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Nursing and Midwifery



REPORT OF THE RESEARCH PROJECT:

SHORT-TERM PSYCHO-EDUCATION FOR CAREGIVERS TO REDUCE OVERMEDICATION OF PEOPLE WITH INTELLECTUAL DISABILITIES (SPECTROM)

AN AUSTRALIAN FEASIBILITY STUDY



**BEHAVIOUR
SUPPORT**
Working with clients, families, carers and staff
LIFE WITHOUT BARRIERS



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DISCLAIMER:

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A photograph of a middle-aged man with short, light-colored hair, wearing a bright blue t-shirt. He is laughing heartily, with his eyes closed and his mouth wide open, showing his teeth. He is sitting at a table, and a white ceramic mug is visible in the foreground on the right. The background is softly blurred, showing what appears to be a window with some foliage and a string of red berries hanging down. The overall atmosphere is warm and joyful.

PREAMBLE

In 2020, Dr Jeffrey Chan from the Australian National Disability Insurance Scheme Quality and Safeguards Commission (The NDIS Commission), Mandy Donley from Life Without Barriers, and Associate Professor Nathan Wilson from Western Sydney University met to explore a shared interest in reducing the unnecessary use of psychotropic medication in people with intellectual disability. From here, a research partnership was developed, led by Western Sydney University, funded by Life Without Barriers, and with in-kind support from the NDIS Commission and Imperial College London. This partnership delivered Short-Term Psycho-Education for Caregivers to Reduce Overmedication of People with Intellectual Disabilities (SPECTROM) training to disability support workers for the first time in Australia and evaluated its feasibility in the Australian context. This report summarises the outcomes from this work.



BACKGROUND

Up to 60% of adults with intellectual disability may display behaviours of concern. Oftentimes, these behaviours are a form of communication, such as for pain, to gain something or to avoid something. Although there is not a lot of evidence suggesting that they are effective, psychotropic medications (medications that affect mood, behaviour, thoughts and emotions) are often prescribed without a psychiatric diagnosis to help manage such behaviours (Deb, Bertelli, and Rossi 2022, Sheehan et al., 2015).

“Behaviours of concern are escalated behaviours that can impact the wellbeing, rights or physical safety of an individual or those around them.”

(DEPARTMENT OF HEALTH AND HUMAN SERVICES, 2018)

Disability support workers are important in the lives of many people with intellectual disability. Their role often extends to influencing what types of support strategies are used, and this includes the prescribing and administration of psychotropic medications (de Kuyper & van der Putten, 2017; Donley et al., 2012). In the Australian context, although the scope of practice for disability support workers around health, both physical and psychological, remains unclear, providing appropriate training for them is vital. This extends to helping them to learn about psychotropic medications, as well as alternatives to them in order to try to reduce their use (Richter et al., 2012).

WHAT IS SPECTROM?

SPECTROM is a suite of resources developed in the UK to offer disability support workers a tool to increase their knowledge about psychotropic medications, and their alternatives (Deb, Limbu, Crawford, & Weaver, 2020). Not only does SPECTROM aim to educate and empower disability support workers, but also help them to better understand the person they support, regulate their own responses to others behaviour, and advocate for the people they support. For more information about SPECTROM, click on this link: (<https://spectrom.wixsite.com/project>)

WHAT IS ALREADY KNOWN ABOUT SPECTROM?

A pilot study in the UK showed that SPECTROM training offered several positive outcomes to staff who participated in the pilot:

1. Helped change staff attitude toward behaviours of concern and their management,
2. Improved staff's self-reflection skills,
3. Improved staff knowledge about psychotropic medications,
4. Improved the support to adults with intellectual disability,
5. Empowered the staff (Deb, Limbu, Unwin, Woodcock, Cooper, & Fullerton, 2021).

While these are wonderful outcomes, the disability support sector in the UK is quite different to Australia, as there are no Community Intellectual Disability Teams in Australia like there are in the UK. These specialist teams provide vital support to people with intellectual disability and their support staff from health professionals such as clinical psychologists, intellectual disability nurses, psychiatrists, behaviour therapists, speech and language therapists, occupational therapists and social workers (Mafuba & Gates 2015). This support includes health professionals with the scope of practice to support complex areas such as reducing psychotropic medications. Finding out if SPECTROM is appropriate and feasible in the Australian context is an important step in the goal to reduce the use of psychotropic medications in Australians with intellectual disability.

OBJECTIVES OF THE AUSTRALIAN PROJECT

1. Explore the feasibility of SPECTROM in the Australian context,
2. Identify if SPECTROM increased staff knowledge of psychotropic medication and attitudes toward behaviours of concern,
3. Describe Australian disability support workers' perceptions of SPECTROM,
4. Understand how Australian disability support workers perceive their role in this complex area of practice.

ETHICS APPROVAL

Approval was received from the Western Sydney University Human Research Ethics Committee (Project ID: H14559). No adverse events were reported.

SPECTROM TRAINING

SPECTROM training consisted of eight hours of training, divided into two, four-hour modules. The first module focused on psychotropic medications, and the second module focused on alternatives to medications for behaviours of concern. All training was delivered virtually using Zoom. One group of staff was based in NSW and the other in Victoria, with training for each group occurring on a different day and delivered by different trainers. The first module was presented by registered nurses with expertise in supporting adults with intellectual disability and complex support needs. The second module was presented by a registered psychologist (NSW) and a registered nurse (Victoria) with expertise in behaviours of concern and positive behaviour support.

MEASURING KNOWLEDGE, ATTITUDES, & TRAINEE FEEDBACK

The disability support staff completed three surveys:

1. *Psychotropic Knowledge Questionnaire (PKQ)*,
2. *Management of Aggression and Violence Attitude Scale, Revised, Intellectual Disabilities (MAVAS-R-ID)*,
3. *Trainee Feedback Questionnaire (TFQ)*.

The PKQ was used to assess knowledge of psychotropic medications and is a 50-item questionnaire with a maximum score of 50. Higher scores = greater knowledge. Eight items were focused on individualised approaches to supporting medication use/review/withdrawal in people with intellectual disabilities. Forty-two items covered clinically important items such as: different drug classes, serious adverse

THE DISABILITY SUPPORT STAFF

A total of thirty-three staff completed the entire eight hours of the training programme. Of these, ten were interviewed once the training had been completed.

THE DISABILITY SUPPORT STAFF		N = 33 (%)
Gender	Male	8 (24)
	Female	25 (76)
Age (years)	Mean	45
	Range	21 – 63
State	Victoria	11 (33)
	New South Wales	22 (67)
Highest qualification	Vocational Certificate	22 (67)
	Bachelor's Degree	5 (15)
	Post-graduate Degree	5 (15)
	Not reported	1 (3)
Job title	Disability support worker	13 (39)
	House/Operations Manager	14 (42)
	Practice support coordinator	3 (9)
	Health Professional	3 (9)

outcomes, common side effects, and minimum routine screening tests for people taking Risperidone and Lithium.

The MAVAS-R-ID assessed attitudes toward non-pharmacological approaches to supporting behaviours of concern. Twenty-two questions covered five domains: (1) internal causative factors, (2) external causative factors, (3) situational/interactional causative factors, (4) management-medication, and (5) management-non-medical. The MAVAS-R-ID has a maximum score of 110 and higher scores indicated an improvement in staff attitudes towards people with intellectual disabilities who display behaviours of concern.

The TFQ consisted of thirty-eight items and determined the applicability, acceptability, practicality, relevance and delivery of SPECTROM.

INTERVIEWS

Semi-structured individual interviews were used to gather feedback from some of the disability support staff who attended the training. The interviewer was a registered nurse who did not deliver any of the training. Questions were asked about experiences of receiving SPECTROM training, the content that was delivered, and how it was delivered. In addition, questions were asked about how applicable SPECTROM was to the Australian context.



RESULTS

KNOWLEDGE, ATTITUDES AND FEEDBACK

Following the SPECTROM training, there was a statistically significant increase in the disability support staff's knowledge of psychotropic medication (The PKQ). This significant increase in knowledge was recorded two weeks after the training ($p=0.004$), three months after the training ($p=0.005$), and also five months after the training ($p=0.011$).

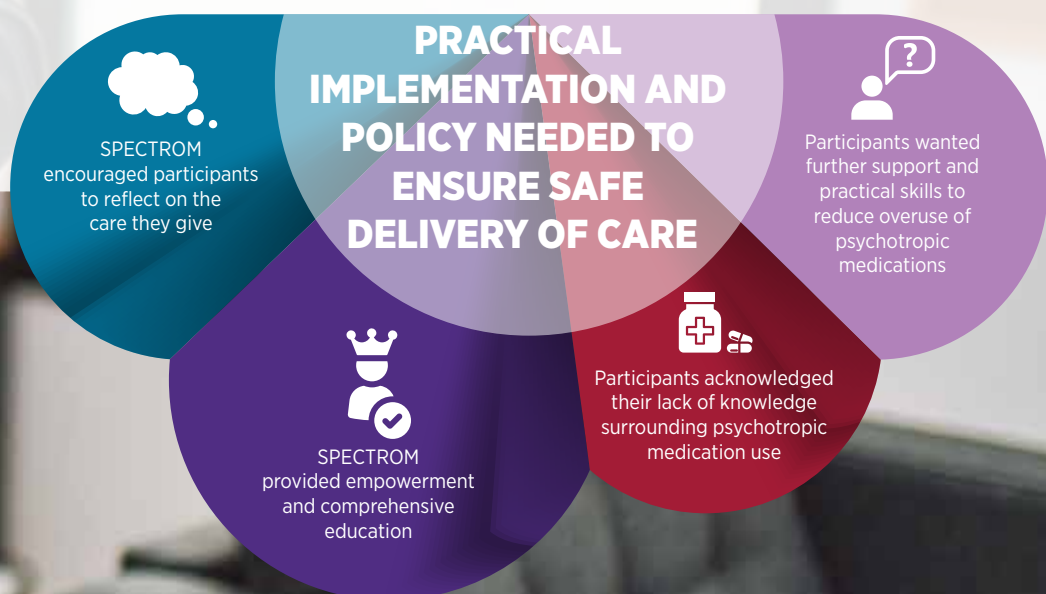
By contrast, after the SPECTROM training, there was no difference in the disability support staff's attitudes toward non-pharmacological approaches to supporting behaviours of concern. This was likely because the mean score before the training was already very high (101 out of a possible 110) and there was little room for improvement.

Two weeks after the SPECTROM training, the feedback questionnaire showed an 80% agreement that the SPECTROM training was appropriate, useful and valid.

DESCRIBING DISABILITY SUPPORT STAFF PERCEPTIONS

Disability support staff told the researchers that they had some limitations in their scope of practice around such complex issues as reducing psychotropic medications. Nevertheless, they felt empowered by the training through the range of prescriptive and reflective teaching methods provided and had broad satisfaction with the SPECTROM training. Finally, they suggested that they needed future mentoring from Multi-Disciplinary Team members, such as from nurses with specialised knowledge, to apply the SPECTROM goals in practice.

That is, although the staff had limited knowledge of psychotropic medications before the SPECTROM training, it could be improved through education such as SPECTROM. That being said, without a practice framework surrounding psychotropic medication use and their reduction, making meaningful changes was improbable. Mentoring frontline disability support workers would be ideal to help decrease the use and dependence on psychotropic medications in managing behaviours of concern.





[SPECTROM] left me with a sense of, when I have capacity to maybe unpack people's current mental health conditions, current behaviours, medications that are linked to those and associated with them, and ensuring that we're on the right track, we're doing the right thing for those people, we're advocating correctly for them ... making sure that all staff are little more focused in that space.

It's about training people. It's not about individual people. It's not about what you're doing in the group home ... this is beyond disability support worker education training anyway. But this is how do we best support you to best support the client.

STAFF PERCEPTIONS OF THE SPECTROM TRAINING COURSE

Being a disability support worker, [SPECTROM] will give you the confidence to say, “Hey, well, what about this?” Or, “Hey, have you seen that? I can show you it. And what do you think about that. Maybe that might be suitable for this client.” And just get the chat going.

I think, if it’s completely new subject matter for that person, they’re going to need assistance, they’re going to need practical experience on top of the SPECTROM training.

If you want to make a real change, I think the starting point is educating and providing information, but then what’s going to be put in place to actually make sure that this happens?



WHAT WAS SIGNIFICANT ABOUT THIS RESEARCH?

1. This was the first Australian study that assessed the feasibility of the SPECTROM training program for disability support staff
2. SPECTROM helped to improve disability support staff's knowledge of psychotropic medications. This is important as they are at the frontline of administering psychotropic medications as well as being responsible for monitoring effectiveness and side effects.
3. Disability support staff generally enjoyed the SPECTROM training and found it useful in their work.
4. The disability support worker scope of practice in this complex area requires further investigation and regulatory clarity. Disability support workers are not health professionals, and future success likely requires the added expertise of specialised professionals such as nurses with expertise in this complex area of practice
5. This was a small study and so the results should be interpreted with caution. The study has offered an excellent starting point for showing ways to improve disability support workers knowledge about psychotropic medications and their attitudes toward alternatives to support behaviours of concern.





FUTURE RESEARCH

A future study needs more time and also the inclusion of data about whether the SPECTROM training does lead to the reduction of psychotropic medication use in people with intellectual disabilities. Following up on disability support workers practice over time will also show to what extent they use the SPECTROM resources in their day-to-day practice in the longer term.

A photograph of a woman with voluminous, curly, light-brown hair, smiling and looking towards the right. She is wearing a white collared shirt and a grey blazer. The background is a bright, indoor setting with a large green plant and a window with a view of trees.

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