and ecological validity, and change and continuation (Parsons et al., 2019). That is, it is critical to get the training programme to a level where the content is appropriate to the Australian disability support worker and the resources are a natural “fit” with the Australian context. Crucially, once these steps are taken, a controlled trial needs to be conducted to determine the effect of the training on reducing/rationalising the use of psychotropic medications in people with intellectual disability and behaviours of concern.

5.2. Limitations

The major limitation of the study was that although invitations to participate in an interview were given to all attendees of the training, no front-line disability support workers agreed to participate in an interview. This meant that these findings represent the voice of senior staff from the same disability service with information-rich experiences in addition to likely higher qualifications and more experience than most disability support workers. Nevertheless, this fact reinforces the need for a ‘fit for purpose’ practice framework that takes account of the scope of practice needed to do the work promoted by the SPECTROM training—to conduct medication reviews and to promote the reduction of psychotropic medication use—as the participants were some of the most experienced staff. As this was a qualitative study, the findings cannot be generalised to all settings for adults with intellectual disability and behaviours of concern nor all service providers who may differ in their approach to the recruitment of skilled staff and may have different emphasis on staff training.

6. CONCLUSION

This article offers qualitative insights from participants in a novel education programme aimed at reducing the use of psychotropic medication in adults with intellectual disability. Although a non-randomised pilot study, exploring the appropriateness of the educational intervention from the perspective of attendees is an important step towards modifying the intervention for a future controlled pilot study. This is an area of practice that is fraught with difficulty and, as the unauthorised chemical restraint data from the NDIS Commission suggest (NDIS Quality and Safeguards Commission, 2021), is in a parlous position. For the sake of many thousands of adults with intellectual disability and behaviours of concern, as well as the dedicated workforce of disability support workers who are doing their best, a robust and realistic debate needs to occur about scope of practice within the disability sector. Australia does not have access to intellectual disability community teams funded by the local health authority such as in the [United Kingdom](#) where SPECTROM was designed, where a

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wealth of expertise and highly specialised staff are available to adults with intellectual disability, their families and disability support workers. A practice framework that can support programmes such as SPECTROM to reduce the use of psychotropic medications for managing behaviour is urgently needed.

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~~**Data availability statement:** The data that support the findings of this study are available from the corresponding author upon reasonable request.~~

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CONFLICT OF INTEREST ~~disclosure~~

Three of the co-authors were employed by Life Without Barriers, who funded this project, for the duration of the study. The views of the authors are not the same as the views of their employers.

~~Ethics approval~~

~~The research project was reviewed and approved by the Western Sydney University Research Ethics Committee, project number H14559.~~

~~Participant consent statement~~

~~All participants who took part in the study provided written informed consent to the research team. Participants were eligible to withdraw consent at any time and anonymity of participants has been preserved in the publication of this study.~~

~~No clinical trial registration number.~~

AUTHOR CONTRIBUTIONS Authorship

Macey Barratt **MaB**: Research assistant, data curation, data collection, data analysis, writing, editing, reviewing.

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Mandy Donley^{MD}: Conceptualisation of research design, Participant recruitment, Trainer for programme, Writing, editing, Data analysis.

Moira Buchholtz^{MoB}: Trainer for programme, Writing, editing, Data analysis.

Victoria Smith^{VS}: Trainer for programme, Writing, editing, Data analysis.

Mikaela Jorgensen^{MJ}: Contributed to study design, data checking and interpretation, critical revision of the manuscript.

Shoumitro (Shoumi) Deb^{SD}: ~~development~~ Development of original protocol and programme, writing, editing.

Bharati Limbu^{BL}: ~~development~~ Development of original protocol and programme, writing, editing.

Nathan Wilson^{NW}: Conceptualisation of research design, Project leader. Overall supervision, Trainer for programme, Writing, editing, Data analysis.

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TABLE 1: Demographic data for participants who consented to be interviewed

Participant variables		<i>N</i> = 10
Gender	Male	3
	Female	7
Age (years)	Mean (range)	49.8 (29—63)
State	Victoria	6
	New South Wales	4
Country of birth	Australia	9
	Other	1
Highest qualification	TAFE	6
	Bachelor	2
	Post-graduate	2
Currently completing a qualification	Yes	1
	No	9
Job title	Manager	3
	House supervisor	2
	Behaviour support practitioner	2
	Practice support coordinator	2
	Operational support	1
Years at current workplace	<6 months	1
	1—3 years	2
	3—5 years	2
	Over 5 years	5
Works across multiple workplaces	Yes	7

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	No	3
Family member with intellectual disability	Yes	3
	No	7

TABLE 2. Interview question guide

What is your general impression of the training?
What did you find particularly helpful?
What did you find not so useful?
What would you like to change in the training if any?
Were the contents below or above your level of knowledge?
What did you think about the overall time taken for the training (pace of delivery)?
What did you think of the format of the training?
What did you think of the case studies?
What did you think of the discussion and your involvement in that?
What did you think of the video clips?
What did you think of the handouts?
What did you think of the tasks?
What did you think of the homework?
Did you have a chance to explore the SPECTROM site after the training session?
What did you think of the site (easy to navigate through, important information accessed through hyperlinks, too much information, too little information, too confusing, hyperlinks are useful so that you can take your time to explore each module in detail etc.)?
What did you think of CATS (would this be useful in your day to day practice, would you use it)?
What did you think of the Yellow book?
What did you think of the accessible medication leaflets (will you use them, when and how)?
Would you be able to use information in SPECTROM on a regular basis (if so, how)?
Has your own practice changed anyway because of the training (how)?
Has your attitude to addressing behaviour of concern or use of psychotropic medication for that changed because of the training (how)?
Do you think this training will be useful to your colleagues (why, how and if not, why not)?

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