12-1-2022

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10.1111/jppi.12435
Raj, S. E., Mackintosh, S., Kernot, J., Fryer, C., & Stanley, M. (2022). Development and feasibility testing of an evidence-based occupational therapy program for adults with both Down syndrome and dementia. Journal of Policy and Practice in Intellectual Disabilities, 19(4), 396-407. https://doi.org/10.1111/jppi.12435

Received: 24 August 2021 | Accepted: 27 May 2022

DOI: 10.1111/jppi.12435

ORIGINAL ARTICLE

Journal of Policy and Practice in Intellectual Disabilities

Development and feasibility testing of an evidence-based occupational therapy program for adults with both Down syndrome and dementia

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Abstract

This paper describes the development of a home-based occupational therapy intervention program for people with Down syndrome who experience early on-set dementia causing a decline in their performance skills and increasing care dependency on their informal caregivers. A six-step methodological process adapted from the Medical Research Council framework for developing and evaluating complex interventions was formulated to develop an evidence-based occupational therapy program for people with both Down syndrome and dementia and their informal caregivers. The first two steps gathered evidence through systematic reviews of the literature and determined the scope of current occupational therapy practice. The gathered evidence was synthesised in step three to develop a client-centred occupational therapy intervention program for persons with both Down syndrome and dementia and their informal caregivers. In steps four and five, opinions were sought from occupational therapists working in this area of practice on the content of the developed program and its feasibility within the Australian disability services context. The final testing step can be conducted in the future using a single-case experimental design study. It is important to use rigorous frameworks and gather comprehensive evidence using multiple methods to develop interventions for small heterogeneous populations. The developed occupational therapy program for persons with both Down syndrome and dementia and their informal caregivers appears feasible to be implemented within the Australian disability services; however, funding limitations imposes barriers for its implementation in clinical practice.

KEYWORDS

adult, Down syndrome, intellectual disability, occupational therapy, practice, dementia

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Abbreviations: AAMR, The American Associations on Mental Retardation; ACT, The Australian Capital Territory; COPM, The Canadian Occupational Peformance Measure; DS, Down syndrome; IASSIDD, The International Association for the Scientific Study of Intellectual Disability; MRC, The Medical Research Council; NDIS, The National Disability Insurance Scheme; NSW, New South Wales; OPPM, The Occupational Performance Process Model.

INTRODUCTION

Early-onset dementia is a major health problem for adults with Down syndrome (DS) causing progressive loss of skills (disability) (Fonseca et al., 2020), and increasing care dependency on their significant others (Coppus et al., 2006; Janicki et al., 2010). Coppus et al. (2006) reported that dementia among people with DS is observed after 40 years of age with prevalence increasing with age (40–49 years = 8.9%; 50–54 years = 17.7%; 55–59 years = 32.1%). In addition, these individuals experience premature ageing-associated health issues such as visual and auditory impairments (Coppus et al., 2006) and musculoskeletal problems (Carr & Collins, 2014) affecting their participation and performance in daily occupations, and escalating caregiving demands on their informal caregivers (Janicki et al., 2010). Although there is growing epidemiological evidence describing age-related health issues experienced by this population (Carr & Collins, 2014; Coppus et al., 2006; Hithersay et al., 2018; Lott & Head, 2019), there is no guidance on how non-pharmacological interventions such as occupational therapy can be developed from the best available evidence to optimise participation and performance in daily activities for these individuals and to meet caregiving needs of their informal caregivers.

Many families of people with DS perform the role of an ‘informal caregiver’ for a prolonged period to avoid admissions to residential care for their care recipients (Carling-Jenkins et al., 2012). Informal caregivers are people who are not paid for their caregiving support but provide ‘hands-on’ care to enable people with health problems to maintain their independence in their daily activities (Roth et al., 2015). Generally, informal caregivers of adults with both DS and dementia are long-term caregivers and prefer to provide care as long as possible (Carling-Jenkins et al., 2012; Janicki et al., 2010). However, many informal caregivers experience increased physical and mental caregiving burden (e.g., physical burnout, depression) due to increasing caregiving demands from dementia-related issues such as behavioural issues and increased assistance with self-care activities without any formal support (Janicki et al., 2010). Jokinen (2014) proposed combining intervention programs for persons with both DS and dementia and informal caregivers similar to interventions with the informal caregivers of the general older population with dementia (Graff et al., 2006). However, there is a lack of occupational therapy evidence about how such programs can be developed and determined to be effective.

The American Association on Mental Retardation/International Association for the Scientific Study of Intellectual and Developmental Disability (AAMR/IASSIDD) practice guidelines for persons with both intellectual disabilities and dementia underscores the importance of tailored healthcare interventions for both the care recipient and their informal caregiver to support continuing care for the care recipient (Janicki et al., 1996). The tailored interventions involve adapting interventions to the residual skills of the care recipient and supporting the skills of informal caregivers in their caregiving practices. This recommendation was also highlighted in a survey of occupational therapists providing interventions for adults with both DS and dementia who reported that it was important to individualise interventions using a client-centred approach to obtain meaningful outcomes (Raj et al., 2020). From the available evidence, it is apparent that intervention programs for persons with both DS and dementia and their informal caregivers need to be framed using a client-centred approach (Sumsion & Law, 2006).

A client-centred approach for persons with both DS and dementia may involve applying specific concepts in planning and developing occupational therapy programs (Sumsion & Law, 2006). For example, the concepts of encouraging care recipients to make decisions concerning their interventions and collaborating with them to develop meaningful goals. Sometimes, it might be challenging to implement these concepts due to the person's cognitive and communication impairments (Stanton & Coetzee, 2004). However, occupational therapists can still apply strategies relevant to these concepts such as sharing information with the care recipient in a graded process and/or gaining assistance from their informal caregivers to facilitate the process (Hobson, 2006). Although a client-centred intervention program could be developed from the best available evidence for persons with both DS and dementia, it is unknown if clinicians can implement the intervention within the Australian National Disability Insurance Scheme (NDIS) practice context.

In Australia, the NDIS was introduced in 2016 to replace the National Disability Agreement Scheme (Parlimentary library, 2017) to promote an inclusive approach for persons with disabilities by providing ‘choice and control’ over their funding (Gilchrist, 2017). People with a disability receive ‘individualised funding’ to plan and prioritise their care and support needs (Parlimentary library, 2017) and choose service providers to meet their needs (Green et al., 2018). In this practice context, health practitioners are required to offer interventions that are grounded in the best available evidence to meet the specific needs of people with disabilities (National Disability Insurance Agency, 2021). In addition, health practitioners are required to provide justifications for their services to both service users and the NDIS funders to obtain funding. This paper describes how a systematic methodological process can be used to develop and evaluate the feasibility of an evidence-based home-based occupational therapy program for adults with both DS and

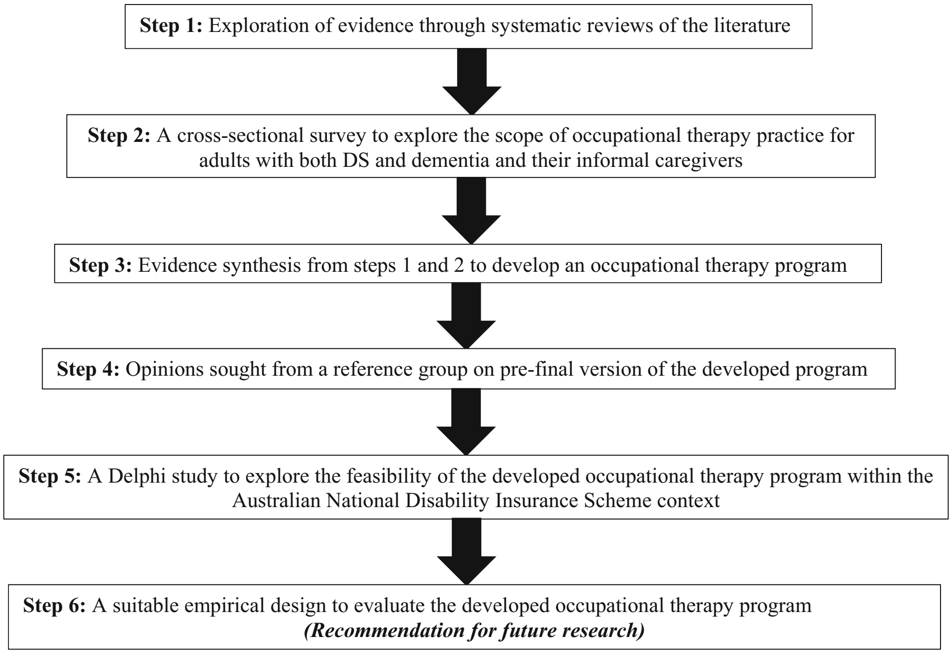


FIGURE 1 A six-step methodological process adapted from the updated version of the MRC framework (Craig et al., 2008) to develop and test a home-based occupational therapy program for adults with both DS and dementia and their informal caregivers.

dementia and their informal caregivers within the NDIS practice context.

METHODS

A six-step methodological framework was adapted from the updated version of the Medical Research Council (MRC) framework for complex interventions (Craig et al., 2008) for the development of a home-based occupational therapy program and test the feasibility of the developed program for adults with both DS and dementia and their informal caregivers. The Cochrane Dementia and Cognitive Improvement Group recommends health professionals use the MRC framework to develop and evaluate complex non-pharmacological interventions such as psychosocial and behavioural interventions (Cochrane Dementia and Cognitive Improvement Group, 2022). This paper describes Steps 1 to 5 of the framework. For Step 6, empirical testing of the developed program has been recommended for future research (Figure 1).

Steps 1 and 2: Identifying and gathering evidence

Steps 1 and 2 involved identifying and gathering evidence to develop the occupational therapy program for persons with both DS and dementia and their informal caregivers. In Step 1, systematic reviews of the literature were conducted to determine empirical evidence available on the effectiveness of home-based occupational therapy interventions to optimise occupational performance in daily occupations for adults with (1) DS, (2) intellectual disabilities, and (3) dementia among the general older population (Raj et al., 2021); and reduce the burden of caregiving for their respective informal caregivers. For each review, a comprehensive electronic search was conducted using a combination of MeSH (Medical Subject Headings) terms, Keywords, and Subject Headings for each of these databases as suitable: CINAHL, the Cochrane Database of Systematic Reviews, EMBASE, MEDLINE, ProQuest Central, Google Scholar, OT Seeker, and Scopus (ranging from 1946 to 2019 depending on the database). Two reviewers independently screened all titles and abstracts using the inclusion criteria. When eligibility was unclear from titles and abstracts, articles were retrieved in full-text, and they were screened by two reviewers for eligibility. Any differences of opinion between the reviewers were resolved through discussion with a third reviewer. Findings from included studies were synthesised descriptively. In Step 2, evidence of current practices was gathered using a cross-sectional on-line survey exploring the scope of occupational therapy practice for adults with both DS and dementia and their informal caregivers across four countries (Raj et al., 2020).

Step 3: Evidence synthesis from steps 1 and 2

In Step 3, evidence synthesis was conducted by extracting relevant details from the three systematic reviews and the survey data. The extracted information included assessment tools, theoretical models, intervention procedures (e.g., therapy time, number of sessions), and review methods. Each assessment tool was examined against five criteria to determine its suitability for this specific population: (feasibility, applicability to adults with both DS and dementia and their informal caregivers, replicability, sensitivity to change, psychometric properties) (Moniz-Cook et al., 2008). The preliminary testing of tools was conducted with a volunteer consumer representative of informal caregivers who had previous experience caring for a person with dementia. The volunteer provided feedback from a consumer's view on the selected assessment tools to inform the final selection of assessment tools for the program. Following the evidence synthesis, an occupational therapy program guided by the Occupational Performance Process Model (OPPM) (Fearing et al., 1997) was developed. The OPPM was chosen because it supports the key aspects of a client-centred model of practice and offers flexibility to tailor intervention programs for care recipients with occupational performance needs (Fearing et al., 1997).

Steps 4 and 5: Experts' opinions on the developed program

In Steps 4 and 5, opinions were sought on the developed program from two separate groups of occupational therapy experts. In Step 4, the content of the program was reviewed by a reference group of experienced occupational therapists who participated in the Step 2 survey from Australia, Canada, the United Kingdom, and the United States of America (Raj et al., 2020). Feedback from the group was incorporated into the final version of the developed program.

In Step 5, a Delphi study was conducted to explore the feasibility of the developed program within the NDIS context. Occupational therapy experts from Australia were recruited. For this study, an 'expert' was someone who considered themselves having clinical experience and knowledge (Keeney et al., 2006) in the area of intellectual disability, who was a registered occupational therapist in Australia and familiar with the NDIS. Potential participants were identified via an online database of Occupational Therapy Australia members (Occupational Therapy Australia, 2019), speakers from the past two National Occupational Therapy and the Australasian Society for Intellectual Disability conferences, and the NDIS service providers webpage (National Disability Insurance Agency, 2019). In addition, snowball techniques were employed by asking therapists who responded to recruitment invitations to recommend other occupational therapists who might meet the eligibility criteria. An email invitation was sent to participants who satisfied the eligibility criteria and volunteered to participate in the study. The study was approved by the University of South Australia Human Research Ethics Committee-Application ID: 202479.

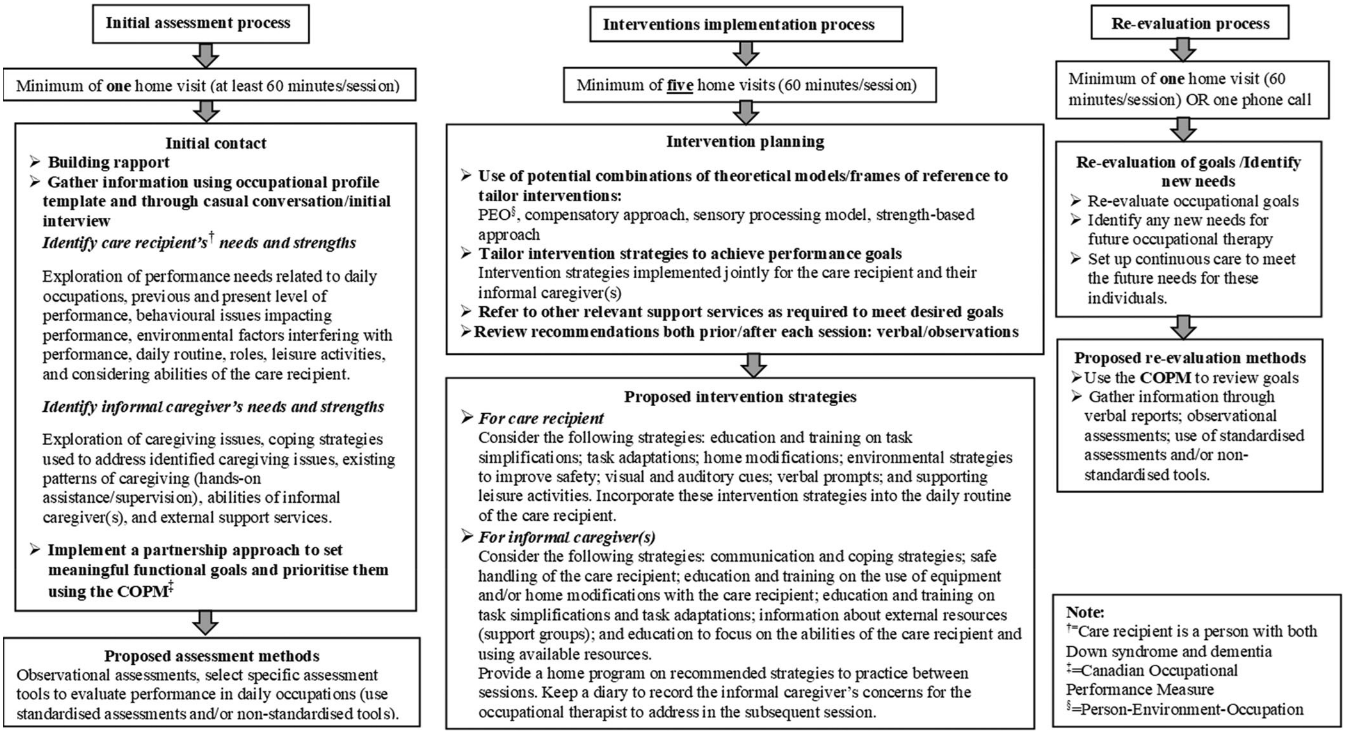
The Delphi study consisted of two rounds of surveys. The round 1 survey was conducted with a web-based questionnaire consisting of both closed and open-ended questions addressing the three main processes of the developed program: initial assessment, intervention implementation, and re-evaluation. Details about the program (as shown in Figure 2) were provided and participants were asked questions about the feasibility of each process such as 'Do you think this process of initial assessment can be implemented in clinical practice within the current context of NDIS for adults with both Down syndrome and dementia AND their informal caregivers?' and 'What changes if any, need to be made to the initial assessment process for it to be implemented in the current context of the NDIS?'. Prior to the round 1 survey, a draft questionnaire was piloted with three occupational therapy academics who had knowledge about the NDIS, intellectual disability, and the Delphi method. Feedback was incorporated into the final version of the survey.

In the round 2 survey, participants were asked to rate their level of agreement on a four-point Likert scale (strongly agree, agree, disagree, and strongly disagree) for each statement provided by participants in round 1. Respondents were also invited to add comments for each question. The consensus level of agreement was set at 70% (Keeney et al., 2011). Data collection occurred from December 2019 to February 2020 using an online survey software, 'SurveyMonkey-Advantage' (SurveyMonkey Inc., 2019).

RESULTS

Steps 1 and 2: Identifying and gathering evidence

Three separate systematic reviews of the literature were conducted. The reviews on home-based occupational therapy for adults with DS (one study, [$n = 1$] [Kottorp et al., 2003]) and adults with intellectual disabilities (Three studies, [$n = 10$] [Applegate et al., 2008; Hallgren & Kottorp, 2005; Kottorp et al., 2003]) yielded a small number of low-quality studies with limited details



Initial assessment process

Minimum of **one** home visit (at least 60 minutes/session)

Initial contact

- **Building rapport**
- **Gather information using occupational profile template and through casual conversation/initial interview**

Identify care recipient's[†] needs and strengths

Exploration of performance needs related to daily occupations, previous and present level of performance, behavioural issues impacting performance, environmental factors interfering with performance, daily routine, roles, leisure activities, and considering abilities of the care recipient.

Identify informal caregiver's needs and strengths

Exploration of caregiving issues, coping strategies used to address identified caregiving issues, existing patterns of caregiving (hands-on assistance/supervision), abilities of informal caregiver(s), and external support services.

- **Implement a partnership approach to set meaningful functional goals and prioritise them using the COPM[‡]**

Proposed assessment methods

Observational assessments, select specific assessment tools to evaluate performance in daily occupations (use standardised assessments and/or non-standardised tools).

Interventions implementation process

Minimum of **five** home visits (60 minutes/session)

Intervention planning

- **Use of potential combinations of theoretical models/frames of reference to tailor interventions:**
  PEO[§], compensatory approach, sensory processing model, strength-based approach
- **Tailor intervention strategies to achieve performance goals**
  Intervention strategies implemented jointly for the care recipient and their informal caregiver(s)
- **Refer to other relevant support services as required to meet desired goals**
- **Review recommendations both prior/after each session: verbal/observations**

Proposed intervention strategies

- ***For care recipient***
  Consider the following strategies: education and training on task simplifications; task adaptations; home modifications; environmental strategies to improve safety; visual and auditory cues; verbal prompts; and supporting leisure activities. Incorporate these intervention strategies into the daily routine of the care recipient.
- ***For informal caregiver(s)***
  Consider the following strategies: communication and coping strategies; safe handling of the care recipient; education and training on the use of equipment and/or home modifications with the care recipient; education and training on task simplifications and task adaptations; information about external resources (support groups); and education to focus on the abilities of the care recipient and using available resources.
  Provide a home program on recommended strategies to practice between sessions. Keep a diary to record the informal caregiver's concerns for the occupational therapist to address in the subsequent session.

Re-evaluation process

Minimum of **one** home visit (60 minutes/session) OR one phone call

Re-evaluation of goals /Identify new needs

- Re-evaluate occupational goals
- Identify any new needs for future occupational therapy
- Set up continuous care to meet the future needs for these individuals.

Proposed re-evaluation methods

- Use the **COPM** to review goals
- Gather information through verbal reports; observational assessments; use of standardised assessments and/or non-standardised tools.

Note:
[†]=Care recipient is a person with both Down syndrome and dementia
[‡]=Canadian Occupational Performance Measure
[§]=Person-Environment-Occupation

FIGURE 2 The proposed home-based occupational therapy program for adults with both Down syndrome and dementia AND their informal caregivers

about intervention procedures for generalisation. The review on home-based occupational therapy for people with dementia yielded 22 empirical studies (Raj et al., 2021). The common findings from these three systematic reviews were the application of a collaborative approach to develop intervention programs and the use of compensatory and remedial intervention strategies to promote occupational performance for care recipients.

Survey findings on the scope of occupational therapy practice for people with both DS and dementia (Raj et al., 2020) indicated that occupational therapy services were fragmented and lacked a client-centred approach. Survey participants perceived that occupational therapy services could be effective if a collaborative partnership approach was implemented for this population.

Step 3: Evidence synthesis

The seven stages of the OPPM (Fearing et al., 1997) were applied to the gathered evidence from systematic reviews and the survey to frame the content of the program described below. The seven stages of the OPPM include: (1) identifying and prioritising occupational performance issues; (2) selecting appropriate theoretical intervention models to address the identified issues; (3) evaluating occupational performance issues; (4) collaboratively identifying available strengths and resources to address the identified performance issues for the care recipient; (5) negotiating therapy goals and developing an intervention plan; (6) implementing interventions; and (7) reviewing therapy recommendations (Fearing et al., 1997).

The developed program for persons with both DS and dementia and their informal caregivers begins with an initial home visit (see Figure 2) where the occupational therapist implements stages 1 to 5 of the OPPM. Stages 1 and 3 are combined by identifying the occupational performance issues (stage 1) of the person with both DS and dementia and caregiving needs of their informal caregiver. The Canadian Occupational Performance Measure (COPM) tool is used to identify and prioritise intervention goals for people having performance difficulties (Law et al., 1990). Additional relevant assessments such as home safety with clinical observations about the usual pattern of performance and caregiving practices of informal caregivers are conducted (stage 3).

After completing assessments, the therapist selects appropriate theoretical models and/or frames of reference based on a person's performance difficulties to guide their clinical reasoning to choose assessments and develop an intervention plan (stage 2) (American Occupational Therapy Association, 2014). For example, a combination of theoretical models such as the Person-Environment-Occupation model (Law, 1996) and the compensatory approach (Seidel, 2003) may be chosen to tailor interventions to address the changing needs for a person with both DS and dementia. The therapist then discusses with the person with both DS and dementia and their informal caregiver about their strengths and available resources to support their needs based on the information gathered from assessments and negotiates intervention goals (stages 4 and 5). During this period, appropriate strategies are applied to facilitate informed decision-making for the person with both DS and dementia and to set realistic and achievable goals and a plan is made.

In the subsequent visits (stage 6), the therapist implements individualised interventions to address the identified goals. Based on the best available evidence for people with intellectual disabilities a minimum of five intervention sessions is recommended for the care recipient to observe performance changes in their daily activities (Hallgren & Kottorp, 2005). In stage 7, a re-evaluation is conducted with the person with both DS and dementia and the informal caregiver to determine if the intervention goals (stage 2) have been achieved. If so, the therapist can discuss concluding current interventions and identifying new goals and selected interventions with the care recipient and their informal caregiver. To address new performance needs, the therapist begins from the stage 1 again.

Steps 4 and 5: Experts' opinions on the developed program

Reference group: Opinions on the content

In Step 4, opinions from the reference group were sought on the content of the developed program. No specific changes were suggested. The final version of the developed program was presented to the Delphi panel in Step 5.

A Delphi study: Feasibility testing

In the round 1 survey, 11 expert occupational therapists responded from five Australian States and Territories. One respondent only completed the demographic section of the survey. A total of 10 responses were included in the data analysis.

Four participants (40%) were from Queensland, two (20%) were from New South Wales (NSW) of which one participant provided services in both the Australian Capital Territory (ACT) (10%) and in NSW, two (20%) were from Victoria, and one participant (10%) was from South Australia. More than three-quarters of the participants (80%) had more than 10 years of clinical experience as an occupational therapist (see Table 1). All of them (10/10) had worked with people with intellectual disabilities and the majority (90%) had provided interventions for persons with DS. Fifty percent worked in private organisations.

TABLE 1 Demographic characteristics of expert participants who participated in round 1 ($N = 10$)

Descriptions	Frequency: $n = (\%)$
Location of current practice	
Queensland	4 (40)
New South Wales	2[a] (20)
Victoria	2 (20)
Australian Capital Territory	1[a] (10)
South Australia	1 (10)
Years of clinical experience as an occupational therapist	
≥20 years	4 (40)
15–19 years	2 (20)
10–14 years	2 (20)
6–9 years	1 (10)
2–5 years	1 (10)
Years of clinical experience with people with intellectual disabilities	
10–14 years	4 (40)
6–9 years	3 (30)
≥20 years	2 (20)
2–5 years	1 (10)
15–19 years	0
Clinical experience in areas related to intellectual disabilities	
Adults with intellectual disabilities	10 (100)
Adults with DS	9 (90)
Adults with both intellectual disabilities and dementia	7 (70)
Type of health care provider currently practising	
Private organisation	5 (50)
Public organisation	3 (30)
Non-profit organisation	2 (20)

[a] Participant provided services in both ACT and NSW.

The three main processes of the program and participants' suggested changes to each process to improve its feasibility for implementation within the NDIS practice context are described below.

Initial assessment process

In round 1, 70% of the participants (7/10) agreed that the proposed initial assessment process could be implemented within the NDIS context. Two participants indicated that 'this process would work'. One participant elaborated that gathering information on a participant's caregiver,

TABLE 2 Level of agreement with specific statements in round 2 ($N = 7$)

Statements from the participants (n = number of participants making the statement in round 1)	**Level of agreement n (%)**
Initial assessment process	
In the current context of service provision, funding for occupational therapy service is a problem ($n = 1$)[a]	7 (100)
Informal caregivers need to be made aware about benefits of occupational therapy assessment for their caregiving support ($n = 2$)[b]	7 (100)
Clients can take longer than one 60-minute session of an initial assessment ($n = 1$)[a]	7 (100)
Prolonged initial assessments need to be funded ($n = 1$)[a]	7 (100)
Clinicians may choose assessment tools containing more questions/prompts to explore caregiving strengths and abilities ($n = 1$)[c]	7 (100)
Occupational therapists use various assessment methods available within their area of clinical practice (e.g. paper-based forms, iPads) ($n = 2$)[b]	7 (100)
Based on referral information, appropriate assessment tools are chosen ($n = 1$)[a]	7 (100)
One hour is inadequate to assess the needs of the care recipient and their informal caregiver ($n = 2$)[a]	6 (86)
Occupational therapists confirm with the care recipient and their informal caregiver if the identified goals are still relevant ($n = 1$)[a]	6 (86)
Information on occupational needs is given to the therapist prior to the initial assessment ($n = 1$)[a]	5 (71)
Funding to address informal caregivers' needs may be acquired through other sources (e.g. 'coordination of supports') outside of the 'therapy services' ($n = 1$)[a]	4 (57)[d]
Goal-setting is completed by the NDIS planner prior to an initial occupational therapy assessment ($n = 1$)[a]	4 (57)[d]
The COPM tool is difficult to administer for adults with both DS and dementia ($n = 1$)[a]	3 (43)[d]
Informal caregivers are not included in the initial occupational therapy assessment process ($n = 1$)[a]	2 (29)[d]
Intervention process	
Funding for therapy hours is a concern ($n = 2$)[a]	6 (86)
If the NDIS planner considers dementia as a health issue rather than a condition needing continuing care, funding for the required intervention sessions could be compromised ($n = 1$)[c]	6 (86)
Funding for occupational therapy interventions is taken from the entire funding for 'therapies', which includes other therapies ($n = 1$)[c]	6 (86)
Funding for the number of occupational therapy intervention sessions is communicated to the therapist by the NDIS planner ($n = 1$)[a]	6 (86)
In the current disability services context, five intervention sessions are not feasible ($n = 5$)[b]	5 (71)
NDIS funding is not allocated to offer interventions to address caregiving needs of informal caregivers; funding cannot be combined ($n = 2$)[a]	5 (71)
The number of therapy sessions is determined by the care recipient and their informal caregiver as they have 'choice and control' over the required services ($n = 1$)[c]	5 (71)
Care recipients may not wish to have five home visits ($n = 1$)[c]	5 (71)
Three intervention sessions may be feasible ($n = 1$)[a]	4 (57)[d]
Occupational therapy interventions are offered as 'packages' by working in partnership with relevant stakeholders, leading to shared funding ($n = 1$)[a]	4 (57)[d]
Re-evaluation process	
Re-evaluation should take place as part of the intervention process ($n = 3$)[b]	6 (86)
Re-evaluation is performed informally at the beginning OR at the end of every intervention session ($n = 3$)[b]	6 (86)
Limited allocated therapy time is a barrier to complete a follow-up visit ($n = 1$)	6 (86)

TABLE 2 (Continued)

Statements from the participants (n = number of participants making the statement in round 1)	Level of agreement n (%)
Informal caregivers need to complete the COPM on behalf of the person with both DS and dementia ($n = 1$)[c]	6 (86)
Re-evaluation is more likely to be completed via a phone call ($n = 2$)[c]	5 (71)
Mail appropriate forms for caregivers to complete to maximise therapy time ($n = 1$)[c]	3 (43)[d]
The COPM is difficult to use as a re-evaluation measure with adults with both DS and dementia ($n = 1$)[a]	3 (43)[d]

[a] Participant who stated 'No' to the program.

[b] Similar statements raised by the participants who reported 'Yes' and 'No' to the proposed program.

[c] Participants who reported 'Yes'.

[d] Statements that did not reach the consensus level of agreement.

building rapport, and setting occupational goals were important and appropriate to complete for service users. However, three participants (30%) responded 'No' and suggested changes.

Eight participants (80%) including those who had responded 'No' (3/10) offered their suggestions. Similar statements were grouped together, and three key issues emerged: concerns about assessment procedures, limited awareness among informal caregivers about the benefits of occupational therapy services and a lack of funding availability to provide therapy for informal caregivers, and to perform extended initial assessments (>60 minutes).

Intervention process

Seven participants (70%) indicated that the developed intervention process could be implemented within the NDIS context. Two participants also added that this intervention process would be possible if the NDIS goals were included within the process and/or if the NDIS planners considered dementia as a 'disability' requiring disability-specific services. However, three participants (30%) responded 'No' and reported limited funding hindered the implementation of the intervention process.

Six participants (60%) including those participants who had responded 'No' (3/10; 30%) raised three key issues: a lack of funding to provide a minimum of five sessions, the number of intervention sessions being pre-determined by the care recipient, their informal caregiver and the NDIS planner, and 'dementia' being considered as a health issue rather than a disability requiring continuing care.

Re-evaluation process

Eight participants (80%) agreed that the re-evaluation process could be implemented within the NDIS context. One participant added that best practice would require a follow-up of therapy goals and intervention outcomes. Another participant reported that completing the re-evaluation process could help to motivate informal caregivers to review intervention goals and understand post-intervention changes observed in the care recipients. However, two participants (20%) indicated 'No'.

Six participants (60%) including the two participants who indicated 'No' reported that it is necessary to incorporate the re-evaluation process within the intervention process—either at the beginning or at the end of every intervention session to identify emerging needs of the care recipient; to complete the re-evaluation process via phone calls; allocated therapy time for a review visit was limited; it was difficult to use the COPM for persons with both DS and dementia due to their inherent impairments and therefore an informal caregiver needs to involved to complete this process.

Round 2

In the round 2 survey, seven participants (70%) completed the survey. Table 2 describes the statements from round 1 and the consensus level of agreement reached for each of those statements. 10 of the 14 statements for the initial assessment process reached 70% consensus level of agreement. Three of the four statements that did not reach the level of agreement were related to NDIS procedures.

Eight of the 10 statements (80%) for the intervention process reached the consensus level of agreement. Over 50% of the agreed statements (5/8) were concerning funding for occupational therapy services and the two statements that did not reach the level of agreement were also related to funding issues.

Five of the seven statements (71%) for the re-evaluation process reached the consensus level of agreement. Three statements reached a similar level of agreement (86%), which was about integrating the re-evaluation process within the intervention process, funding constraints to perform follow-up visits, and informal caregivers needing to complete the COPM when funding is provided only for the care recipients. After the Delphi study, the recommendation made by the experts to incorporate the re-evaluation process within the intervention implementation process was included in the developed program (see Figure 2).

DISCUSSION

Through employing a methodological framework guided by the updated version of the MRC framework (Craig et al., 2008) to develop and test the feasibility of a home-based occupational therapy program for persons with both DS and dementia and their informal caregivers, this paper identified three key findings: (1) each step of the framework needs to be adapted using appropriate research methods to improve quality of evidence for the program; (2) funding constraints within the NDIS context limits the feasibility of the developed program for persons with both DS and dementia and their informal caregivers; and (3) flexibility to tailor the program to accommodate specific needs of the care recipient and their informal caregiver.

Adapting a methodological framework to suit the study population appears to be a useful approach to build evidence-based intervention programs for small populations, which corresponds with the recommendation of Craig et al. (2008). To identify high-quality evidence for developing complex interventions where there is scarce evidence in published literature, it is essential to identify a broader scope of evidence using appropriate research methods. This can be relevant when developing intervention programs for small populations, and this study illustrates the use of a survey of clinicians and a Delphi study in Steps 2 and 5 to build a rigorous evidence-base for program development. Minas and Jorm (2010) support the use of the Delphi study method to build evidence in areas where there is limited evidence.

The second aspect of the study explored the feasibility of the developed program using a Delphi study with occupational therapy experts. There was consensus agreement from the experts that the client-centred program developed for people with both DS and dementia and their informal caregivers can be implemented within the NDIS context. However, the experts raised three key concerns about the program's implementation process within the current disability services context: funding limitations to perform extended assessments and to provide five or more intervention sessions for persons with both DS and dementia; and no funding availability to provide therapy support for their informal caregivers. These concerns highlight that the current service delivery for people with both DS and dementia and their informal caregivers continue to inadequately support both these groups of people to maintain their quality of life in their communities (Carling-Jenkins et al., 2012). Furthermore, the current services for this population do not comply with the recommendations of the AAMR/IASSIDD practice guidelines which recommends to provide combined interventions for both the care recipients experiencing an intellectual disability and dementia, and their informal caregivers (Janicki et al., 1996). To address this gap in service delivery, it is necessary to disseminate and advocate the best available evidence from this study to stakeholders including the NDIS funders to justify provision of combined interventions for people with both DS and dementia and their informal caregivers. Local changes should be followed by changes to funding policy to support an evidence-based and a client-centred model of practice for these individuals. The support of professional bodies can highlight and advocate for evidence-based knowledge informing funding systems to improve occupational therapy practice.

The third aspect is that the components of the intervention program may need to be tailored to meet specific needs of the care recipient and their informal caregiver. For example, the number of sessions required to complete an initial assessment may vary on an individual basis. Therapists are encouraged to implement the best available evidence; however, it is important to accommodate specific needs of a person with both DS and dementia and their informal caregiver and adapt the program accordingly. Similarly, re-evaluations of interventions may need to occur either prior to or after every intervention session for therapists to monitor the care recipient's performance and/or to address the informal caregivers' caregiving needs. Thus, it is necessary for therapists to individualise intervention programs for this population who experience age-related health issues (Glasson et al., 2014) and dementia, a progressive health problem impacting performance skills (World Health Organization, 2022).

LIMITATIONS

This paper has two main limitations. For the Delphi study, there was no representation from three Australian states (Western Australia, the Northern Territory, and Tasmania). Only a small number of experts participated from the other states to generalise the findings. Another limitation is that empirical testing to determine the effectiveness of the developed program was not conducted. Thus, the developed program may need to be considered cautiously.

FUTURE RESEARCH

There are two key aspects to be considered when planning empirical research to examine the effectiveness of a developed program for persons with both DS and dementia and their informal caregivers. First, it is important to use a robust methodological design such as the Single-Case Experiential Design (Portney & Watkins, 2015) to accommodate heterogenous characteristics of these people. Second, the research process should involve consumers including individuals with both DS and dementia and their informal caregivers in decision making from the planning stage to achieve meaningful outcomes (Miller et al., 2017).

CONCLUSION

This paper has illustrated the application of a stepwise methodological framework applied to develop an evidence-based intervention program for a small population, where there is a paucity of research evidence. Although developing such healthcare intervention programs, it is important to consider potential system issues that may impact its implementation. Funding constraints remain a challenge to implement the developed home-based occupational therapy program for persons with both DS and dementia and their informal caregivers within the NDIS context.

ACKNOWLEDGMENT

Open access publishing facilitated by University of South Australia, as part of the Wiley - University of South Australia agreement via the Council of Australian University Librarians.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

ETHICS STATEMENT

The study was approved by the University of South Australia Human Research Ethics Committee-Application ID: 202479.

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How to cite this article: Raj, S. E., Mackintosh, S., Kernot, J., Fryer, C., & Stanley, M. (2022). Development and feasibility testing of an evidence-based occupational therapy program for adults with both Down syndrome and dementia. *Journal of Policy and Practice in Intellectual Disabilities*, *19*(4), 396–407. https://doi.org/10.1111/jppi.12435