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ASPIRE-Med project: a study protocol on an Australian psychotropic medicines training programme for disability support workers

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ABSTRACT

Introduction Overmedication of off-label use of psychotropic medicines to address behaviours of concern in people with intellectual and developmental disabilities is a major public health concern. Disability support workers (DSWs) play a pivotal role in supporting adults with intellectual and developmental disabilities who are prescribed psychotropic medicines. Therefore, there is an urgent need to train DSWs to help understand the appropriate use of these medicines. This paper describes the protocol of a project that aims to develop such a programme.

Methods and analysis A participatory action framework will underscore the programme and follow a Universal Design for Learning approach. It will be a co-production involving all stakeholders, including people with intellectual and developmental disabilities, their families, members of the disability workforce, healthcare professionals and educational designers. The programme will be developed using the following steps: (a) development of a consumer advisory committee and expert panel groups, (b) an online survey of learning needs analysis, (c) a rapid umbrella review of the relevant literature, (d) focus groups involving participants from different parts of Australia, (e) co-design events in four Australian cities, (f) field testing on 6–12 DSWs to determine any practical difficulties of implementing the programme, (g) a feasibility trial involving at least 1200 DSWs using a train-the-trainer model and online resources and (h) a mixed-method process evaluation using interviews of a purposive sample of trainees and online questionnaire survey.

Ethics and dissemination Ethics approval will be sought at each stage of the co-design process. Each step of the project will include an academic language paper and Easy Read report developed. The training programme will be shared across Australia, with DSWs able to complete the project for free. We expect the training will help improve DSWs' knowledge of appropriate psychotropic medicine prescribing in people with intellectual and developmental disabilities, confidence in effectively communicating with health professionals and using non-pharmacological approaches to support behaviours of concern, promote shared decision-making with clients, advocate for psychotropic medicine reviews by healthcare professionals, encourage positive interactions with people with intellectual and developmental disabilities and their families and self-reflection on their own behaviour and attitude can influence their client and behaviours of concern.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The training programme is developed using a co-design approach involving disability support workers (DSWs) and relevant stakeholders throughout the development process.
⇒ Multiple stakeholder groups, including people with intellectual and developmental disabilities, family members, healthcare professionals, disability professionals and subject matter experts, will support the project from conception to evaluation.
⇒ A pre–post study design will be used to evaluate changes in DSW knowledge and self-reported confidence regarding psychotropic medicines.
⇒ Recruiting a large and geographically diverse sample of DSWs across Australia may be challenging.

INTRODUCTION

The misuse and overuse of psychotropic medicines in people with intellectual and developmental disabilities requires urgent intervention. People with intellectual and developmental disabilities can experience adverse events or side effects from prescribed psychotropic medicines, some of which are serious and can lead to early death.[1 2] The Australian Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC) 2023 found substantial evidence to suggest that psychotropic medicines are being over-prescribed to people with intellectual and developmental disabilities. The DRC 2023 also found that in many cases, psychotropic medicines are used as a form of chemical restraint to manage behaviour in the absence of a diagnosed medical or psychiatric condition despite limited evidence to support

this approach.[3] International guidelines in prescribing psychotropic medicines for behaviours of concern recommend the use of psychosocial/behavioural interventions first and resorting to the use of psychotropic medicines only when non-pharmacological interventions have failed, are only partly successful, there is a serious risk of harm to the person or others and/or used to support psychosocial interventions.[4–7]

Disability support workers (DSWs), also known in international literature as community support workers, direct support professionals, direct care workers, care staff, support staff and paid support staff, are a group of professionals who work day-to-day with people with intellectual and developmental disabilities. DSWs have reported that they do not have sufficient knowledge about psychotropic medicines,[8] and research has shown that disability-specific training could enhance DSW understanding of these medicines and promote advocacy, which may reduce the inappropriate use of such medicines.[8] Training DSWs about psychotropic medicine information is therefore an important step in improving communication and advocacy in the disability and healthcare sector for people with intellectual and developmental disabilities. Therefore, we propose to develop a training programme, ASPIRE-Med (Awareness, Supportive Practices, Inclusion, Rights and Education on psychotropic Medicines), to directly address this priority area by improving DSW's knowledge and promoting informed decision-making around psychotropic medicines use for people with intellectual and developmental disabilities.

Training programmes have been previously developed to support the overuse of psychotropic medicines for people with intellectual disabilities. One example is the Short-term Psycho-Education for Carers to Reduce Over Medication (SPECTROM) programme.[9] SPECTROM is a United Kingdom (UK)-based programme aimed at reducing the overuse of psychotropic medicines in people with intellectual disabilities.[9] The SPECTROM programme primarily provides education and training to DSWs around the quality use of psychotropic medicines and alternative ways to support people with intellectual disabilities when they display behaviours of concern without relying on medicines and has been shown to improve knowledge and understanding of psychotropic medicines and attitudes regarding behaviours of concern.[9] Field testing of SPECROM in Australia (n=60 participants) and the UK (n=140 participants) has shown improvement in DSW's psychotropic knowledge and improved attitudes to addressing behaviours of concern without using medicine, leading to improved quality of life for people with intellectual disabilities.[10 11] However, participants reported that existing programmes were not contextualised to their work in Australia.[8] Based on international work that has developed contextual training for DSWs, this project aims to co-produce an Australian-based psychotropic medicines training programme for DSWs to improve their knowledge of and confidence in appropriate psychotropic medicine prescribing and thus reduce the overuse of inappropriate psychotropic medicines among people with intellectual and developmental disabilities.

METHODS AND ANALYSIS

This project is a mixed-methods intervention-based study that follows Participatory Action Research (PAR).[12] PAR focuses on working with consumers and community members, designed to acknowledge lived experience and subject matter experts, to bring about sustainable change in practice.[12] The principles of PAR focus on delivering social change, participation, empowerment of the community and collaborative research. A co-design model will be used to ensure community and all relevant stakeholders' representation at all steps of the intervention planning, development, implementation and evaluation.[13] By using a co-design model embedded within PAR methodology, the voice and expertise of people with intellectual and developmental disabilities, those who support them and healthcare professionals will be represented throughout all stages of the research process and within the training programme. This ensures that the training programme is developed 'by the community, for the community'. This work will be undertaken across Australia, including metropolitan, regional and rural areas. The training programme developed will be freely available to DSWs, both online and in person.

Groups included as part of community representation include the following:

- People with intellectual and developmental disabilities and their families. This includes people with mild, moderate, severe and profound intellectual and developmental disabilities where appropriate. Family members will support and represent the views of their people with intellectual and developmental disabilities where appropriate.
- Disability industry professionals, including DSWs, managers and behaviour support practitioners.
- Health professionals, including people from nursing, mental health, psychology, psychiatry, occupational therapy, speech and language therapy, occupational therapy, behaviour therapy, social work, general practice and general medicine.
- Government professionals from organisations such as the National Insurance Disability Scheme (NDIS) Quality and Safeguards Commission.
- Academics with a focus on educational development, pedagogy and simulation.
- Industry partners with expertise in developing online training resources.

Patient and public involvement

Community representation will occur through established partnerships with three Consumer Advocacy Groups (New South Wales Council for Intellectual Disability (NSW CID), South Australian Council on Intellectual Disability (SACID) and Victorian Advocacy League for

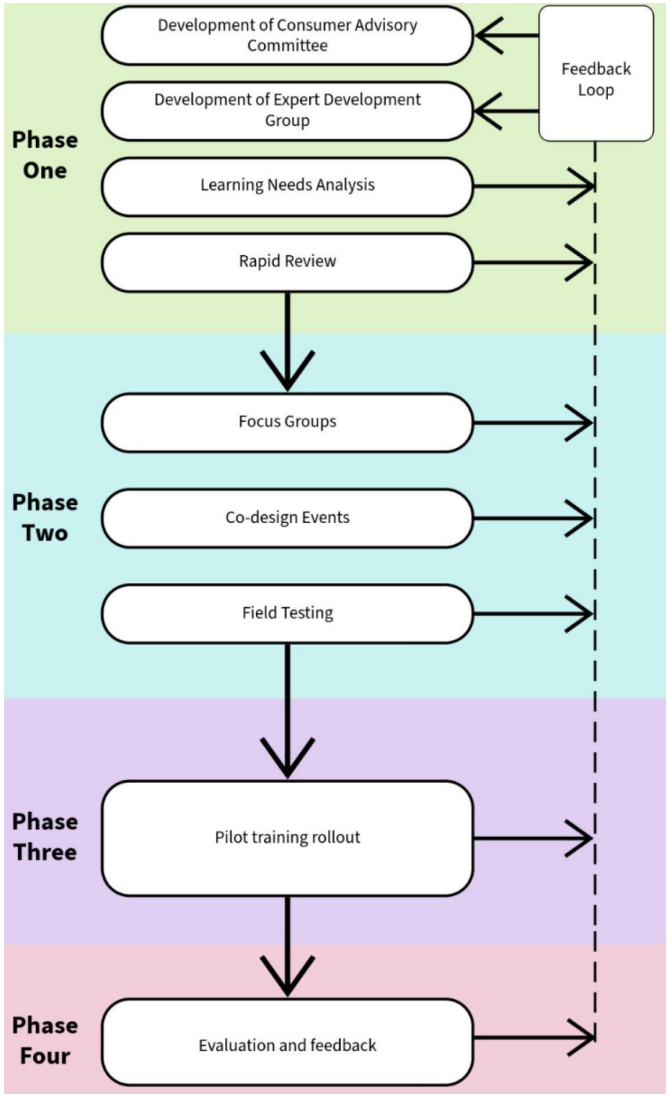

Figure 1 Flow diagram of study phases.

Individuals with Disability (VALiD)), industry partners (Aruma and Minda Inc.) and healthcare/academic partners (University of Canberra, Flinders University, the National Centre of Excellence in Intellectual Disability Health at UNSW Sydney, Monash Health and the Central and North West London National Health Services Trust (CNWL NHS UK)). The research team includes a community researcher with lived experience of intellectual and developmental disability to provide expertise as a subject matter expert and ensure the research and training accurately reflect the needs of the community.

Project plan

This study will consist of the following phases (figure 1), which will be discussed in further detail below:

Phase One: project governance.

Phase Two: development of the training programme, including online resources and field testing.

Phase Three: implementation of the training programme.

Phase Four: evaluation of the training programme.

Phase One: project governance

Phase One is broken down into the following components to help prepare the research team to understand the needs of psychotropic medicines training and planning of the training programme:

1. Creation of a consumer advisory committee (CAC).
2. Creation of an expert development group (EDG).
3. Completion of an online survey of DSW's learning needs analysis (LNA).
4. Completion of a rapid umbrella review.

Consumer advisory committee

We will establish a CAC, comprising people with intellectual and developmental disabilities and consumer advocates, to provide oversight of the project. The CAC aims to include people from diverse backgrounds, with people with lived experience as the primary members of the CAC. A total of eight committee members will be included in the group, comprising four people with lived experience of intellectual and developmental disabilities and their support staff. The CAC will be co-led by the community researcher and another member of the research team who will act as the CAC facilitators and report back to the research team. The role of the CAC will be to draw from their own experiences to inform and guide the planning of the project, the development of the training programme and all resources and documentation to ensure they meet the needs of the community and are accessible. The CAC will meet for 1 hour bi-monthly, with a set of terms of reference developed during the first meeting.

Expert development group

An EDG will be established, including subject matter experts from a range of disability, health and community backgrounds. A total of 20 experts will be sought. This group will represent subject-matter experts in the health and disability fields. The 20 members of the EDG will represent expertise within pharmacy, frontline disability staff, mental health, occupational therapy, psychiatry, general practice, nursing, pedagogy, psychology, behaviour support specialists, industry representatives from companies to help develop online training resources and education delivery, consumer experts, psychology and social work, with members recruited from government, health and industry organisations. The role of the EDG will be to share their expertise as subject matter experts, work with the research team on the development of the training programme and review and provide feedback on the training programme's content, layout, flow, methods of delivery and engagement. The EDG will meet monthly during the development of the training programme, with a term of reference developed during the first meeting.

Learning needs analysis

A LNA will be conducted to determine psychotropic medicine knowledge and confidence, needs and training preferences for DSWs employed across Australia. The survey questions will be developed by the research team, who have experience in conducting LNAs, and in consultation with disability service provider partners (Aruma and Minda). Some questions will be based on the contents and formats of the original UK SPECTROM training (https://spectrom.wixsite.com/project). Furthermore, the Australian Commission on Quality and Safety in Health Care (2024) Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard will be used to develop questions, as a national benchmark for safe psychotropic medicines use.[14] Industry partners will review the questionnaire and provide frontline staff feedback. The aim will be to recruit at least 90 participants across all Australian states and territories. An online Qualtrics questionnaire will be sent to service provider organisations in Australia who are partners in the study. They will then circulate the survey questionnaire among their DSW employees. The feedback will remain anonymous. Therefore, the research team will not know who returned the questionnaire and from which organisations. There will be options in the questionnaire to elicit respondents' views through free-text boxes. However, the survey will have questions on demographic data such as the participant's (a) age, (b) gender, (c) location of work in terms of different Australian territories, (d) level of education, (e) duration of working with people with intellectual and developmental disabilities and (f) the work setting. Questions will also cover participants' knowledge of psychotropic medicines and their confidence in administering them safely. We will also explore the participants' preferences regarding the programme's content and format and the methods of training delivery. The demographic data will help stratify the data and correlate DSWs' levels of knowledge and confidence with demographic variables.

Rapid umbrella review

We will conduct a rapid review of published reviews, systematic reviews and meta-analyses following the Prospective Register of Systematic Reviews guidelines.[15] Grading of Recommendations, Assessment, Development and Evaluations will be used to assess the strength of the evidence.[16] We will search the electronic databases CINAHL (Cumulative Index of Nursing and Allied Health Literature), Medline, Scopus, Web of Science and Google Scholar for the last 20 years' publications and import them into Covidence for data analysis. We are likely to explore the following areas of DSW training: (a) study populations, (b) training techniques and delivery methods, (c) background of the trainers, (d) curriculum content, (e) programme durations, (f) assessment and evaluation of training methods and delivery, (g) retention rates, (h) satisfaction scores and (i) measures used to assess post-training improvements in trainees' knowledge, confidence in appropriate and safe implementation of the tools and attitude toward behaviours of concern or any other targets for training.

Phase Two: co-production of the training programme

Phase Two is broken down into the following components to co-produce the training programme based on the experiences, preferences and needs of DSWs and other key participants and community members.

Focus groups

Focus groups with participants with intellectual and developmental disabilities and their family members will occur 'in-house' through consumer advocacy groups (NSW CID, SACID and VALiD). For healthcare workers and DSWs, an option to participate in person or online will be offered. Each focus group, consisting of up to 10 participants, is expected to run for 2 hours, with two groups planned per stakeholder group. A total of 80 participants will be recruited through purposive sampling to ensure representation across metropolitan, regional and rural Australia. A focus group topic guide will be developed by the CAC, EDG and the research team informed by the topic guides used in the original UK SPECTROM training development. This will guide discussions and document participant feedback during the focus groups. The aim of the focus groups will be to understand experiences surrounding psychotropic medicines and what the gaps are in training for DSWs on these medicines. All focus groups will be run by a member of the research team, with focus groups with participants with intellectual and developmental disabilities co-facilitated by the community researcher and consumer advisory group who have experience supporting this cohort. Focus groups will be audio-recorded and transcribed verbatim. The transcripts will be anonymised by providing participants with pseudonyms. Two members of the research team will analyse transcript data to provide consistency. Any disagreement will be resolved through discussion and, if necessary, by a third-party arbitration. The emerging themes from the focus groups will be shared with the CAC and EDG, who will support the research team in drafting initial learning outcomes and module content based on the focus group data. The themes emerging from the focus groups will also inform the next stage of the project: co-design events. Appropriate quotes from the focus groups will be included in the instruction manuals for the co-design groups.

Co-design events

The co-design events will take place following the focus groups to help develop the training programme, including learning outcomes, module content and format. The co-design events will take place across diverse locations to ensure broad representation (metropolitan, regional and rural areas). The co-design events will be attended by people with disabilities, family members, members of the disability workforce and healthcare professionals. The co-design events aim to co-create the training programme

by generating content and ideas such as module learning outcomes, theories to be embedded within modules, self-guided learning activities, resources, use of imagery, videos (including videos presented by people with intellectual and developmental disabilities and their families, DSWs, their managers and multidisciplinary team members, including nurses, psychologists, speech therapists, doctors and psychiatrists). It is anticipated that four co-design events will take place with 10–20 participants per day. During each co-design event, participants will be divided into 4–5 groups with equal representation from different stakeholder groups as much as possible. Each group will be provided with a specific theme for content and format development, including suggestions for case vignettes, if and where appropriate. Each group will discuss two different topics in the morning and the afternoon. A representative from each group will present a summary of their deliberations to the whole group for further discussion. A scribe will make a note of the discussion, which will be provided to the research team for analysis. This will be a reiterative process, in which the themes emerging from previous co-design events will be used to further develop the programme's content through discussions during subsequent co-design days. These themes will be further discussed in the CAC and EDG for deliberation and to inform recommendations for developing the training programme.

Creating the training programme

Following the co-design events, the training programme will be created, using a Universal Design for Learning (UDL) and person-centred approach. UDL is a framework that focuses on creating accessible education that values different cultural, educational and linguistic backgrounds.[17] The training programme will consider accessibility, backgrounds and different viewpoints in its development. The LNA, data from the rapid umbrella review, focus groups and co-design events will help shape the training programme and its content. The industry partners, in consultation with educational and pedagogical experts, will develop online resources that can be accessed on mobile devices, including phones, as well as tablets, laptops and other computers. Once a prototype of the programme is developed, feedback will be sought from the participating service provider partner organisations and their DSWs.

Field testing

We will field-test the face-to-face training and online resources among 6–12 DSWs recruited through a one of the partnered service provider organisations. Field testing will ensure that the programme meets the needs of DSWs and iron out any practical difficulties in implementing the training at a larger scale in the next stage.

A small number of DSWs will be able to provide feedback on the training to ensure usability of the programme at a larger scale.

Feedback and outcome measures will include the following:

- Pre-training and post-training assessment of participants' knowledge of psychotropic medicines will be measured using the Psychotropic Knowledge Questionnaire-Revised (PKQ-R)[11] and attitude to behaviours of concern using Management of Violence and Aggression Scale-Revised-ID (MAVAS-R-ID).[10] An online Training Feedback Questionnaire (TFQ) will be developed by the research team, following the items from the recent UK SPECTROM feasibility trial,[10] which focuses on the quality, relevance, practicality and applicability of the programme.
- A focus group run by the partnered service provider organisation and research team to identify how well the resource is understood and applied by participants, including barriers and enablers to implementation, technological, logistical or knowledge gaps identified by DSWs.

Phase Three: implementation

Phase Three focuses on the delivery and implementation of a psychotropic medicine training pilot programme with industry partners. The training will be delivered online and face-to-face, with 1000 DSWs recruited for online training and 200 DSWs recruited for face-to-face training, which could be delivered in person, or in a hybrid format.

The primary outcomes for both the online and face-to-face training will be as follows:

1. Improved knowledge, confidence and awareness for DSWs on psychotropic medicines (using the PKQ-R)[9 10] and a better attitude toward using medicines for behaviours of concern (using the MAVAS-R-ID).[11]

Secondary outcomes for the face-to-face training will include the following:

1. Satisfaction with training content and delivery (informed by the TFQ used within the field testing).
2. Reduced inappropriate use of psychotropic medicines for people with intellectual and developmental disabilities facilitated by medicine reviews completed by healthcare staff (such as general practitioners, psychiatrists or pharmacists where appropriate).
3. Improved confidence to advocate with and on behalf of people with intellectual and developmental disabilities, in negotiating an appropriate medicine review by the prescribers with the view to reducing the dose and eventually withdrawing medicine if and when appropriate.
4. Improved confidence to support their clients' understanding of their own medicines and improved decision-making by people with intellectual and developmental disabilities and their families.
5. Improved skills for using tools to observe/measure antecedents for behaviours of concern, document behaviour, monitor side effects of medicines and their client's quality of life.
6. Improved quality of life of people with intellectual and developmental disabilities supported by DSWs and

their families through reduced psychotropic medicine-related side effects.

Phase Four: process evaluation

Apart from the quantitative analysis of trainees' knowledge and attitude toward medicine use for behaviours of concern, we will use a mixed-methods process evaluation to assess the impact of the training, barriers and enablers for its implementation through interviews with a purposive sample of approximately 30 trainees and some people with intellectual and developmental disabilities and their families stratified according to gender, qualification, service experience and different geographic areas of the country, which will be supplemented by the online survey of all trainees using the TFQ.

Data analysis

Each phase of the project will employ a distinct but complementary analytical approach. In Phase One, the LNA survey data will be analysed using descriptive and inferential statistics to summarise participant characteristics and identify patterns relevant to the training context. Free-text reporting from the LNA online survey will be analysed using thematic analysis.[18] Data from the rapid review will be synthesised narratively, with evidence extracted, categorised and thematically summarised to identify effective approaches and gaps within existing training. In Phase Two, qualitative data generated through the focus groups and co-design events will be analysed inductively using constant comparative analysis to explore participant experiences and key priorities for the training programme. Emerging themes from the focus groups will inform the questions asked during the co-design events, which will, in turn, inform the development of the training programme. In Phase Three, mixed-methods analysis will be used to assess the feasibility of the pilot training project. Quantitative measures (eg, knowledge, confidence, attitudes to training and satisfaction scores) will be descriptively analysed, while qualitative feedback will undergo thematic analysis to refine content and delivery. Finally, Phase Four will use a convergent mixed-methods approach to evaluate implementation and outcomes, integrating quantitative findings with qualitative insights to provide a comprehensive understanding of the training programme's feasibility, usability and perceived impact.

ETHICS AND DISSEMINATION

Ethical approval will be sought at each milestone from University of Canberra Human Research Ethics Committee, with informed consent required from participants to participate in the training. Ethics approval was provided for Phase One of the project (14420).

For participants within focus groups and co-design events, informed consent is required. For participants who cannot provide informed consent but wish to participate in this phase, informed assent is required, with assent rather than informed consent sought from their guardian or next of kin.

Remuneration will be provided to participants who take part in the CAC, EDG, focus groups, co-design events and evaluation stages for their time and travel costs. No payment or financial contribution is required from DSWs or industry organisations to complete the training in the pilot programme. Data will be securely stored online for 5 years in accordance with the university's human ethics protocol.

Publications are expected at each phase of the training programme's development, with accessible Easy Read publications also produced. Further dissemination will be through the project website, which will publish regular newsletters with accessible versions. The summary findings will be circulated to all participants who wish to receive them and also posted on the websites of the partnering service provider organisations and other organisations (governmental, non-governmental and lived experience group organisations). Where appropriate, data will be disseminated through conference presentations.

Project timeline

The project commenced in July 2025 with setting up fortnightly research team meetings and recruitment for the CAC and EDG. The project duration will be 36 months. Phase One will occur through months 1–6. Phase Two will occur through months 6–18. Phase Three will occur through months 18–30. Phase Four will occur through months 22–36. There is some overlap between Phases Three and Four, as post-training surveys commence immediately after training. Phase Four interviews will be completed between 30 and 36 months.

DISCUSSION

International research suggests that psychotropic medicines continue to be frequently prescribed to people with intellectual and developmental disabilities, often in the absence of a psychiatric diagnosis.[2 19–21] These medicines can impact quality of life, lead to severe adverse effects and premature mortality.[22] The overuse of these medicines in the absence of a diagnosed mental health condition requires greater consideration and management.

This project aims to create and pilot an Australian psychotropic medicine training programme for DSWs who frequently support people with intellectual and developmental disabilities who are prescribed these medicines. The ASPIRE-Med training programme will aim to provide information on psychotropic medicines, communication, advocacy and alternative suggestions to psychotropic medicines. The ASPIRE-Med project is influenced by the original SPECTROM UK programme, which has demonstrated effectiveness in improving DSW knowledge and confidence surrounding these medicines.[8 10 11] Contextualising the training programme to the DSW profession of Australia, as well as community needs and geographical considerations, is important to ensure the training

programme meets the needs of the DSW community and can impact those they support in metropolitan, regional and rural areas.

Using PAR to co-design and co-produce the training programme with key stakeholder participation at all levels of the research will ensure community representation and design throughout the development of the training programme. Although the training programme will be developed primarily for DSWs, the resources developed will be useful to people with intellectual and developmental disabilities, their family members and healthcare professionals.

The potential implications of this training programme include improved support for decision-making, improved support for accessing non-medicine interventions and enhanced support for safe medicine use for people with intellectual and developmental disabilities. DSWs may increase their knowledge, confidence and understanding of psychotropic medicines, leading to safer administration, better care, stronger advocacy and improved quality of life for the people they support.

We expect the training will help improve DSWs' confidence in effectively communicating with health professionals and using non-pharmacological approaches to support behaviours of concern, support medicine reviews by healthcare teams, encourage positive interactions with adults with intellectual disabilities and their families and self-reflect on how their own behaviours and attitudes can influence the quality of life of adults with intellectual disabilities they support.

This training programme also sets an expectation of the use of co-design when developing training programmes for the disability workforce. Considering the experiences and expertise of people with intellectual and developmental disabilities, their family members, DSWs and health professionals is key to ensuring the training programme meets the needs of the community and is 'built by the community, for the community'. There are also systemic impacts to consider, such as the potential to scale up and strengthen DSWs' knowledge base nationally, ensuring they practise in line with national best-practice guidelines.

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