


RESEARCH ARTICLE



A stakeholder-involved adaptation of pathways and resources for engagement and participation (PREP) material with young adults with complex disability in Australia: an implementation feasibility study

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ABSTRACT

Purpose: Pathways and Resources for Engagement and Participation (PREP) is an intervention to optimise individuals' participation by building problem-solving capacity and addressing environmental barriers. We investigated the feasibility of implementing PREP with young adults (18–30 years) with complex disability in Australia.

Materials and Methods: Explanatory sequential mixed methods study in three stages. (i) PREP materials were collaboratively adapted by the research team and consumer research partners. (ii) Steps 1 and 2 of PREP (YA Supplement) were completed with three young adults with disability, and preliminary feasibility explored using qualitative methods. (iii) The feasibility of implementing adapted materials was examined using quantitative and qualitative methods involving four young adults with disability, six support people and two service providers.

Results: Stage 1: PREP Young Adults Supplement (PREP (YA Supplement)) for use alongside PREP was developed. Stages 2 and 3: findings indicated PREP (YA Supplement) was acceptable, appropriate and feasible. Three themes were identified: setting and achieving goals were associated with challenges and benefits; finding the right time to implement the program was necessary; and PREP (YA Supplement) drives a shift to a participation-focused approach.

Conclusion: PREP delivered alongside PREP (YA Supplement) appears feasible with Australian young adults with complex disability.

ARTICLE HISTORY

Received 13 March 2024
Revised 21 August 2024
Accepted 22 August 2024

KEYWORDS

Pathways and resources for engagement and participation; disability; participation; family of participation-related constructs; young adults; consumer involvement; feasibility study; implementation

► IMPLICATIONS FOR REHABILITATION

- A novel supplement for the evidence-based Pathways and Resources for Engagement and Participation (PREP) intervention has been developed to enhance participation in life situations for young adults with disability in an Australian context (PREP Young Adult Supplement).
- Setting participation goals may be a substantial shift for young adults with disability and rehabilitation professionals, and involves considering attendance at, and involvement in, life situations.
- Implementation of PREP/PREP Young Adult Supplement is inherently flexible and can be adapted to suit the needs, preferences and circumstances of the participant.


Introduction

Participation of young adults with disability in meaningful activities including work, community engagement and recreation are key outcomes of rehabilitation services. Participation in activities can enable individuals to build a sense of competence, develop social networks and acquire new skills, consequently promoting health and wellbeing [1,2]. Young adults with childhood-onset disabilities have lower rates of participation in employment and leisure activities in comparison to their non-disabled peers [3–5]. Rehabilitation

services can promote the wellbeing of these young adults and create opportunities for the development of life skills and participation in life situations to mitigate these discrepancies [6].

Participation restrictions may be more exaggerated for young adults with complex disability. People with complex disability have a range of impairments, which in interaction with contextual factors, may compound to impact their participation [7]. Impairments that can increase complexity may include combinations of physical, intellectual and sensory disability, difficulties

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 Supplemental data for this article can be accessed online at <https://doi.org/10.1080/09638288.2024.2397083>.

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with communication, and associated medical conditions such as epilepsy, and respiratory and gastrointestinal conditions.

In this study, participation is viewed through the lens of the Family of Participation-Related Constructs (fPRC) [8]. The fPRC is an evidence-informed framework in which participation is viewed as comprising two components: attendance and involvement. *Attendance* is defined as being present in a life situation and involvement refers to the subjective experience of participating. *Involvement* can include elements of engagement, persistence and affect [8]. Environmental barriers are major contributors to restricted participation for individuals living with disabilities [9] and they may present as physical, social or attitudinal barriers [10].

Interventions that target the environment and activity, rather than the individual's body function and structure, can enhance participation [9–11]. PREP, developed by Anaby and colleagues [12], is a person-centred, strengths-based intervention that aims to optimise individuals' participation in activities of choice by modifying physical, social, attitudinal and institutional aspects of their environment [13]. PREP involves five steps: (1) Make goals; (2) Map out a plan; (3) Make it happen; (4) Measure the process and outcomes; and (5) Move forward. The steps are navigated collaboratively between a client, therapist and, if required, members of a support team; collectively called the participation team. Therapists use coaching techniques and build on existing supports to guide clients to complete these five steps. According to the PREP manual [13], clients participating in PREP identify three participation goals using the Canadian Occupational Performance Measure (COPM) [14]. After a 4-week baseline period, the goals are addressed one at a time in three blocks of 4 weeks, followed by a 4-week follow up period, for a total intervention period of 20 weeks. Concurrently, participants rate their chosen goals in terms of self-perceived COPM Performance Scale twice per week, and on the COPM Satisfaction with Performance scale six times during the 20 weeks.

Research about the effects of PREP has been available since 2015 [15], and in 2023, Hsieh [16] synthesised available evidence about PREP, from 11 studies demonstrating multi-dimensional outcomes. PREP has been evaluated in Canada, Ireland, Israel and Taiwan, predominantly with adolescents. Intervention implementation may differ between Australia and other countries due to cultural, climate, health service or health policy differences.

An important consideration in Australia is the implementation of the National Disability Insurance Scheme (NDIS) [17], which offers individualised funding packages for people with disability [18]. In Australia, concurrent to the presently reported study, PREP was trialled with young people with intellectual impairments, to support employment goals [19]. In the current project we sought to ensure that the PREP intervention materials were age and stage appropriate for young adults with complex disability. The overall purposes of this study, therefore, were to adapt PREP for young adults aged 18–30 years with complex disability in Australia and investigate the feasibility of implementing the adapted PREP. The research questions were:

1. What, if any, adaptations are necessary for PREP to be applicable in an Australian context and for young adults with complex disability?
2. What is the stakeholder-perceived feasibility of implementing PREP?

Material and methods

This explanatory sequential mixed methods study progressed in three stages. Two preparatory stages were (i) adapting PREP materials (including forms and appendices) to create supplementary

resources for implementing PREP with young adults (YA), named “PREP (YA Supplement)”, and (ii) preliminary exploration of the feasibility of the PREP (YA Supplement) by implementing only the first two steps of PREP. The third stage was a study exploring the (iii) feasibility of implementing all steps of PREP (YA Supplement) with young adults with disability. The methods and results for each stage are reported sequentially in this publication as each stage underpinned the subsequent stage.

The stages were informed by the Knowledge-to-Action Cycle (KTA) [20] and Bowen and colleagues' [21] evidence-based framework for feasibility studies. In this study, researchers addressed the KTA steps related to adapting knowledge (PREP) for the local context, and exploring the feasibility of implementing the adapted intervention. The action steps do not need to be addressed in a linear fashion and are reflected across the different stages of this research. Likewise, several aspects of feasibility were examined across the stages of the study: adaptation, acceptability, implementation, practicality and limited efficacy testing. Feasibility studies are intended to be iterative and adaptive, to focus on process rather than outcome and identify whether proceeding with a larger study evaluating the intervention in question is valid and advisable [21–23].

All stages of this study involved consumers. Two young adults with physical disability were integral members of the research team as investigators (OH and NG) and contributed throughout. The research team also collaborated with six young adults with physical disability as research advisory partners (RAP). RAP were aged 18–30 years and had varied lived experience of disability, including complex disability. The involvement of consumers in the research is reported in Table 1 using the Guidance for Reporting Involvement of Patients and the Public – Short Form (GRIPP-2) [24]. Consumer involvement in this study was evaluated in a parallel project and will be reported elsewhere [25].

This study was conducted in partnership with the Young Adult Complex Disability Service, St Vincent's Hospital Melbourne, registered with the Australian New Zealand Clinical Trials Register (ACTRN12619001361190p), and approved by the Human Research Ethics Committees of St Vincent's Hospital Melbourne (Project ID: 56954; 215/19), Australian Catholic University (2020-117R) and the University of Melbourne (14516). All participants gave written informed consent. PREP authors' approval to adapt PREP materials to the current context was obtained from the CanChild Centre for Childhood Disability Research.

Stage 1: Adapting PREP materials for young adults in Australia

The PREP manual includes materials designed for occupational therapists to use when implementing PREP with youth and families [13]. Each element of the PREP manual was systematically explored to determine if any adaptations to the materials or process of implementation would optimise applicability for young adults with complex disability and the Australian context. This process was carried out over seven 2-h videoconference workshops from July to September 2020. The workshops involved the research team (consumer investigators, researchers, research students) and RAP. During the workshops, the materials were reviewed, and consensus about adaptations were reached using discussion.

Adapted PREP materials

The final adaptations to PREP materials were predominantly to optimise the involvement of young adults in PREP implementation including simplifying language, additional diagrams and removal of occupational therapy jargon to enhance appropriateness for

Table 1. GRIPP-2a short form- co-developed with consumer investigators (CI) and research advisory partners (RAP) and reporting consumer involvement in this research.

Aim	To incorporate the lived experience of young adults aged 18–30 years who have physical disability to enhance the applicability and acceptability of the study design and implementation and the adaptation of PREP.	
Methods	Two different methods were used to involve CIs ($n=2$) in all stages of the research and RAP ($n=6$) in the implementation and dissemination phases of the research.	
Recruitment	CIs: were invited by researchers.	RAP: expression of interest distributed via CP-Achieve ^b and YACDS ^c at St Vincent's Hospital Melbourne.
Remuneration	Paid using grant funds from the Endeavour Foundation Disability Research Fund	
Orientation	CIs: Provided with information about the study by lead investigators. OH participated in PREP training workshop.	RAP: Orientation “package” which included: information sheet about PREP (sourced from the PREP online module), “how to use zoom” guide, and a video of a CI (OH) discussing his involvement in the study and sharing experiences. Orientation meeting including explanation of the study and research cycle. Discussion with non-consumer investigators about their preferred methods of involvement.
Methods of involvement	CIs: Fortnightly zoom meetings with the whole research team. Individual meetings/phone calls. Research document review. Research/RAP workshops. Co-presenters at conferences and co-author on publication.	RAP: RAP workshops. PREP and PREP (YA Supplement) materials review. Individual meetings/phone calls.
Study results	CIs contributed to development of RAP recruitment and orientation materials and workshop agendas. Creation of PREP (YA Supplement) which guides therapists on appropriate language, behaviour and expectations to use when working with young adults with complex disability. Refer to Table 2. CIs reviewed PREP advertising materials, participant information and consent form and interview protocols. Consumers' lived experience influenced the delivery of mock-PREP Consumers' lived experience embedded in PREP (YA Supplement) to guide <i>how</i> therapists interact with young adult PREP participants.	
Discussion and conclusion	PREP has been adapted for young adults and will be a genuine contribution to the field of person-directed intervention. PREP (YA Supplement) will guide therapists to listen and give young adults a voice in selecting their own goals and developing strategies to address environmental barriers. Study procedures for mock-PREP supported feasibility, recruitment and retention of participants. All consumer research partners need: <ul style="list-style-type: none"> • Explanation of research terms and absence of jargon. • To receive meeting materials and agenda prior to the meeting so they can prepare for discussions. • Regular communication between researchers and consumers regarding upcoming meetings and progress of PREP (YA Supplement). Different consumers required additional or alternate types of supports, such as Additional time to complete work. <ul style="list-style-type: none"> • Support person being present at meetings/workshops. • Communication aids e.g., support with using electronic communication devices. • Summaries of meetings/workshops to help consumers keep track of what has been discussed. • Simplification of language. Both consumers and non-consumers perceived that the personal, professional and study benefits of consumer involvement outweighed the challenges involved. Consumers believed their voices were genuinely heard and that involvement had impact. <i>Impacts of consumer involvement</i> for non-consumer researchers included building understanding about lived experience of cerebral palsy and disability. This understanding changed perceptions of disability and promoted change in professional and community behaviours. Changes in perception of disability had immediate impact on therapists/student-therapists doing the study, but also impacted clinical practice. <i>Facilitators of consumer involvement:</i> <ul style="list-style-type: none"> • Experienced CIs providing support and role-modelling for less experienced RAP. • Orientation to enable CIs and RAP be familiar with the study. • A small-group setting promoted discussion and sharing of experiences. • Tailored support for the individual communication needs and preferences of consumers. • Non-consumers being curious about consumers lived experience. • Non-consumers validating the impact and importance of consumers' contributions. <i>Barriers to involvement:</i> Lack of clarity about consumers' role. Research jargon.	
Reflections and critical perspective		

^aStaniszewska et al. [24].^bCP-Achieve – NHMRC-Funded Centre for Research Excellence: CP-Achieve focusing on adolescents and young people with cerebral palsy. Consumer involvement is an embedded them.^cYACDS: Young Adult Complex Disability Service at St Vincent's Hospital Melbourne.

young adults and invite them to be agents in their own PREP/PREP (YA Supplement) experience. In addition, examples of participation goals and environment modification strategies provided in PREP were adapted to provide context more familiar to an Australian audience. Adapted forms and PREP implementation processes were compiled into a supplement to be used in conjunction with the original PREP manual [13] and online modules [12]. This supplement is named Pathways and Resources for Engagement and Participation (Young Adults Supplement) which is referred to as PREP/PREP (YA Supplement) hereafter. The adaptations are described in Table 2.

Stage 2: Preliminary feasibility of the adapted materials

Stage 2 design

This stage explored the *feasibility* (specifically acceptability and practicality) of, and barriers to, implementing PREP/PREP (YA Supplement) with young adults with complex disability. *Acceptability* was defined as young adult, family and clinician responses to the intervention. Participants' perspectives of the

practicality [21] were also sought. *Practicality* was defined as the extent to which PREP/PREP (YA Supplement) could be implemented in the current staff and resource environment. Initially, this study proposed the *implementation* of all five steps of PREP/PREP (YA Supplement). The methods were revised, with ethical approvals, to be conducted online and only include two steps (see below), in response to COVID-19 restrictions which precluded face-to-face contact and community participation. As Stage 2 was completed in preparation for the feasibility study, a brief summary of the methods and results are reported, with the full results available in [supplementary materials](#).

Stage 2 participants and recruitment

Two groups of participants took part in Stage 2.

- i. Young adults with complex disability were identified through YACDS at St Vincent's Hospital Melbourne. Three took part: two females and one male, aged 19, 27 and 19 years respectively, living in Melbourne, Australia (see Table 3). They were able to formulate, communicate and rate their

Table 2. Description of adaptations to PREP manual – according to whether adaptations were additions to, or adapted from, the original, and whether adaptations were needed for young adults or the Australian context.

Title of document	New content	Adapted content	Reason for adaption		Summary of adaptations
			Young adults	Australian context	
Acknowledgements	✓		✓		Acknowledge the contributions of consumer investigators and RAP in adaptation of PREP.
Recommendations for fostering a therapeutic relationship	✓				Contains recommendations from CI and RAP about fostering a therapeutic relationship and delivering PREP/PREP (YA Supp) when working with young adults.
Who can deliver PREP/PREP (YA Supp)	✓				A section clarifying the preparation, knowledge and experience required of health professionals to deliver PREP/PREP (YA Supp)
Pre-PREP Introduction to PREP Information Sheet for Young Adults	✓				Preparatory material for young person to orient and prepare them for PREP/PREP (YA Supp) intervention.
Initial meeting key discussion point checklist	✓		✓		Key points identified during the workshops with CIs and RAP that are useful to discuss as part of the initial meeting with young adults.
Initial meeting script for young adults		✓	✓	✓	Edited language of PREP/PREP (YA Supp) initial meeting script to remove or explain unfamiliar jargon and simplify language. Addition of suggestions for implementing PREP/PREP (YA Supp) during COVID-19 restrictions and related impacts on community participation.
Visual aid for initial meeting to accompany initial meeting script	✓				A visual aid that details the steps involved in PREP/PREP (YA Supp) and the timeline of the intervention.
Strategies to guide identification of participation goals for young adults		✓	✓		Replaced child-specific aid to identifying participation goals with an interest checklist and questionnaire validated for adults to assist young adults to identify participation goals.
Strategies for rating COPM Performance for young adults		✓			Additional questions developed to assist young adults with goal setting. Edited language used to describe COPM Performance rating to enhance understandability.
Addition of the Involvement Scale	✓				To capture the experience of participating in the activity related to the goal, consistent with the concepts of attending and involvement of the fPRC
Rating scale visual aids	✓				Developed visual aids to supplement verbal explanation of how to score the COPM.
COPM Performance and Involvement Scales scoresheets for young adults		✓			Change in format of scoring sheets to allow for comments as well as numerical scores. Inclusion of explanations of COPM Performance so young adults can recall what they are scoring.
Planning form for young adults		✓		✓	New worked example: changed from a participation goal of "playing baseball" to "going to an AFL football match"
Intervention form for young adults		✓		✓	Addition of a checkbox where the young adult can specify if an identified environmental/activity factor is a barrier or support. New worked example: changed from a participation goal of "playing baseball" to "going to an AFL football match"
Glossary	✓				Contains definitions of key terms and concepts in PREP/PREP (YA Supp) and examples of participation goals contrasted with skill-based goals.

CI: Consumer investigator; RAP: Research Advisory Partners; AFL: Australian Rules Football; COPM: Canadian Occupational Performance Measure; fPRC: Family of Participation-Related Constructs (Imms et al. [8]).

This table documents changes made over the three stages of this research.

Table 3. Stage 2 PREP/PREP (YA Supplement) young adult participant characteristics.

Young adult	Sex	Age (years)	Diagnosis	Function	Life situation
YA1	Male	19	YA1 has CHARGE syndrome, vision impairment, broncho-tracheomalacia and gastro-oesophageal reflux. He has intellectual disability, and speech, language, hearing and vision impairments.	YA1 walks in most settings and can handle objects and complete activities which have been set up or adapted. YA1 completed the interview with a parent to support with comprehension of information. No other communication aids were used.	YA1 lives with his parents and siblings and has completed high school education.
YA2	Female	19	YA2 has cerebral palsy, intellectual disability, and epilepsy.	YA2 walks independently at home and in the community and can handle objects and complete activities which have been set up or adapted. YA2 completed the interview with a parent to support with comprehension of information. No other communication aids were used.	YA2 lives with her parents and has completed high school education.
YA3	Female	27	YA3 has a chromosome deletion, ligamentous hyperlaxity, multiple joint dysplasia, and scoliosis. She has intellectual disability, vision impairment and mental health issues.	YA3 walks using a mobility device and can handle objects and complete activities which have been set up or adapted. YA3 completed the interview with a parent to support with comprehension of information. No other communication aids were used.	YA3 lives with her parents and siblings, and has completed high school education.

YA: Young adult and YA1, YA2, YA3 will be used to identify quotes in results.

- goals with their usual supports (e.g., communication aids/devices and support persons), and had access to an electronic device to communicate remotely with researchers.
- ii. Clinicians from YACDS who had supported or may support delivery of PREP/PREP (YA Supplement) with young adults with complex disability, and who were interested in providing their perspectives about its feasibility for their service were invited to participate. Three took part: two were employed at the outpatient hospital-based clinic, YACDS, and the other was a fourth-year occupational therapy student completing a professional practice placement at YACDS (see Table 4).

Stage 2 procedures

This stage was termed “mock-PREP” as only part of PREP was implemented to explore preliminary feasibility. In preparation for mock-PREP, participants received an introduction to PREP using an information sheet which outlined the five steps of PREP/PREP (YA Supplement) and were encouraged to consider participation goals. During mock-PREP the interventionist delivered the first two steps of the 5-step PREP/PREP (YA Supplement), “Make Goals” and “Map out a Plan”, in a manner consistent with PREP implementation. Mock-PREP was delivered using videoconference technology over 2-h, by a supervised 4th year occupational therapy student.

In a second session, participants met remotely with a researcher to discuss, but not implement, the additional three steps of PREP/PREP (YA Supplement). This session was to inform subsequent discussions about the feasibility of PREP/PREP (YA Supplement) implementation. This discussion was tailored for each participant using the specific goals and plans they identified in mock-PREP.

Stage 2 data collection and analysis

Two methods were used to collect data from young adults. Online interviews, completed within one week of mock-PREP, gathered immediate perspectives about acceptability and practicality [21]. A subsequent 2-h online focus group allowed further time for young adults to reflect on their experience of mock-PREP and provide additional insights alongside their peers. Clinicians took part in a 2-h focus group. Participants were asked open-ended questions to explore perceptions of acceptability and practicality of PREP/PREP (YA Supplement) in their own and an Australian context, whilst also probing for barriers to, and strategies to support, implementation (see supplementary materials for interview and focus group schedules). Interviews and focus groups were

Table 4. Stage 2 clinician participant characteristics and information they received about PREP.

Clinician	Time spent working at complex disability service	PREP information and training provided			
		PREP face-to-face workshop	Online PREP module	Overview of PREP and PREP (YA Supplement) delivered in PowerPoint presentation	Implemented mock-PREP
C1	6 years	✓	✓	✓	
C2	10 years			✓	
C3	8 weeks on student placement	✓	✓	✓	✓

C: Clinician, and C1, C2, C3 are used to identify quotes in results. PREP (YA Supplement): Pathways and Resources for Engagement and Participation for Young Adults Supplement. Additional descriptors were not included due to risk of identifying the participants.

audio and video recorded. Audio recordings from interviews and focus groups were transcribed verbatim and analysed together using qualitative content analysis [26]. Data were organised into themes to explore participants’ perspectives of the feasibility of implementing PREP/PREP (YA Supplement).

Stage 2 results

Analysis of data from interviews and focus groups resulted in three themes and eight sub-themes related to the feasibility of implementing PREP. Full findings are reported in supplementary materials. A summary of findings is reported in Table 5, along with a description of how the findings informed Stage 3, the feasibility study. In short, this stage provided support for the acceptability and practicality of PREP/PREP (YA Supplement) and an imperative to progress to Stage 3 and further evaluation of the feasibility of implementing all five steps of the intervention with young adults with complex disability.

Stage 3: Feasibility of implementation of the adapted materials

Stage 3 design

An explanatory sequential, mixed-method research design was used to explore the feasibility of implementing all five steps of PREP/PREP (YA Supplement). PREP [13] was designed to be

Table 5. Stage 2 themes and sub-themes related to feasibility of PREP and implications for Stage 3.

Themes	Sub-themes	Example quote	Implications for Stage 3
PREP/PREP (YA Supplement) for young adults with complex disability is needed		A lot of the young adults come to us from [organisation] or other paediatric services. They're very shy, they're insecure, they're just completely lacking in confidence. Having a mentor to help them along the way to achieve what they want to achieve, I think would be fabulous for them.	Findings lent support to Stage 3 as participants identified that there was a need for PREP and for pursuing participation goals
	Pursuing meaningful participation goals is important and rewarding	...rather than it being about a pressure mattress or medications, there is something really healthy and meaningful in having an overarching goal.	
How will it work?	Thinking of new activities and strategies is both challenging and beneficial.	We tried to think of something I hadn't done before—I found that a bit hard.	Strategies to guide identification of participation goals for young adults were added to PREP/ PREP (YA Supplement)
	PREP/PREP (YA Supplement) seems achievable	I definitely do think its achievable, like we can do centre-based, we can do home-based, there's no restrictions on the time we see people for. We do have a lot of flexibility within the way we work so I think that that sits well with PREP.	Findings lent support to Stage 3 as participants identified that PREP was achievable and could be pursued
	Different style of roll-out depending on the client's complexity	For the more able, that shorter timeframe, three goals, really community focused [is doable]. But for some clients with more complex needs you'd probably need a longer timeframe	Flexibility of implementation is inherent in PREP, however, Stage 3 progressed according to the standard implementation so that the methods were comparable to previous studies.
PREP/PREP (YA Supplement) would be really worthwhile at the right time with the right resources	Organisational fit	Selling it to management, how it's going to benefit the service and productivity alongside the best practice	Findings from the Stage 3 feasibility study could inform implementation of PREP in clinical settings
	Rating goals twice each week seemed too frequent	...maybe once a week ...I might do it, because you know, not having enough time, because I have other activities I do.	Flexibility of implementation is inherent in PREP, however, Stage 3 progressed according to the standard timeframes for outcome measurement so that the methods were comparable to previous studies.
	Support networks are very important	I think your support networks are very important. I think your carers, parent supports and friend supports are important.	Inclusion of a participation team is inherent to PREP implementation and was emphasised during Stage 3.
	PREP/PREP (YA Supplement) fits really well with the National Disability Insurance Scheme	It fits really well with the NDIS because they really like you to articulate your goals. It's all about social and community engagement which is key to PREP	PREP was considered to align with the values of the NDIS and likely to be fundable, providing added impetus to explore its feasibility for young adults in an Australian context.

delivered in a manner which enables evaluation of outcomes using an Interrupted Time Series (ITS) design with multiple base-lines. This study implemented PREP/PREP (YA Supplement) in the same way to enable limited efficacy testing alongside other aspects of feasibility, specifically implementation, acceptability and practicality [21]. *Implementation* was defined as how PREP/ PREP (YA Supplement) could be implemented as planned and proposed [21].

Stage 3 participant recruitment

The study involved three stakeholder groups.

- Young adults living in Melbourne, Australia. Clinicians at YACDS identified potential participants from amongst their caseload to refer to research staff who met the following criteria: were aged 18-30 years; had a complex disability; had an interest in pursuing participation goals; were able to provide informed consent and effectively communicate and engage with PREP/PREP (YA Supplement).
- Support people (SuppP) who assisted young adults during PREP/PREP (YA Supplement) and were nominated by young adult participants.
- Service providers (ServP) who implemented PREP/PREP (YA Supplement) with participants and who were not involved in Stage 2.

The original plan was to recruit 8-10 participants. This number was considered sufficient as it was similar to sample sizes in other studies which successfully researched the effectiveness and

feasibility of PREP [27]. The proposed sample size was not achieved due to COVID-19 related delays and restrictions.

Stage 3 intervention

The full 20-weeks and 5 steps of PREP/PREP (YA Supplement) were implemented.

- Step 1) Make Goals. Participants completed the COPM [14] to identify three participation goals.
- Step 2) Map out a plan. Participants identified environmental barriers to pursuing their nominated goals and developed solution-based strategies that would help them achieve these goals. These two steps were facilitated by the interventionist who adopted a coaching role.
- Step 3) Make it happen – working to achieve implementation goals.
- Step 4) Measure the process and outcomes – rating goals each week on the COPM Performance and Satisfaction with Performance scales, and the Involvement Scale.
- Step 5) Move forward – use skills learned to participate in other life activities.

The 20-week timeline started with a 4-week baseline phase used to establish baseline ratings on the outcome measures and participants were encouraged to begin self-directed planning to address the goals. This was followed by a 12-week intervention phase, consisting of three 4-week periods during which each goal was addressed sequentially [13], with an average of 1.4 face-to-face sessions provided per goal and weekly phone calls to support

goal progression. The order of addressing the goals was determined by the participant. A four-week follow-up phase followed the intervention phase. PREP/PREP (YA Supplement) was implemented by two YACDS ServP. ServP received education and support to deliver PREP/PREP (YA Supplement), including: (i) a PREP/PREP (YA Supplement) workshop, (ii) the self-directed PREP online module, (iii) PREP readings, (iv) PREP-YA [supplementary materials](#), and (v) community of practice and research team meetings.

Stage 3 data collection

Data were collected by a researcher not involved in delivery (NB), using four methods.

- i. A survey of feasibility using the 12 questions from the Acceptability of Intervention Measure (AIM), Intervention Appropriateness Measure (IAM), and Feasibility of Intervention Measure (FIM) [28]. The AIM, IAM and FIM were rated by participants on a five-point Likert scales (1 = completely disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = completely agree), where higher scores indicated greater acceptability, feasibility, and appropriateness.
- ii. Semi-structured interviews were completed with participants and, if requested, a support person, at the conclusion of intervention implementation. Interviews consisted of semi-structured, open-ended interview questions relating to the acceptability and practicality of PREP/PREP (YA Supplement). An interview guide was sent to participants prior to their interview (see [supplementary materials](#)). Interviews took on average 50-minutes to complete and were conducted via Zoom [29].
- iii. The study-specific survey for ServP used open-ended questions to explore the demand for PREP/PREP (YA Supplement) in their workplace and whether their service had the appropriate resources/supports to implement PREP/PREP (YA Supplement). SuppP questions sought information about their involvement in implementing PREP/PREP (YA Supplement) and perceptions of changes in the participation of the person they supported. The participant-completed survey was distributed to ServP by email in a Word document and to SuppP by Qualtrics online survey software [30].
- iv. Progress and outcome measures involved the COPM [14] and Involvement Scale. COPM was developed to identify and prioritise occupational performance goals, so the PREP/PREP (YA Supplement) contains guidance to prompt participants to focus on participation goals. Examples are asking participants to consider activities in the community that they would like to do but are not doing, or would like to be more involved in, activities undertaken for enjoyment or to experience satisfaction, to help others, or for work. Participants rated these goals on the Performance and Satisfaction with Performance scales of the COPM. The Performance Scale asked participants *how well you believe you can achieve your participation goal*. The Satisfaction with Performance scale asked *how satisfied you feel with how well you can achieve your goal*. The COPM Performance and Satisfaction with Performance scales are 10-point scales where 1 equates to lower, and 10 equates to higher, perceived Performance and Satisfaction with Performance.

Goals were also rated on a study-specific 10-point Involvement Scale, co-developed for this study by the research team in

collaboration with the RAP. This scale explores the construct of involvement as defined by fPRC, that is, the experience of participating whilst attending [8]. The Involvement Scale asked *how involved you felt in each activity when you were taking part*. Additional descriptions and prompts were provided to assist in clarifying the intent of the scale. Prompts included how participants felt about the activity undertaken, and how focused, persistent and interested they felt. The scale ranges from 1 equating to “not at all involved” to 10 representing “fully involved”. Involvement is not rated if the goal activity was not undertaken (i.e., they did not attend). The Involvement Scale has not previously had work completed on its psychometric properties, and was also applied in a concurrent study of PREP in Australia [19].

Although Stage 2 participants suggested that twice per week data collection might be onerous, we continued with twice weekly data collection to retain consistency with previous studies to facilitate meta-analyses. COPM Performance scale (the primary outcome) and Satisfaction with Performance scales were therefore collected according to the original PREP manual. The Performance scale was collected twice weekly, throughout the 20-weeks, and the Satisfaction with the Performance scale was collected six times; at the first baseline point and the end of each four-week phase. The Involvement Scale was collected twice weekly. Rating scales were collected by email or Zoom, according to participant preference, and took on average five-minutes to complete.

Step 3 data analysis

- i. AIM, IAM and FIM scores [28] were summarised for each stakeholder group using medians and ranges.
- ii. Audio recordings of participant interviews were transcribed verbatim and analysed thematically, guided by qualitative description [31]. Qualitative description is pragmatic and fits within an interpretive paradigm [32]. It aims to build a rich description rather than theory and, framed in the language of participants, is useful to inform practice, service providers and policy makers, thus facilitating knowledge translation [32,33]. Thematic analysis proceeded in an iterative and recursive manner, beginning with developing a strong familiarity with the transcripts. NB coded meaning statements in the transcripts, staying close to the words used by participants. Like codes were grouped, before collapsing like grouped codes into themes [33]. Developing codes and themes were repeatedly discussed with the full research team, including consumer investigators, clinicians and researchers, to provide diverse and rich perspectives on the data. Team members reflected on the perspectives they brought to the discussion and offered alternative viewpoints. Themes, theme descriptions, and quotes used to illuminate the themes were discussed in a workshop with RAP in the form of member checking [33]. RAP were asked to offer their perspectives as part of finalising the findings.
- iii. Narrative responses to study specific surveys were content analysed [34] separately, then integrated into the thematic analysis as related themes were identified. NB completed these analyses, then triangulated findings with the research team to strengthen the trustworthiness of the analysis [35].
- iv. *COPM and Involvement Scale*. Too few participants were recruited to enable analyses typically undertaken for interrupted time series design. Limited efficacy testing involved in feasibility studies is not intended to evaluate outcomes, rather to be part of determining whether are larger study

can be done [21,23,36]. In addition, participants and their goal activities were substantially impacted by COVID-19 restrictions. Consequently, results for these scales are presented in [supplementary material](#) and consist of visual analyses of graphed data.

Stage 3 results

Participant characteristics. Four young adults (two female, two male), aged 19–28 years, were recruited (Table 6). Six SuppP (two support workers, three parents and one partner – all female), and two ServP were recruited. ServP were a fourth-year occupational therapy student who delivered PREP/PREP (YA Supplement) and the student's supervisor, an experienced registered occupational therapist.

Intervention delivered. PREP/PREP (YA Supplement) was delivered from March – July 2021. Continuous COVID-19 related activity

restrictions (e.g., person density limits and travel restrictions) were in place for this period and occasionally the location was in COVID-19 lockdown. Consequently, participants took part in the majority of the intervention *via* phone call or Zoom.

All participants chose three goals and an array of environmental barriers to participation were identified (e.g., physical inaccessibility of facilities, negative public attitudes/perceptions and need for knowledge about available community services).

AIM, IAM and FIM responses. Figure 1 displays the responses of each stakeholder group to the AIM, IAM and FIM [28]. Each stakeholder group reported high scores for each measure, indicating their agreement that PREP/PREP (YA Supplement) was an acceptable, appropriate and feasible intervention. Young adults and ServP, strongly agreed that the intervention was acceptable.

Table 6. Stage 3 PREP/PREP (YA Supplement) young adult characteristics.

ID	Age (yrs)	Sex	Diagnosis and Function	Life situation
P1	28	Male	P1 has muscular dystrophy; is able to walk in most settings and handle most objects well, with reduced speed and/or quality. P1 communicated independently and effectively using speech.	P1 lives with his partner; has a bachelor's degree and is looking for work. He is able to drive and does not require a modified vehicle.
P2	23	Male	P2 has cerebral palsy, an intellectual disability, mental health issues, and a communication impairment which is supported by his PODD communication book, Tobii speech-generating device and assistance from a communication partner. P2 walks using a hand-held mobility device, though when outdoors and in the community; he transports in a wheelchair or uses powered mobility. At times, he may need assistance to handle objects or prepare/modify activities.	P2 lives at home with his parents and siblings, has completed high school and is currently studying part-time as well as volunteering. He is supported by his family members/friends or carers to drive him, does not require a modified vehicle and also uses public transport/taxis.
P3	19	Female	P3 has cerebral palsy, mental health issues and chronic lung disease; uses a powered wheelchair indoors, outdoors and in the community; and can handle a limited selection of objects and may require assistance from others at times. P3 communicated independently and effectively using speech.	P3 lives at home with her parents and siblings, has completed high school and is currently looking for work. She is supported by her family/friends or carer to drive her, requires a modified vehicle for transportation, and also uses taxis/other paid transportation services.
P4	27	Female	P4 has an intellectual disability, connective tissue disorder and scoliosis; uses wheeled mobility in most settings; requires assistance for transfers; and is able to handle objects easily and successfully. P4 communicated with speech, scaffolded with assistance from communication partners for understanding and interpretation.	P4 lives with her parents and siblings, has completed high school and is currently unemployed. She is supported by her family/friends or carers to drive her, does not require a modified vehicle and often uses public transport.

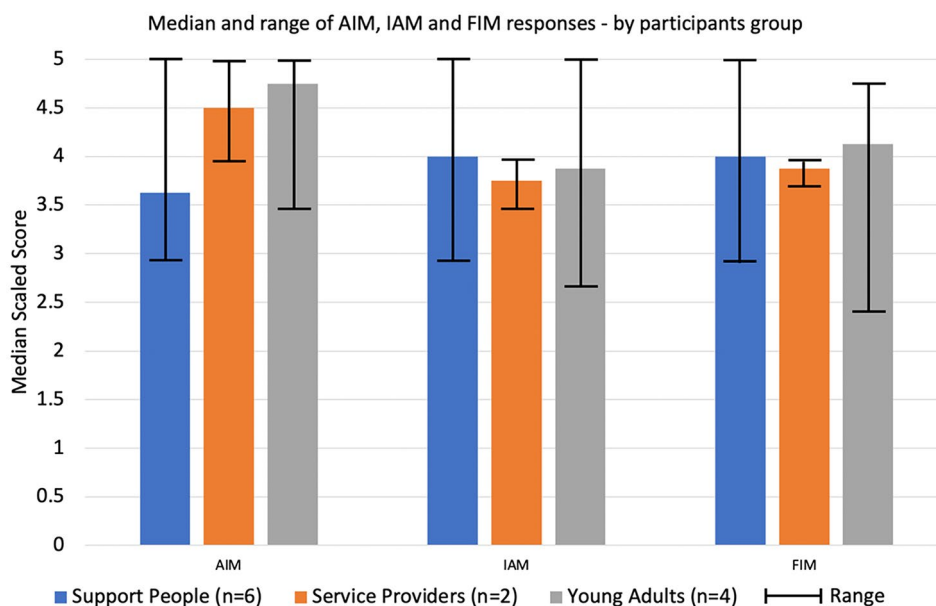


Figure 1. Stage 3 AIM, IAM and FIM responses. AIM: acceptability of intervention measure, IAM: intervention appropriateness measure; FIM: feasibility of intervention measure.

Interviews and study specific survey results: feasibility of PREP/PREP (YA Supplement). Three major themes were identified from analysis of participant interviews, SuppP and ServP survey responses: (i) *Setting and achieving goals – challenges and benefits*; (ii) *Finding the right time for PREP/PREP (YA Supplement)*; and (iii) *PREP/PREP (YA Supplement) empowers a clinical shift from skill-focused therapy to participation-focused therapy; and with this, a shift in resources and support team education is needed.*

Theme 1: Setting and achieving goals: Challenges and benefits. Some participants found the initial PREP/PREP (YA Supplement) goal setting process difficult. P3 found choosing her goals “a bit challenging, because I didn’t really know what I wanted to do”. In contrast, P1 found it “quite helpful having to think about ... what I wanted to do with my time”, although also commented that “maybe there might be some people who would feel a bit ... pressured” when choosing their goals.

Participants reported that PREP/PREP (YA Supplement) was beneficial in different ways, for different people. Referring to the PREP/PREP (YA Supplement) intervention, P1 said “I think it’s a good opportunity to get out there”, whilst P2 stated “I liked the program” and that “it helped me to achieve what I wanted to achieve”. P3 spoke about how “PREP-YA ... can help you achieve the goals that you have been struggling with in life”. Other than participation outcomes, participants spoke about additional PREP/PREP (YA Supplement) benefits. P3 learnt “that I can be organised” and that PREP/PREP (YA Supplement) “showed me different ways to complete a goal, and that people around me are like willing and wanting to help”. P4 stated that “if you’re someone who isn’t confident ... [PREP/PREP (YA Supplement)] can actually help you to build on that”. SuppP and ServP articulated benefits they observed beyond goal achievement. SuppP1 expressed how P2 “seemed very motivated to implement the strategies that would help them to achieve their goals”. Similarly, SuppP3 thought that P3 “plans her activities now more independently, including stepping outside of her comfort zone”, and SuppP6 stated that “P1 is more confident in outdoor activities”. ServP2 referred to changes in participants’ autonomy, that participants “became more self-determined which reduced occupational therapy input from goal 1 to 3”.

Participants identified challenges that COVID-19 imposed on their participation during PREP/PREP (YA Supplement). P1 stated there was “a lot of things ... I wasn’t really able to do, obviously, because of COVID” and how “almost 90% of the time I couldn’t do anything”. P2’s parent, who attended the interview, expressed that due to COVID-19, [his goals] “weren’t observed [by clinicians], so you couldn’t actually clearly see the barriers that stopped him from achieving them successfully as he would have liked to”. P4 stated [referring to appointments with clinicians] that she “would have preferred it to be face-to-face instead of over the phone”.

Theme 2: Finding the right time for PREP/PREP (YA Supplement). All participants expressed the need for increased time and/or flexibility to implement each PREP/PREP (YA Supplement) goal – which would ultimately depend on the individual and their circumstances. P4 believed that the four-week timeframes “gave enough time at each goal” and P1 thought “...the four weeks to work on each goal is good”. In contrast, P3 mentioned that “four-weeks was too quick”, and P2 suggested “more time to reach the goals” is necessary. P2’s parent, felt there was “too short a timeframe to achieve the goals; for him to introduce the task and then master it was ... not as realistic as what it could have been”. However, the parent also stated this “may not be the case for others”. Similarly, SuppP5 and SuppP6 respectively stated that “more time needs to be given to reach each goal” and that PREP/PREP (YA Supplement) “is appropriate however also needs to take

into consideration of the young adults’ routine and daily life plans ... more flexibility and [personalisation] will be better.” From a clinical perspective, ServP1 described how “implementing in a flexible way with young adults is important ... having longer time frames might be more suitable for some clients”. ServP2 wrote:

The intervention timeframes ... would have supported young adults if they were extended (e.g., 6–8 weeks per goal). It was difficult to organise services (community organisations/allied health supports) within this timeframe and the young adults also had many other areas of importance in their life where they had to distribute their time. (narrative survey response).

Another factor related to time was fitting PREP/PREP (YA Supplement) activities, such as phone calls and clinical appointments, into one’s daily life. This seemed to be a factor for which young people and their support people were not prepared. P1 stated that PREP/PREP (YA Supplement) was “almost hard to implement into my every day” and that it was sometimes hard “trying to find the time within those four weeks to do [the goals]”. P1 would have preferred more independence, suggesting an alternate communication routine where “if there was a problem, that I would be the first one to call [the clinicians] otherwise I just keep working on it”. P2 and his parent found it challenging to align PREP/PREP (YA Supplement) clinical appointments with their schedule; stating that “the last appointment was at 2:30pm, so I had to pull [him] out of his pre-vocational placement for [meetings] to occur”.

Theme 3: PREP/PREP (YA Supplement) empowers a clinical shift from skill-focused therapy to participation-focused therapy; and with this, a shift in resources and support team education is needed. ServP identified that PREP/PREP (YA Supplement) shifted their focus from skills-based to participation-based therapy, overall increasing their person-centredness. ServP1 conveyed that “focusing on participation is an important and vital component of a young adult’s life”, and that it “focuses on the things people want to do and is meaningful to them”. ServP2 found “focusing on environment modification rather than a focus on individual limitations” important and that [PREP/PREP (YA Supplement)] “helped me to understand and implement person-centred practice”. ServP welcomed the shift to a participation focus. ServP1 articulated that “as participation is at the heart of everything that OT [occupational therapy] does, I wonder whether the framework of PREP-YA could become more overarching in everything we do”.

This shift to a participation focus, however, was identified as potentially creating a need for additional resources. ServP1 wrote that “there is limited capacity within the current EFT [workforce capacity] to implement the PREP-YA program” and that “there may be capacity in the future if there is more EFT [equivalent full time staff] or YACDS [staff] become NDIS [National Disability Insurance Scheme] providers to be able to expand to meet more of the community participation goals”. Similarly, ServP2 wrote that “I believe the service at YACDS requires more staffing to complete [PREP/PREP (YA Supplement)] on top of service as usual”. ServP1 suggested that “PREP-YA could be used at day centres to guide people in the activities they would like to participate in” while ServP2 mentioned that “[PREP/PREP (YA Supplement)] may have been better delivered from a community occupational therapy role due to the requirements of the service user within the YACDS clinic”.

SuppP believed that a shift to a participation-focus required clinicians to support all the participation team to learn and implement the coaching and education elements of PREP/PREP (YA Supplement) so all could share the responsibility of delivering participation-focused therapy. SuppP5 identified that, at times, the “focus was too much on me as the parent” and “my time was

[spent] training support workers in new skills”, that is, NDIS funded workers who supported the participant to engage in PREP/PREP (YA Supplement) and which was “time consuming”. Likewise, SuppP3 stated that “this could be a program that carers and support workers would also benefit from, they would then be able to enable their clients”.

COPM and involvement scale. Complete data sets were obtained for each participant (see [supplementary material](#) for graphed data and summaries). Increases in participation outcomes were evident in four out of twelve goals, with two additional goals demonstrating ambiguous outcomes. Overall, each PREP/PREP (YA Supplement) participant achieved at least one goal demonstrated by sustained or increased Involvement, Performance, and Satisfaction with Performance scores during the follow-up phase with no continued intervention from clinicians.

Discussion

This study used Bowen’s framework [21] to guide an investigation of aspects of the feasibility of implementing PREP with young adults with complex disability in an Australian context. In Stage 1, forms and resources used to implement PREP were reviewed and adapted in collaboration with young adults with disability, and PREP (YA Supplement) was co-created. Preliminary feasibility was explored in Stage 2 and then evidence about feasibility of PREP/PREP (YA Supplement) was gathered in Stage 3.

Acceptability

Participants in Stages 2 and 3 perceived PREP/PREP (YA Supplement) as an intervention that could improve the participation outcomes of young adults with complex disability living in Australia and enhance their confidence, motivation, and independence. Acceptable elements included a focus on achieving participation goals that were meaningful for the young adult, the inclusion of families and other support people in the intervention and addressing environmental barriers. These findings of acceptability were also demonstrated in the results of the survey of feasibility by each stakeholder group, particularly young people and service providers.

Close collaboration between young people and clinicians to identify participation goals was considered crucial. Participation goals can be difficult to identify from both young person and clinicians’ perspectives, with a shift necessary from previous experiences with setting goals which are more immediately focussed on body functions and structures and activity performance. Second, collaboration is needed to ensure participation goals are meaningful and individualised. Participants also reported that identifying strategies to address barriers in pursuing new participation goals can be challenging. This is important knowledge to use when implementing PREP/PREP (YA Supplement) in the future. The importance of goal setting to enable effective practice has been well established [37]. The strategies identified in this study could be used to support collaboration in setting meaningful and attainable goals to support autonomy and competence in young adults with disability. Lists of tools to facilitate a discussion around desired activities and participation goals (in addition to COPM) are offered in the PREP manual [13] and PREP (YA Supplement).

Participants identified a need for intervention implementation to be more flexible in terms of timeframes to achieve goals. Timeframes in this study were constrained by the research context,

but the PREP manual clearly supports tailoring intervention to individuals’ contexts. Young adults and clinicians may need to progress more slowly through the steps of PREP/PREP (YA Supplement) so that adequate time is available to support a mind-set where the agency is with the young person and their participation team to develop meaningful goals and constructively identify barriers and solutions. This flexibility is important; it also brings resource considerations from an implementation perspective.

Young adult participants agreed that PREP/PREP (YA Supplement) was acceptable for use in an Australian culture and funding system. Australia’s NDIS [17] enables individually negotiated funding packages to allow choice and control in the selection and purchase of care and support by people with disability. Young adult participants appeared to consider PREP/PREP (YA Supplement) sufficiently acceptable as to warrant investing their valuable funding packages in the intervention. Future work could estimate the costs compared with the benefits of implementing PREP/PREP (YA Supplement) with young adults to inform knowledge translation efforts more comprehensively. PREP (YA Supplement) contains adaptations to wording and context to enhance cultural validity for Australia and young adults, but those wishing to implement PREP/PREP (YA Supplement) more globally may need to consider contextual elements including those posed by health and disability policy and services, and funding models.

Practicality

Young adult participants considered time as a major barrier to participating in PREP/PREP (YA Supplement). Young adults have competing demands on their time, including work and other commitments, and the added time it often takes people with a disability to navigate everyday life. In addition, planning around the timing of participation in PREP/PREP (YA Supplement) needs consideration to optimise engagement and outcomes. The frequency with which COPM scores were collected was frequently mentioned as a barrier to practicality. COPM Performance scores were measured twice per week to monitor progress and guide discussions about the ongoing implementation of strategies identified to address barriers to participation goals. These multiple data points are also used in interrupted time series design to evaluate outcomes of PREP [38,39]. Flexibility is inherent in PREP/PREP (YA Supplement) implementation, including the timing, method and frequency of collecting COPM data. The extent to which frequent measurement and feedback on goal progress maintains motivation and enables implementation requires consideration before altering the frequency of measurement, but could be individually negotiated with young people participating in PREP.

Clinicians considered the practicality of implementing PREP/PREP (YA Supplement) from their perspectives of working in a hospital-based, outpatient clinic. Clinicians identified that implementing PREP/PREP (YA Supplement) would require a change to their current practice to one which espoused a participation focus. Although this would require considerations around resources and staffing, clinicians believed this would be acceptable for their organisation. Clinicians also considered the ways that PREP/PREP (YA Supplement) could be implemented to make it practical for their complex clients who have differing presentations. Suggestions included increasing timeframes and flexibility for working on goals, and increasing levels of clinicians’, parents’, and others’ involvement. These findings are consistent with Burrough and Beanland’s [40] feasibility study which investigated the perceptions of

clinicians who implemented PREP in a rehabilitation setting for children with acquired brain injury. They also found that delivering PREP required a shift to a participation perspective, and implementation must be tailored for the individual client, level of ability, family, and other contextual elements. PREP was developed to enable a strong person-centred and flexible approach and the findings from these studies draw attention to this feature. The original PREP Manual [13] is clear that each aspect of PREP can be modified to accommodate individual client circumstances, number of goals, timing of implementation, and availability of resources.

Implementation

Fewer than planned participants were recruited in both Phases 2 and 3, but all who started the intervention completed PREP/PREP (YA Supplement). Longer timeframes for recruiting participants in each phase may have increased samples sizes. The concept of participation focused intervention is also novel, as exemplified by both participants' and clinicians' responses, and perhaps potential participants were unsure of the value and relevance to them of engaging with PREP. Some potential participants cited time as a reason for declining to participate.

Limited efficacy

Consistent with feasibility study methods [21], this study paid limited attention to the outcomes of PREP whilst developing an understanding of acceptability, practicality, and implementation in the local context. Consequently, statistical methods were not used for analysis. The findings of the visual analyses of the graphed COPM Performance and Satisfaction with Performance, and Involvement scales were relatively weak when compared with previous studies [13,39,41]. A range of factors may have contributed to these findings, including the complexity of the presentations of participants, the competing life demands typical of young adults and the inflexibility of implementing PREP within the constraints of the study methods (e.g., not extending the period of time working on a goal if needed). COVID-19 related restrictions also played a large part with unanticipated limitations to some participants' ability to be involved in their participation goals. Participants 1 and 4 for example, were unable to be involved in kayaking or dining out at restaurants, respectively, during the scheduled time for addressing these goals. Clinicians used this time to discuss interventions plans with participants and offered support to achieve the goals outside of the PREP timeframes. Most interactions between participants and clinicians took place online, whereas ideally participants would be supported in their own environments to navigate barriers and identify solutions. Each of these potential reasons for weaker than anticipated outcomes could be mitigated by a flexible approach to implementing PREP. Adjustments to timing and processes used to delivery interventions are usually possible within clinical practice, and individual outcomes can be tracked.

Strengths and limitations

Multiple factors impacted on participant recruitment including study time constraints and COVID-19. This study was planned in early 2020 and commenced in July 2020 and was substantially impacted by COVID-19 lockdowns and restrictions. This was a barrier to recruiting participants and to achieving breadth and

diversity of participant perspectives. It also impacted participant ability to identify participation goals that were meaningful and feasible during the extraordinary times imposed by the pandemic activities and the ability to be involved in desirable participation goals. Anaby and colleagues [42,43] addressed the challenges of identifying and realising participation goals during crises such as the COVID-19 pandemic. They offer strategies for implementing PREP during such crises with a focus on the importance of supporting capacity-building for people with disability and their participation team.

Consumer involvement was a substantial strength and warrants comment. Consumer involvement in this study can be viewed through the lens of the fPRC [8]. Researchers strived to co-create an environment that was available, accessible, affordable, accommodating, and acceptable [44] to promote attendance and involvement of consumers in all aspects of the research. These involvement strategies included comprehensive orientation, flexibility of involvement, responsiveness to consumer queries and communications, overtly valuing involvement, explicit inclusion of consumer feedback/recommendations, and payment for involvement [45]. Consumer investigators were involved in all aspects of the study, contributing to fortnightly research team meetings throughout the duration. Research advisory partners were involved at several key stages to influence decisions and directions. The supportive context meant consumers attended nearly all the scheduled meetings, were highly involved, and contributed both positive perceptions and concerns regarding PREP/PREP (YA Supplement). This resulted in a thorough investigation of the applicability of PREP/PREP (YA Supplement) for young adults in Australia, which appeared to enhance the acceptability of the intervention.

Future directions

PREP/PREP (YA Supplement) and its underpinning principles appear an acceptable and practical intervention to implement in an Australian context with young adults with complex disability. Findings from this study contribute to the increasing body of knowledge regarding the feasibility of participation-focused interventions when implemented with differing demographic groups. PREP was developed to be applicable across ability levels and the lifespan. The participants in this study volunteered that PREP would have relevance to a range of other people. PREP has been effectively implemented with children and young people in Canada, the United Kingdom, Israel, Australia and Ireland [16,39,40,46–49].

Critical information for future implementation has been elicited. Attention is needed to focus clinicians, young adults, and families on participation as an outcome, the nature of participation goals and how to identify them, and altered means to achieving these, that is, a focus on the individual's strengths and actively identifying environmental barriers and facilitators. PREP was originally developed to be inherently flexible but its implementation in research-to-date gives the impression that it is implemented in a strict 20-week, phased process. This was not the intention of PREP in clinical implementation and the findings of this study reinforce the need for flexibility of each aspect of PREP to respond to participants' individual circumstances and prevailing community and environmental situations.

Having established the feasibility of PREP/PREP (YA Supplement), the next stages of the knowledge to action cycle [20] can be addressed to translate this intervention into practice and evaluate knowledge translation outcomes. This will involve collaborating with stakeholders, such as people with disability,

clinicians, managers, service provider organisations, and in policy making positions, to optimise uptake and outcomes. The objectives of such collaboration would be to identify, tailor and implement strategies to promote the use of PREP/PREP (YA Supplement) in selected clinical or community settings and evaluating client and resource use outcomes with larger samples.

Acknowledgements

Researchers acknowledge and thank the Young Adult Complex Disability Service at St Vincent's Hospital Melbourne; Research Advisory Partners including Matthew Cucanic, Brenton Ponza, Helen Briffa, Sevastine Katsakis, Jerusha Mather, Emily Cross, and Amy Marks; young adult participants and their families; and clinician participants.



Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by a grant from the Endeavour Foundation Disability Research Fund. The study is embedded within the NHMRC-Funded Centre for Research Excellence: CP-Achieve (APP1171715).

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