

## Systematic Review

# Supporting active engagement of adults with intellectual disabilities in lifestyle modification interventions: a realist evidence synthesis of what works, for whom, in what context and why

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## Abstract

**Background** Lifestyle modification interventions for adults with intellectual disabilities have had, to date, mixed effectiveness. This study aimed to understand how lifestyle modification interventions for adults with intellectual disabilities work, for whom they work and in what circumstances.

**Methods** A realist evidence synthesis was conducted that incorporated input from adults with intellectual disabilities and expert researchers. Following the development of an initial programme theory based on key literature and input from people with lived experience and academics working in this field, five major databases (MEDLINE, EMBASE, CINAHL,

PsycINFO and ASSIA) and clinical trial repositories were systematically searched. Data from 79 studies were synthesised to develop context, mechanism and outcome configurations (CMOCs).

**Results** The contexts and mechanisms identified related to the ability of adults with intellectual disabilities to actively take part in the intervention, which in turn contributes to what works, for whom and in what circumstances. The included CMOCs related to support involvement, negotiating the balance between autonomy and behaviour change, fostering social connectedness and fun, accessibility and suitability of intervention strategies and delivery and broader behavioural pathways to lifestyle change. It is also essential to work with people with lived experiences when developing and evaluating interventions.

**Conclusions** Future lifestyle interventions research should be participatory in nature, and accessible data

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collection methods should also be explored as a way of including people with severe and profound intellectual disabilities in research. More emphasis should be given to the broader benefits of lifestyle change, such as opportunities for social interaction and connectedness.

**Keywords** Alcohol, Diet, Intellectual disabilities, Physical activity, Realist synthesis, Smoking

## Introduction

Intellectual disabilities occur during the developmental period and are associated with significant impairments in intellectual functioning and adaptive skills (American Association of Intellectual and Developmental Disabilities, 2021; American Psychiatric Association, 2013). Adults with intellectual disabilities are at risk of health inequalities, which include, but are not restricted to, reduced life expectancy, reduced general health and mental well-being and increased risk of obesity (Emerson and Hatton 2014; Glover *et al.* 2017; Hughes-McCormack *et al.* 2017; Hughes-McCormack *et al.* 2018). The health inequalities experienced may be exacerbated by participation in unhealthy lifestyle behaviours by adults with intellectual disabilities.

These behaviours include low levels of physical activity, high levels of sedentary behaviour and unhealthy diets (Adolfsson *et al.* 2008; Dairo *et al.* 2016; Melville *et al.* 2017; Westrop *et al.* 2019; Gast *et al.* 2022). Mixed findings have been reported for the consumption of alcohol and tobacco smoking; yet it appears that rates are comparable for smoking compared to general population, with risk of alcohol misuse potentially being higher (Huxley *et al.* 2018).

Unhealthy lifestyle behaviours may be co-occurring, with participation in one increasing likelihood of engaging in another (Hale *et al.* 2014; Schuit *et al.* 2002). Participation in unhealthy lifestyles increases the risk of poor mental health, obesity, non-communicable diseases, such as type 2 diabetes, and reduced life expectancy (Warburton 2006; Lee *et al.* 2012; De Rezende *et al.* 2014; Smyth *et al.* 2015; Wood *et al.* 2018). These negative health

outcomes are reflective of the health inequalities experienced by people with intellectual disabilities (Emerson and Hatton 2014), making it essential to promote a healthy lifestyle.

Systematic reviews of lifestyle behaviour change interventions for adults with intellectual disabilities have reported mixed effectiveness (Harris *et al.* 2018; Hassan *et al.* 2019; Kerr *et al.* 2013). To date, there is limited comprehensive understanding of why lifestyle modification interventions work for some people but not others. This is an important gap in the literature as increased understanding would help facilitate the development of more effective interventions. A realist synthesis of available evidence could help address these questions, with this approach drawing upon the philosophical perspective of realism to develop a programme theory (Wong *et al.* 2013a; Wong *et al.* 2013b).

The philosophical perspective of realism argues that understanding of reality is 'imperfect' and is influenced by an individual's experiences, their culture, cognition and language (Wong *et al.* 2013a; Wong *et al.* 2013b). However, rigorous methods can help to build our knowledge and understanding of reality, and subsequently, lifestyle modification among adults with intellectual disabilities. Therefore, this can be further facilitated through involvement of people with lived experience of having intellectual disabilities to ensure any interpretations accurately reflect their lives.

In a realist perspective, the programme theory is built of context **mechanism outcome configurations** (CMOCs; Wong *et al.* 2013a; Wong *et al.* 2013b). This refers to the process in which specific 'contexts' trigger 'mechanisms' (e.g. the behavioural and emotional responses), which results in 'outcomes' that can be either intended or unexpected (Wong *et al.* 2013a; Wong *et al.* 2013b). A comprehensive programme theory can inform future interventions, which is a core element of the development and evaluation of complex interventions (Skivington *et al.* 2021). The goal of this study was to conduct a realist synthesis utilising a broad range of evidence and substantial input from people with lived experience, to address the question of what works, for whom and in what circumstances in relation to lifestyle modification interventions for adults with intellectual disabilities.

## Methods

### Design

A realist approach was employed to synthesise a broad and diverse body of literature (i.e. quantitative, qualitative and mixed-methods studies) to develop a comprehensive programme theory. The realist synthesis goes beyond quantifying if interventions were effective and instead produces a usable programme theory outlining the important contexts and mechanisms contributing to the efficacy of lifestyle modification interventions for adults with intellectual disabilities. It illustrated the complex causal mechanisms and how these interact with individuals' agency and social context to produce outcomes. The realist synthesis was conducted as part of a wider evidence synthesis, the protocol for which was registered on PROSPERO and published (PROSPERO CRD 42020223290; Rana *et al.* 2021). It was performed and reported in accordance with the Realist and Meta-Narrative Evidence Synthesis: Evolving Standards (RAMESES; Wong *et al.* 2013a).

### Patient and public involvement

The realist evidence synthesis incorporated patient and public involvement (PPI) through working with People First Scotland, which is a non-profit organisation run by people with intellectual disabilities. As part of PPI, a member of the research team, and co-applicant on this project, was a person with lived experiences of having intellectual disabilities and a member of People First Scotland. This person attended all team meetings and were actively involved in all decisions for each stage for this project. There was an additional group of PPI representatives consisting of four adults with mild intellectual disabilities. Members of the research team met with the group of PPI representatives to discuss preliminary findings at multiple stages to help ensure they were interpreted in a way that complements the lived experiences of adults with intellectual disabilities. All discussions about the research were facilitated by a staff member from People First Scotland.

### Steering committee

The research project was guided by a steering committee that included experts in research involving

people with intellectual disabilities and a researcher with substantial experience in realist evidence syntheses. Importantly, the steering committee included a member with intellectual disabilities who was there to ensure that all decisions made, and interpretations of the findings, reflected the lives of adults with intellectual disabilities.

### Developing a draft programme theory

The process began by performing broad, scoping searches of key literature to identify existing theories that could explain how lifestyle modification interventions for adults with intellectual disabilities work. Initial CMOCs were created by reading and re-reading the identified studies and through extensive discussions between two members of the research team (SW and EG). The draft programme theory was subsequently discussed with experts working in the field of intellectual disabilities and/or lifestyle modification. In addition to this, easy read summaries were produced of the draft programme theory and presented to the PPI group of adults with intellectual disabilities. There was agreement over the content of the draft programme theory and the importance broader influences that impact on healthy lifestyles were emphasised, such as the impact of financial restrictions.

### Searching process

#### *Systematic search*

Systematic searches were conducted to identify a relevant body of literature that could help to further refine the programme theory. Search strategies were developed for each database that included medical subject heading (MeSH) terms and key words for health risk behaviours, health outcomes and intellectual disabilities (Appendix 1). Five databases were searched from inception to January 2021. These were CINAHL (Cumulative index of nursing and allied health literature) via EBSCO Host; PsycINFO via EBSCO Host; Medline via OVID; Embase via OVID; and Applied Social Sciences Index and Abstracts (ASSIA) via ProQuest. The following clinical trial repositories were also searched in March 2021: Clinical trials database; Cochrane Central Register of Controlled Trials (CENTRAL); Evidence for Policy and Practice Information and

Co-ordinating Centre; ISRTC database. In addition, hand searches of reference lists of systematic reviews and intervention studies identified were conducted to ensure no relevant literature was missed.

#### *Additional searches*

Reflecting the quality standards for realist evidence syntheses, and following recommendations from the steering committee, additional searches were conducted to help build upon the emerging programme theory (Wong *et al.* 2013a). The non-systematic searches rapidly identified potentially relevant literature to strengthen emerging aspects of the programme theory that were otherwise lacking in literature. These searches were run in February 2022 using Google Scholar for literature that included people with severe and profound intellectual disabilities, participatory research, mental health and social inclusion along with autonomy and freedom of choice.

In February 2022, further Google Scholar searches were used to reduce the risk of important literature being missed that were published after the initial search in January 2021. First, there were forward citation searches of all systematic reviews identified by the systematic search process ( $n = 19$ ). Next, additional searches for literature published from 2021 onwards with the searches including terms for relevant lifestyle behaviours and terms for intellectual disabilities in the title.

#### **Study selection and appraisal**

##### *Initial screening and study selection*

All identified citations were uploaded into Covidence, and duplicates were removed. Using a set of pre-determined eligibility criteria, two researchers (SW and DR) independently screened all titles and abstracts and full texts of potentially eligible studies. A third researcher (AMcG) screened any studies when there was a conflict that could not be resolved by discussion between the two researchers. This resulted in an initial short list of papers. Eligibility criteria followed a PICO format (population; intervention and comparators; outcomes):

- Population: Adults (>18 years) with intellectual disabilities based on the criteria of significant impairments in intellectual functioning (e.g. an IQ score <70) and significant impairments in adaptive skills with this occurring prior to the onset of adulthood.
- Interventions and comparators: Lifestyle modification interventions targeting smoking, alcohol consumption, physical activity, sedentary behaviour or diet. Not restricted by setting.
- Outcomes: Range of relevant outcomes. Primary outcomes of the intervention directly related to lifestyle modification; secondary outcomes could include quality of life, well-being, cost-effectiveness etc.
- Study design: No restrictions to study design. Qualitative, quantitative and mixed-methods studies were included if they were relevant to understanding lifestyle modification of adults with intellectual disabilities.

##### *Relevance and rigour appraisals*

Inclusion of studies into the synthesis was based on two criteria: (1) relevance to the programme theory and (2) methodological rigour. The methodological rigour of the studies was assessed using the following design-specific critical appraisal tools:

- Randomised interventions: Cochrane ROB-2 tool (Higgins *et al.* 2016)
- Non-randomised interventions: Cochrane ROBINS-I tool (Sterne *et al.* 2016)
- Qualitative literature: Qualitative Critical Appraisal Skills Programme (CASP 2018)
- Other quantitative study designs: The standard quality assessment criteria for evaluating primary research papers from a variety of fields: Quantitative checklist (Kmet *et al.* 2004)

Relevance to the programme theory was determined based on the conceptual richness of a study and the relevance of the data to understanding lifestyle modification in adults with intellectual disabilities. A highly relevant study could be, for example, a qualitative or mixed-methods process evaluation of one of the targeted lifestyle behaviours. To be included in the synthesis, a study had to be considered as relevant to

the developing programme theory and be methodologically rigorous.

The appraisal process was primarily conducted by one researcher (SW), with frequent discussions with a second researcher (EG) about the appraisals and reasons for inclusion and exclusion of studies in the synthesis. The appraisal process was also discussed and agreed upon with the wider research team. An example of relevance and rigour appraisals applied to screened studies is presented in Table 1.

### Data extraction and coding

Data extraction was conducted in two stages. The first stage involved extracting contextual information, such as study and participant characteristics, using a data extraction spreadsheet in Microsoft Excel. The second stage entailed extracting data relevant to the programme theory. This involved first identifying the richest sources that were most relevant and rigorous by re-reading each of the included studies ( $n = 14$ ; Croot *et al.* 2018; Elinder *et al.* 2018; Harris *et al.* 2019; House *et al.* 2018; Kerr *et al.* 2017;

Kouimtsidis *et al.* 2017a; Kuijken *et al.* 2016; Maine *et al.* 2019; Matthews *et al.* 2016; Mitchell *et al.* 2018; O'Leary *et al.* 2017; Spassiani *et al.* 2019; Sundblom *et al.* 2015; van Schijndel-Speet *et al.* 2014b).

The richest sources were the studies that were considered to have the most potential for informing the programme theory. These richest sources were the first to be uploaded to the qualitative data management software NVivo 12 (QSR International, Warrington, UK). Coding was conducted based on initial observations informed directly from the text. Thematically similar codes were then grouped together to develop descriptive themes. This resulted in the development of an initial coding framework, which was then applied to the remaining studies. To ensure it accurately captures the data, the initial coding framework was reviewed by a second researcher (EG).

### Analysis

CMOCs were developed by reviewing the coded excerpts of text while reflecting on potential contexts,

**Table 1** Example of relevance and rigour appraisals for inclusion in the study

Relevance	Rigour	Overall appraisal
Harris <i>et al.</i> (2017) <b>Multi-component weight management cluster RCT</b> Detailed description of a lifestyle modification intervention for adults with intellectual disabilities. Provides important insight on intervention strategies and intervention outcomes. Study would be highly relevant to developing programme theory	The ROB-2 score indicates some concerns with risk of bias. However, overall, the study was methodologically rigorous	Include
Mitchell <i>et al.</i> (2018) <b>Qualitative study exploring perceptions of taking part in intervention</b> Qualitative study including adults with intellectual disabilities taking part in a walking intervention to improve physical activity. Explored perceptions and is highly relevant to understanding underlying mechanisms and contexts within the programme theory	CASP Qualitative tool indicated overall high confidence in the study findings (09/10) score. The study was appraised as being methodologically rigorous	Include
Jackson and Thorbecke (1982) <b>Weight loss RCT for adults with intellectual disabilities</b> The study had limited current relevance to a programme theory for lifestyle modification interventions. The study described methods of lifestyle change that would be unsuitable such as using 'punishing statements' if 'prohibited' food was eaten. Considered to have low relevance to the current programme theory being developed	The ROB-2 score indicated high risk of bias. The study was not considered to be methodologically rigorous	Exclude

CASP Qualitative tool, Qualitative Critical Appraisal Skills Programme (CASP 2018); RCT, randomised controlled trial; ROB-2, Cochrane ROB-2 tool (Higgins *et al.* 2016).



mechanisms or outcomes. The coding framework was revised accordingly. The development of the CMOCs was an iterative process that involved frequent discussions between two researchers (SW and EG). Thematically similar CMOCs were grouped together to develop clusters of CMOCs and produce diagrams of partial programme theories. The partial intervention theories were summarised in an easy read format for input from the PPI group. The feedback was used to prioritise what should be included when presenting the overarching programme theory. The emerging overarching programme theory was shared and discussed with the steering committee and the wider research team.

The first iteration of the programme theory was presented in a multi-level ring format to emphasise the interacting complex contexts and mechanisms that contribute to active engagement with lifestyle modification interventions. The design was inspired by the multi-level rotating structure of the Behaviour Change Wheel through (Michie *et al.* 2014). Although there was agreement that the model produced summarised the findings, there were concerns that it did not clearly highlight the individual CMOCs and how they interact. Input given by the wider research team helped develop and finalise an overarching

programme theory, which focused on the core CMOCs regarded to be the most important when considering lifestyle modification for adults with intellectual disabilities. The first iteration of the programme theory was still retained to be a simplified version of the final complex overarching programme theory.

## Results

### Search results

A total of 79 studies were included in the synthesis (Fig. 1). Initial searches via electronic databases and other methods yielded 166 studies that met initial inclusion criteria for shortlisting articles, out of which 13 were duplicates and 90 were excluded due to low relevance and/or rigour. Additional searches conducted in February 2022 identified a further 16 studies, which were rigorous and relevant enough to be included in the synthesis.

### Study characteristics

Table 2 presents a summary of the study and participant characteristics across the 79 included studies. The studies were primarily based in the

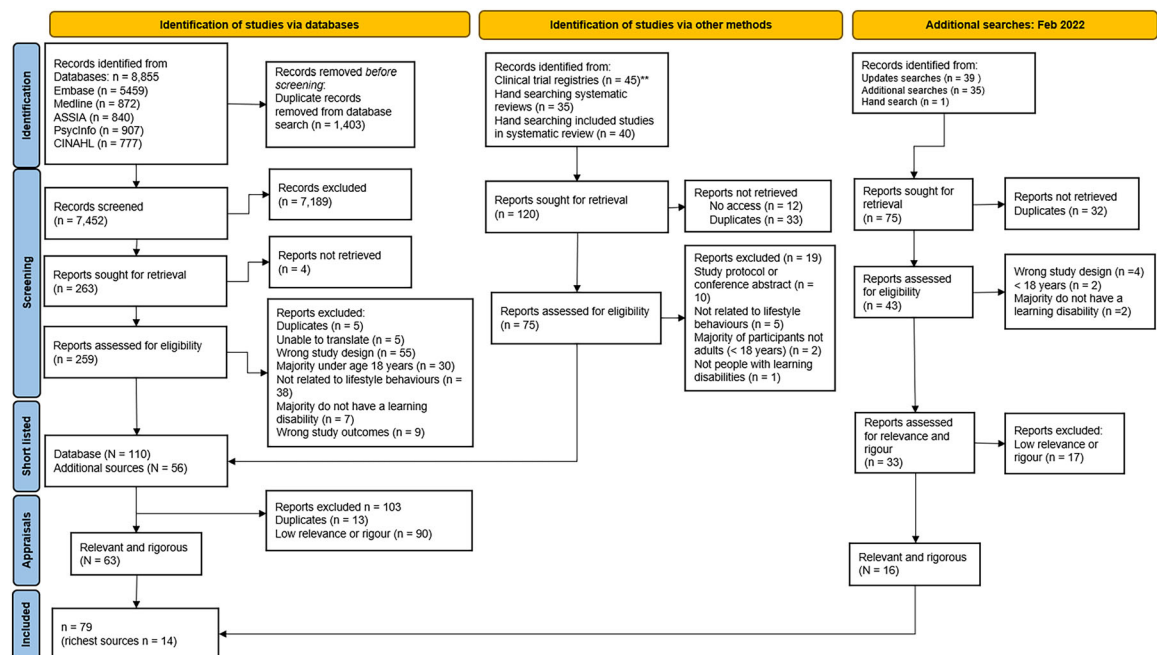


Figure 1. Adapted PRISMA flow chart.

**Table 2** Summary of study and participant characteristics

Study design	Percentage (proportion) of studies
Intervention studies	35.4% (28/79)
Randomised controlled trials (RCTs)	42.9% (12/28)
Other intervention studies (non-RCTs)	57.1% (16/28)
Other quantitative studies (e.g. cross-sectional)	2.5% (2/79)
Mixed-methods studies	22.8% (18/79)
Process evaluations	66.6% (12/18)
Feasibility studies	1.7% (3/18)
Other	1.7% (3/18)
Qualitative studies	39.2% (31/79)
Lifestyle behaviour targeted	
Physical activity and diet	40.5% (32/79)
Physical activity	17.7% (14/79)
Diet	7.6% (6/79)
Physical activity and sedentary behaviour	2.5% (2/79)
Smoking	3.8% (3/79)
Alcohol	8.9% (7/79)
Smoking and alcohol	1.3% (1/79)
General lifestyle behaviour focus	5.1% (4/79)
Level of intellectual disabilities	
Mild	8.9% (7/79)
Mild to moderate	40.5% (32/79)
Mild to severe	6.3% (5/79)
Mild to profound	6.3% (5/79)
Moderate to profound	3.8% (3/79)
Not specified	34.2% (27/79)
Presence of development disabilities	
No, participants reported to have specific developmental disabilities	83.5% (66/79)
Yes, participants were reported to have specific developmental disabilities	16.5% (13/79)
Down syndrome	84.6% (11/13)
Autism spectrum disorder	3.9% (5/13)
Cerebral palsy	1.5% (2/13)
Paid or family caregivers included as participants	
Yes	58.2% (46/79)
No	41.8% (33/79)

Percentage/proportion refers to the studies; non-RCT studies included studies such as pre–post controlled and uncontrolled studies; case–control studies; etc.

United Kingdom (35/79) and the United States (21/79). Most of the studies (55/79) were directly linked to a lifestyle modification intervention (e.g. reports of intervention effectiveness, feasibility and pilot studies,

qualitative and mixed research, such as process evaluations and explorations of participant experiences). The studies primarily focused on physical activity and diet ( $n = 32$ ) and physical activity alone ( $n = 13$ ), with no studies focusing exclusively on sedentary behaviour. Additionally, seven and three studies exclusively addressed alcohol and smoking, respectively, with one considering alcohol and smoking together.

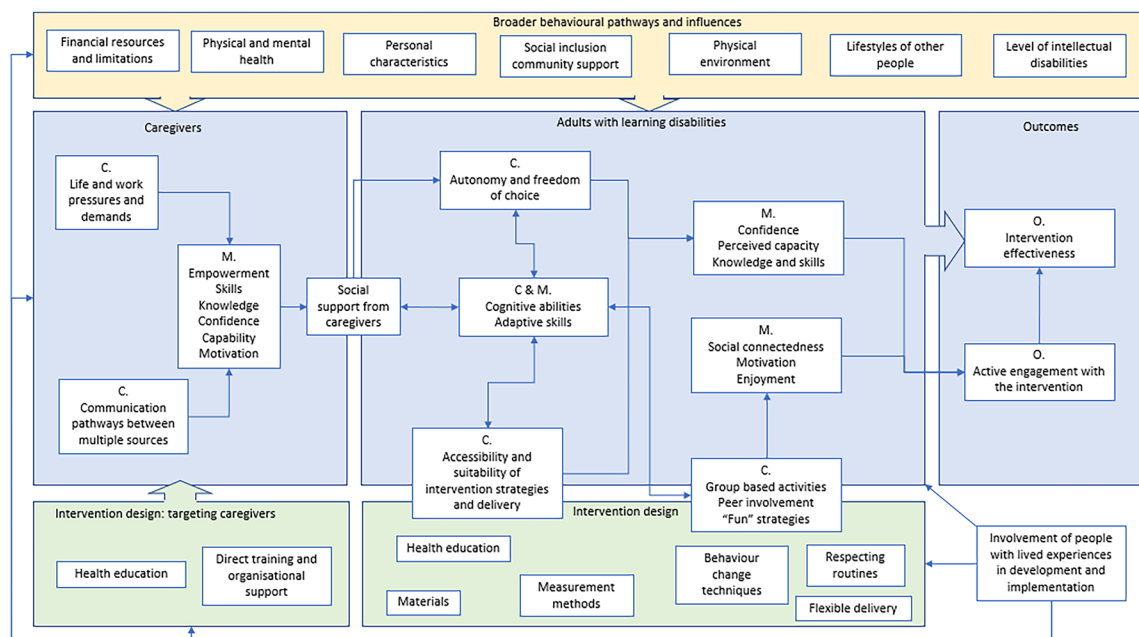
Across the studies that clearly reported sample size, there were data from 3604 adults with intellectual disabilities and 490 caregivers included in the synthesis. Most of the participants with intellectual disabilities had mild to moderate intellectual disabilities, with only 10 studies including people with severe and profound intellectual disabilities. The sex/gender distribution of participants with intellectual disabilities ranged between 0% and 83.3% female/women (Mahy *et al.* 2010; Mendel and Hipkins 2002; Singh *et al.* 2013); however, 27/79 studies did not report the sex/gender of any participants. Additionally, only 21/79 studies reported on participant race/ethnicity, with most participants described as being White/Caucasian and only one study including participants that were mostly from minority ethnic groups (Spasiani *et al.* 2019: 44% African American; 40% Hispanic, non-White).

## Main findings

### *Overarching programme theory*

The included literature highlighted the complex nature of lifestyle modification for adults with intellectual disabilities and emphasised the diverse study designs and outcomes addressed in lifestyle modification. The emerging contexts and mechanisms primarily related to the ability of adults with intellectual disabilities to actively engage with and take part in interventions, such as difficulties using behaviour change techniques (BCTs), and the need for additional support. Therefore, while addressing what works, from and in what circumstances for lifestyle modifications, the outcome and focus of the overarching programme theory is on active engagement of adults with intellectual disabilities in lifestyle modification interventions.

The overarching programme is presented in Figure 2 and details the core contexts and mechanisms that influence the ability of adults with intellectual disabilities to actively engage with interventions



**Figure 2.** Overarching programme theory of lifestyle modification for adults with intellectual disabilities. C, context; M, mechanism; O, outcome; green represents intervention related aspects; blue represents CMOCs central to the programme theory; yellow represents the broader behavioural pathways that exert an influence on the intervention.

(Fig. 2). This was based on the 33 CMOCs produced from the synthesis of the 79 studies and input from the PPI group as well as researchers working in the field within the research team.

The programme theory consisted of the following components: social support provided by caregivers; contexts and mechanisms specific to adults with intellectual disabilities; and broader behavioural pathways influencing lifestyle modification. As a result of both the literature included in this synthesis and through working with the PPI group, the importance of including people with lived experiences at all stages of the project is emphasised. The individual CMOCs and associated citations are presented in Table 3. The core components of the overarching programme theory are summarised in Fig. 3 to help guide researchers and other relevant stakeholders wishing to target unhealthy lifestyle behaviours of adults with intellectual disabilities.

*Programme theory: Caregivers.* Support involvement is an essential aspect of lifestyle modification for adults with intellectual disabilities. There are specific

contexts and mechanisms that contribute to the ability of caregivers, such as paid and family caregivers, to support lifestyle modification for adult with intellectual disabilities (CMOCs 1–7; Table 3). These contexts relate to the life pressures of family caregivers and the work pressures of paid caregivers (e.g. high workload, staff turnover, etc.), which can reduce motivation, trigger stress and make them feel disempowered to support lifestyle modification of adults with intellectual disabilities. Additionally, as adults with intellectual disabilities may have multiple caregivers (including paid and family), this can result in a breakdown of communication. This reduces the ability to exchange information and develop shared goals while decreasing motivation to support lifestyle change. Interventions that directly target caregivers by providing training, health education or additional support can help mediate these contexts and have positive impact on lifestyle change. The outcome of ‘social support’ in this component of the programme theory is also a context when considering the programme theory components relating to adults with intellectual disabilities.



**Table 3** Context mechanism outcome configurations (CMOCs) and citations

Partial programme theory cluster	Context [C], mechanism [M], outcome [O] configurations (CMOCs)	Associated citations
Caregiver involvement	<p>CMOC 1. The underlying knowledge, skills and attitudes of caregivers [C] impacts on their confidence, perceived capacity and motivation [M] to provide social support for lifestyle change [O]</p> <p>CMOC 2. Paid caregivers have large workloads and can look after multiple people [C], contributing to perceived pressure and stress [M]. This subsequently reduces motivation, confidence and perceived capacity [M] to provide social support for lifestyle modification [O]</p> <p>CMOC 3. The life pressures experienced by family caregivers [C] can reduce provision of social support of lifestyle change [O] through reduced motivation, perceived capacity and confidence [M]</p> <p>CMOC 4. Interventions providing training for caregivers [C] increases knowledge, confidence and motivation relating to lifestyle change [M], which improves the social support provided [O]</p> <p>CMOC 5. Confidence, motivation and perceived capacity are increased, and stress decreased [M], when paid caregivers received support from managers and the wider organisation [C], resulting in improved social support for lifestyle modification [O]</p> <p>CMOC 6. Inadequate communication and information sharing between multiple sources of support (i.e. multiple caregivers) [C] prevents forming shared goals, improving knowledge and skills and reduces motivation [M], which reduces the social support provided for lifestyle modification [O]</p> <p>CMOC 7. Developing strategies to enable communication [C] enables sharing information and goals, improving confidence and motivation [M], which improves social support for lifestyle modification [O]</p>	<p>Cartwright <i>et al.</i> (2014); Croot <i>et al.</i> (2018); Doherty <i>et al.</i> (2019); Edwards <i>et al.</i> (2014); Elinder <i>et al.</i> (2018); Harris <i>et al.</i> (2019); House <i>et al.</i> (2018); Jenkins and McKenzie (2011); Kerr <i>et al.</i> (2017); Marks <i>et al.</i> (2013); Mauro <i>et al.</i> (2021); Melville <i>et al.</i> (2009); Mendel and Hipkins (2002); Mitchell <i>et al.</i> (2018); O'Leary <i>et al.</i> (2017); Overwijk <i>et al.</i> (2022); Rostad-Tollefsen <i>et al.</i> (2021); Spanos <i>et al.</i> (2013); Spassiani <i>et al.</i> (2019); Wahlstrom <i>et al.</i> (2014) Borthwick <i>et al.</i> (2021); Croot <i>et al.</i> (2018); Dixon-Ibarra <i>et al.</i> (2017); Elinder <i>et al.</i> (2018); Harris <i>et al.</i> (2019); Humphries <i>et al.</i> (2009); Kuijken <i>et al.</i> (2016); Lally <i>et al.</i> (2021); Marks <i>et al.</i> (2010); Marks <i>et al.</i> (2013); Matthews <i>et al.</i> (2016); Melville <i>et al.</i> (2011); Mitchell <i>et al.</i> (2018); O'Leary <i>et al.</i> (2017); Overwijk <i>et al.</i> (2022); van Schijndel-Speet <i>et al.</i> (2014a); van Schijndel-Speet <i>et al.</i> (2014b); Spanos <i>et al.</i> (2013); Spassiani <i>et al.</i> (2019); Sundblom <i>et al.</i> (2015); Umb Carlsson (2021) Lally <i>et al.</i> (2021); Matthews <i>et al.</i> (2016); Pett <i>et al.</i> (2013); Skelly <i>et al.</i> (2021); Spanos <i>et al.</i> (2013)</p> <p>Dixon-Ibarra <i>et al.</i> (2017); Edwards <i>et al.</i> (2014); Elinder <i>et al.</i> (2018); House <i>et al.</i> (2018); Humphries <i>et al.</i> (2009); Jenkins &amp; McKenzie. (2011); Kuijken <i>et al.</i> (2016); Lally <i>et al.</i> (2021); Marks <i>et al.</i> (2010); Marks <i>et al.</i> (2013); Marks <i>et al.</i> (2019a); O'Leary <i>et al.</i> (2017); Rostad-Tollefsen <i>et al.</i> (2021); Spanos <i>et al.</i> (2013); Sundblom <i>et al.</i> (2015); Umb Carlsson (2021) Elinder <i>et al.</i> (2018); O'Leary <i>et al.</i> (2017); Spassiani <i>et al.</i> (2019); Sundblom <i>et al.</i> (2015); Umb Carlsson (2021)</p> <p>Borthwick <i>et al.</i> (2021); Cartwright <i>et al.</i> (2014); Doherty <i>et al.</i> (2019); House <i>et al.</i> (2018); Lally <i>et al.</i> (2021); Martinez-Zaragoza <i>et al.</i> (2016); Matthews <i>et al.</i> (2016); McLaughlin <i>et al.</i> (2009); Spanos <i>et al.</i> (2013); Sundblom <i>et al.</i> (2015)</p> <p>Borthwick <i>et al.</i> (2021); Harris <i>et al.</i> (2017); Harris <i>et al.</i> (2019); Humphries <i>et al.</i> (2009); Kerr <i>et al.</i> (2017); Marks <i>et al.</i> (2010); McLaughlin <i>et al.</i> (2009); Overwijk <i>et al.</i> (2022); van Schijndel-Speet <i>et al.</i> (2014b); Spanos <i>et al.</i> (2013); Spassiani <i>et al.</i> (2019); Sundblom <i>et al.</i> (2015); Umb Carlsson (2021); Wahlstrom <i>et al.</i> (2014)</p>

Table 3. (Continued)

Partial programme theory cluster	Context [C], mechanism [M], outcome [O] configurations (CMOCs)	Associated citations
Autonomy and behaviour change: Negotiating the balance	CMOC 8. Adults with learning disabilities may have limited control over their lives and reduced autonomy [C], which reduces capacity, confidence and empowerment [M] reducing ability to actively engage with lifestyle modification [O]. This may be more pronounced for people with more severe learning disabilities [C]	Abbott and McConkey (2006); Bigby et al. (2009); Bjornsdottir et al. (2015); Croot et al. (2018); Dunkley et al. (2018); Ferguson et al. (2010); Guerra et al. (2019); Harris et al. (2019); Humphries et al. (2009); Jahoda et al. (2010); Jingree and Finlay (2008); Kerr et al. (2017); Kuijken et al. (2016); Lally et al. (2021); Mahy et al. (2010); Maine et al. (2019); Mitchell et al. (2018); van Schijndel-Speet et al. (2014a); Skelly et al. (2021); Sundblom et al. (2015); Umb Carlsson (2021); Wahlstrom et al. (2014)
	CMOC 9. Caregivers want to both support behaviour change and respect freedom of choice [C]. This contributes to a sense of responsibility [M] and impacts on confidence and perceived capacity [M] contributing to differential support for lifestyle change [O]	Bergstrom & Wihlman (2011); Borthwick et al. (2021); Cartwright et al. (2014); Croot et al. (2018); Ferguson et al. (2010); House et al. (2018); Jingree & Finlay. (2008); Lally et al. (2021); Mahy et al. (2010); Mitchell et al. (2018); O'Leary et al. (2017); Petner-Arrey and Copeland (2014); Pols et al. (2017); Spanos et al. (2013); Umb Carlsson (2021); Wahlstrom et al. (2014); Whitehead et al. (2016)
	CMOC 10. There can be issues with informed consent [O] as people feel nagged and pestered [M] as caregivers encourage adults with learning disabilities to take part in interventions [C]	Ewing et al. (2004); Maine et al. (2019); Matthews et al. (2016); Mendel and Hipkins (2002); Mitchell et al. (2018)
	CMOC 11. Accessible information and additional time are needed [C] to ensure information is processed and understood, with people having the necessary skills [M] contributing to informed decisions [M]	Cartwright et al. (2014); Harris et al. (2019); House et al. (2018); Janson et al. (2021); Maine et al. (2019); Matthews et al. (2016); Mitchell et al. (2018); Pett et al. (2013); Spanos et al. (2013); Spassiani et al. (2019); Umb Carlsson (2021); Whitehead et al. (2016)
Accessibility of intervention strategies	CMOC 12. Confidence is increased [M] when people have support to use intervention strategies [C] with people having the needed skills and knowledge [M] enabling active engagement with the intervention [O]	Croot et al. (2018); Harris et al. (2019); House et al. (2018); Maine et al. (2019); Melville et al. (2011); Mitchell et al. (2018); Ptomey et al. (2017); Singh et al. (2013); Spanos et al. (2016)
	CMOC 13. BCTs that are not chosen when considering the ability of adults with intellectual disabilities and use abstract concepts [C] reduce confidence and motivation [M] as people do not have the necessary cognitive and adaptive skills to process the BCTs [M], resulting in participants not engaging with the intervention and ineffective behaviour change [O]	Harris et al. (2019); House et al. (2018); Janson et al. (2021); Melville et al. (2011); Melville et al. (2015); Ptomey et al. (2017); Ptomey et al. (2018)
	CMOC 14. Complex and difficult to use measurement methods [C] reduce ability to gather accurate results and the ability of people with learning disabilities to self-monitor behaviour	Bergstrom et al. (2013); Bodde et al. (2012b); Dixon-Ibarra et al. (2017); Ewing et al. (2004); Guerra et al. (2019); House et al. (2018); Kouimtsidis et al. (2017a); Kouimtsidis et al. (2017b); Lally et al. (2021); Maine et al. (2019); Mann et al. (2006); Matthews et al. (2016);

Table 3. (Continued)

Partial programme theory cluster	Context [C], mechanism [M], outcome [O] configurations (CMOCs)	Associated citations
	<p>[O]. This is because participants may not have the needed knowledge and skills, reducing perceived capacity, motivation and confidence [M]</p> <p>CMOC 15. Easy read materials and visual aids [C] increase confidence as people have the skills to understand and interact with the materials [M] improving active engagement with the intervention [O]</p>	<p>Melville <i>et al.</i> (2015); Mendel and Hipkins (2002); Mitchell <i>et al.</i> (2018); Ptomey <i>et al.</i> (2017); van Schijndel-Speet <i>et al.</i> (2014b); Shields and Taylor (2015); Spanos <i>et al.</i> (2016); Umb Carlsson (2021)</p> <p>Bazzano <i>et al.</i> (2009); Bigby <i>et al.</i> (2009); Bodde <i>et al.</i> (2012a); Burns <i>et al.</i> (2011); Croot <i>et al.</i> (2018); Dixon-Ibarra <i>et al.</i> (2017); Doherty <i>et al.</i> (2019); Dunkley <i>et al.</i> (2018); Ewing <i>et al.</i> (2004); Harris <i>et al.</i> (2019); House <i>et al.</i> (2018); Janson <i>et al.</i> (2021); Kelman <i>et al.</i> (1997); Kouimtsidis <i>et al.</i> (2017a); Maine <i>et al.</i> (2019); Marks <i>et al.</i> (2019b); Matthews <i>et al.</i> (2016)</p> <p>Mauro <i>et al.</i> (2021); Spanos <i>et al.</i> (2013); Spanos <i>et al.</i> (2014); Spanos <i>et al.</i> (2016)</p>
	<p>CMOC 16. Concrete and self-determined goals [C] can facilitate engagement with the intervention [O] as they facilitate motivation and confidence [M]</p>	<p>Dixon-Ibarra <i>et al.</i> (2017); Doherty <i>et al.</i> (2019); Dunkley <i>et al.</i> (2018); Guerra <i>et al.</i> (2019); House <i>et al.</i> (2018); Jones <i>et al.</i> (2015); Marks <i>et al.</i> (2013); Mitchell <i>et al.</i> (2018); van Schijndel-Speet <i>et al.</i> (2014a); Singh <i>et al.</i> (2013); Singh <i>et al.</i> (2014); Spanos <i>et al.</i> (2013); Spanos <i>et al.</i> (2016)</p> <p>Guerra <i>et al.</i> (2019); Janson <i>et al.</i> (2021); Maine <i>et al.</i> (2019); Matthews <i>et al.</i> (2016); Mitchell <i>et al.</i> (2018)</p>
	<p>CMOC 17. Motivation and a sense of achievement or pride are developed [M] through self-monitoring the lifestyle behaviour [C] resulting in improved engagement with the intervention [O]</p> <p>CMOC 18. Rewards and incentives [C] increase motivation [M] promoting greater engagement and participation with the intervention [O]</p>	<p>Bazzano <i>et al.</i> (2009); Mahy <i>et al.</i> (2010); Matthews <i>et al.</i> (2016); Ptomey <i>et al.</i> (2017); van Schijndel Speet <i>et al.</i> (2014a); van Schijndel Speet <i>et al.</i> (2014b)</p>
	<p>CMOC 19. Participants can process and interact with information, maintaining attention and have improved confidence [M] when active learning strategies and concrete examples are used while avoiding abstract concepts [C]. This facilitates engagement with health education and promotes gaining new knowledge [O]</p>	<p>Bodde <i>et al.</i> (2012b); Burns <i>et al.</i> (2011); Croot <i>et al.</i> (2018); Dunkley <i>et al.</i> (2018); Ewing <i>et al.</i> (2004); Guerra <i>et al.</i> (2019); Jones <i>et al.</i> (2015); Kelman <i>et al.</i> (1997); Kerr <i>et al.</i> (2017); Kuijken <i>et al.</i> (2016); Lindsay <i>et al.</i> (2014); Maine <i>et al.</i> (2019); Mann <i>et al.</i> (2006); Marks <i>et al.</i> (2013); Mauro <i>et al.</i> (2021); Mendel and Hipkins (2002); Overwijk <i>et al.</i> (2022); Pérez-Cruzado and Cuesta-Vargas (2016); Pett <i>et al.</i> (2013); Ptomey <i>et al.</i> (2017); Rostad-Tollefsen <i>et al.</i> (2021); van Schijndel-Speet <i>et al.</i> (2014b); Skelly <i>et al.</i> (2021); Spanos <i>et al.</i> (2013); Sundblom <i>et al.</i> (2015); Umb Carlsson (2021)</p>
Intervention delivery	<p>CMOC 20. There will be reduced engagement and adherence to interventions [O] if daily routines are not respected during implementation [C] as this can trigger distress and reduces motivation to participate [M]</p>	<p>Borthwick <i>et al.</i> (2021); Cartwright <i>et al.</i> (2014); Dixon-Ibarra <i>et al.</i> (2017); Edwards <i>et al.</i> (2014); Guerra <i>et al.</i> (2019); House <i>et al.</i> (2018); Mahy <i>et al.</i> (2010); Maine <i>et al.</i> (2019); Matthews <i>et al.</i> (2016); Mauro <i>et al.</i> (2021); Neumeier <i>et al.</i> (2021); Overwijk <i>et al.</i> (2022); Rostad-Tollefsen <i>et al.</i> (2021); Singh <i>et al.</i> (2013); Umb-Carlsson (2021); Wahlstrom <i>et al.</i> (2014)</p>

Table 3. (Continued)

Partial programme theory cluster	Context [C], mechanism [M], outcome [O] configurations (CMOCs)	Associated citations
Social connectedness and fun	CMOC 21. Adults with intellectual disabilities may have reduced active engagement in an intervention [O] when group-based activities are employed including people with diverse support needs and requirements [C] as some people may be left feeling unsupported or unstimulated [M] while others may not have the necessary skills or capacity to interact or engage with the intervention [M]	Croot <i>et al.</i> (2018); Elinder <i>et al.</i> (2018); Kouimtsidis <i>et al.</i> (2017a); Maine <i>et al.</i> (2019); Mauro <i>et al.</i> (2021); Mitchell <i>et al.</i> (2018); van Schijndel-Speet <i>et al.</i> (2014b); Spassiani <i>et al.</i> (2019); Sundblom <i>et al.</i> (2015)
	CMOC 22. People have the necessary skills and perceived capacity to participate [M] when delivery is flexible and respects individual needs [C], resulting in improved engagement with the intervention [O]	Croot <i>et al.</i> (2018); Doherty <i>et al.</i> (2019); Dunkley <i>et al.</i> (2018); Edwards <i>et al.</i> (2014); Ewing <i>et al.</i> (2004); Harris <i>et al.</i> (2019); House <i>et al.</i> (2018); Humphries <i>et al.</i> (2009); Kerr <i>et al.</i> (2017); Kouimtsidis <i>et al.</i> (2017a); Kouimtsidis <i>et al.</i> (2017b); Mahy <i>et al.</i> (2010); Maine <i>et al.</i> (2019); Marks <i>et al.</i> (2010); Marks <i>et al.</i> (2013); Matthews <i>et al.</i> (2016); Mauro <i>et al.</i> (2021); Mitchell <i>et al.</i> (2018); Neumeier <i>et al.</i> (2021); Pett <i>et al.</i> (2013); Ptomey <i>et al.</i> (2017); van Schijndel-Speet <i>et al.</i> (2014b); Spanos <i>et al.</i> 2014; Spassiani <i>et al.</i> (2019); Sundblom <i>et al.</i> (2015); Taggart <i>et al.</i> (2007); Umb Carlsson (2021)
	CMOC 23. When developing and designing an intervention people with lived experiences should be included [C], this results in improved engagement with the intervention as it reflects to needs, abilities and wants of people with learning disabilities [O]. This is achieved as people with learning disabilities ill have the necessary skills to interact with intervention strategies and have improved confidence and motivation as a result [M]	Bazzano <i>et al.</i> (2009); Bodde <i>et al.</i> (2012a); Croot <i>et al.</i> (2018); Dixon-Ibarra <i>et al.</i> (2017); Kouimtsidis <i>et al.</i> (2017a); Marks <i>et al.</i> (2013); McDonald & Stack (2016); Pett <i>et al.</i> (2013)
	CMOC 24. Facilitating interaction through peer involvement [C] increases confidence and motivation while fostering a feeling of sticking together [M], which promote active engagement and adherence with the intervention [O]	Bazzano <i>et al.</i> (2009); Heller <i>et al.</i> (2004); Kuijken <i>et al.</i> (2016); Marks <i>et al.</i> (2010); Marks <i>et al.</i> (2019b); Mauro <i>et al.</i> (2021); Singh <i>et al.</i> (2013); Spassiani <i>et al.</i> (2019); Umb Carlsson (2021); van Schijndel-Speet <i>et al.</i> (2014a)
	CMOC 25. Social connectedness, enjoyment and motivation are promoted [M] through group-based activities with social elements [C], which increases active engagement with the intervention [O] while also improving social networks [O]	Mahy <i>et al.</i> (2010); Marks <i>et al.</i> (2010); Mitchell <i>et al.</i> (2018); Sundblom <i>et al.</i> (2015); van Schijndel-Speet <i>et al.</i> (2014b)
	CMOC 26. Using music and humour, or other strategies to promote fun and enjoyment [C], increases motivation [M] improving active engagement with the intervention [O]	Borthwick <i>et al.</i> (2021); Dunkley <i>et al.</i> (2018); Kelman <i>et al.</i> (1997); Mahy <i>et al.</i> (2010); Maine <i>et al.</i> (2019); Marks <i>et al.</i> (2019b); Martinez-Zaragoza <i>et al.</i> (2016); Matthews <i>et al.</i> (2016); van Schijndel-Speet <i>et al.</i> (2014a); van Schijndel-Speet <i>et al.</i> (2014b)

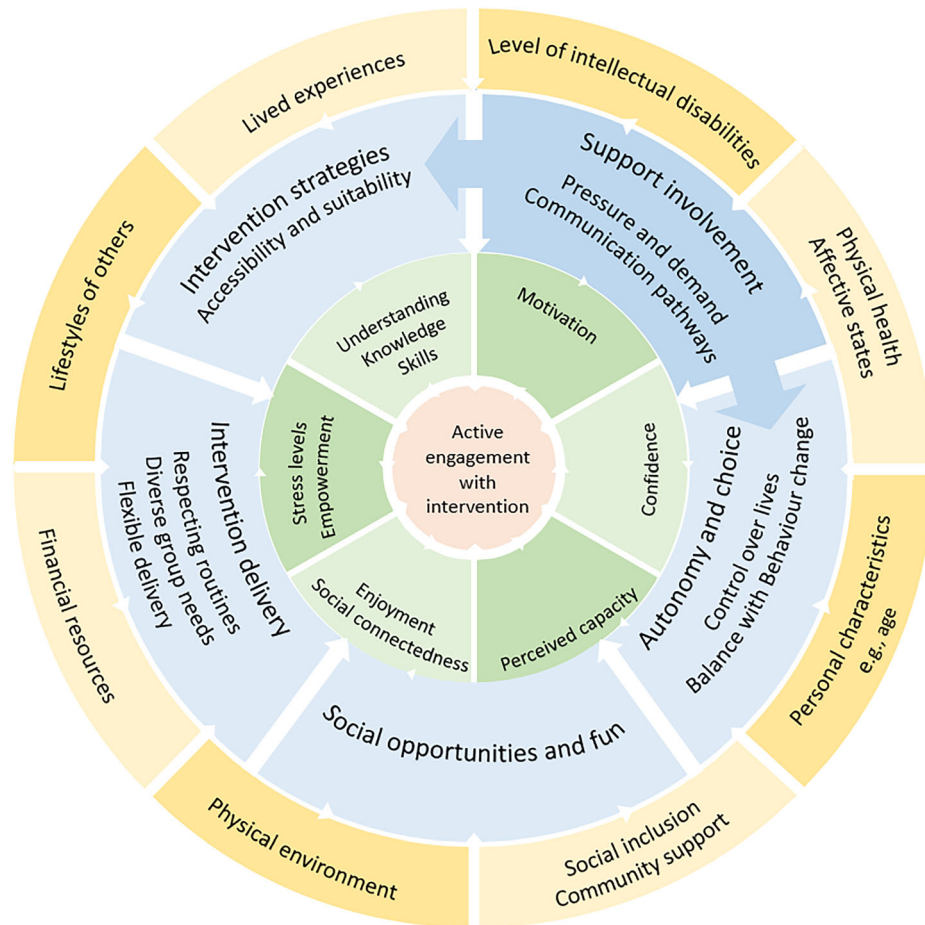
Table 3. (Continued)

Partial programme theory cluster	Context [C], mechanism [M], outcome [O] configurations (CMOCs)	Associated citations
Broader behavioural pathways	CMOC 27. Unhealthy lifestyles [O] are exacerbated by negative emotion and stress [C] as unhealthy behaviours are used as maladaptive coping mechanisms [M]	Ewing <i>et al.</i> (2004); Guerra <i>et al.</i> (2019); Jahoda <i>et al.</i> (2010); Kerr <i>et al.</i> (2017); Kouimtsidis <i>et al.</i> (2017b); Lindsay <i>et al.</i> (2014); McLaughlin <i>et al.</i> (2009); Taggart <i>et al.</i> (2007)
	CMOC 28. The unhealthy lifestyles of others close to a person with learning disabilities are observed [C] and modelled [M] with motivation and confidence to change their own behaviours [M] contributing to engaging in unhealthy lifestyles [O]	Cartwright <i>et al.</i> (2014); Dixon-Ibarra <i>et al.</i> (2017); Kerr <i>et al.</i> (2017); Kuijken <i>et al.</i> (2016); O'Leary <i>et al.</i> (2017); Rostad-Tollefsen <i>et al.</i> (2021); Skelly <i>et al.</i> (2021); van Schijndel-Speet <i>et al.</i> (2014b); Wahlstrom <i>et al.</i> (2014)
	CMOC 29. Reduced participation in healthy lifestyles [O] impacted on by health conditions and physical abilities [C], which can reduce confidence and perceived capacity to engage [M]	Borthwick <i>et al.</i> (2021); Mahy <i>et al.</i> (2010); Matthews <i>et al.</i> (2016); Mauro <i>et al.</i> (2021); Spassiani <i>et al.</i> (2019); van Schijndel-Speet <i>et al.</i> (2014b)
	CMOC 30. Being in the wider community [C] triggers fears over safety, reduced confidence and motivation [M] reducing participating in outdoor lifestyle activities [O]	Abbott and McConkey (2006); Croot <i>et al.</i> (2018); Guerra <i>et al.</i> (2019); Harris <i>et al.</i> (2019); House <i>et al.</i> (2018); Kerr <i>et al.</i> (2017); Mauro <i>et al.</i> (2021); Mitchell <i>et al.</i> (2018); O'Leary <i>et al.</i> (2017); Skelly <i>et al.</i> (2021); Spassiani <i>et al.</i> (2019); van Schijndel-Speet <i>et al.</i> (2014a)
	CMOC 31. Engaging in unhealthy lifestyles [O] is contributed to by an unsupportive environment with limited available and accessible resources [C], which reduces perceived capacity and confidence [M]	Doherty <i>et al.</i> (2019); Guerra <i>et al.</i> (2019); Kuijken <i>et al.</i> (2016); Mahy <i>et al.</i> (2010); Mauro <i>et al.</i> (2021); Skelly <i>et al.</i> (2021); Spanos <i>et al.</i> (2013); Sundblom <i>et al.</i> (2015)
	CMOC 32. Healthy lifestyles can cost money, such as healthy foods and physical activity resources [C], with people with learning disabilities and caregivers not always having the funds to afford this [C]. This can leave people feeling disempowered with reduced perceived capacity to engage in healthy lifestyles [M] resulting in continuing with unhealthy lifestyles [O]	Abbott and McConkey (2006); Bigby <i>et al.</i> (2009); Borthwick <i>et al.</i> (2021); Guerra <i>et al.</i> (2019); Mahy <i>et al.</i> (2010); Marks <i>et al.</i> (2010); Matthews <i>et al.</i> (2016); Skelly <i>et al.</i> (2021); Spassiani <i>et al.</i> (2019); Sundblom <i>et al.</i> (2015); Umb Carlsson (2021); van Schijndel-Speet <i>et al.</i> (2014a)
	CMOC 33. People may not participate in outdoor activities [O] as they have reduced motivation [M] caused by poor weather [C]	Guerra <i>et al.</i> (2019); Mauro <i>et al.</i> (2021); Mitchell <i>et al.</i> (2018); O'Leary <i>et al.</i> (2017); Skelly <i>et al.</i> (2021); van Schijndel-Speet <i>et al.</i> (2014a)

*Programme theory: Adults with intellectual disabilities.* The context of social support directly contributes to autonomy and freedom of choice experienced by adults with intellectual disabilities, as

well as the accessibility and suitability of intervention strategies. Negotiating the balance between autonomy, freedom of choice and behaviour change is complex (CMOCs 8–11;





**Figure 3.** Simplified programme theory and model of lifestyle modification for adults with intellectual disabilities. Note: yellow = wider contexts not specific to interventions; blue = central contexts specific to interventions; green = mechanisms; orange = outcome; Arrows emphasise that the multi-levels of rings interact.

Table 3). Adults with intellectual disabilities may have limited control over their lives and decisions around lifestyle behaviours, with this being particularly relevant for people with severe or profound intellectual disabilities. For all people with intellectual disabilities, this reduces perceived capacity and confidence to make decisions relating to lifestyle change. Furthermore, caregivers must balance respecting autonomy and freedom of choice while promoting a healthy lifestyle, with some adults with intellectual disabilities feeling nagged or pestered to take part in interventions. It is important for interventions to promote health education and training for both adults with intellectual disabilities

and caregivers in order to support informed choices around lifestyle behaviours.

Social support from caregivers is also a context within the accessibility and suitability of intervention strategies (CMOCs 12–19; Table 3). Social support facilitates greater understanding, perceived capacity and confidence to engage with materials, measurement methods and behaviour change techniques (BCTs). The intervention strategies are impacted by the level of abstraction required, which is in turn impacted by the underlying cognitive abilities and adaptive skills of participants. Failure to ensure strategies fit the knowledge and skills of participants reduces the capacity and confidence to engage with an intervention.

The accessibility and suitability of the intervention delivery is also important (CMOCs 20–23; Table 3). Interventions need to be delivered in a way that respects the routines of adults with intellectual disabilities to avoid causing distress and to ensure participants have the confidence and motivation to take part. Moreover, interventions should be delivered flexibly to reflect attention span and improve motivation. Interventions with group-based components must ensure that the diverse group needs are considered, by delivering the intervention in a way that respects the cognitive and physical abilities, in addition to support needs, of all participants. Failure to do so can cause people to feel unsupported, reducing confidence and motivation. However, group-based activities can have a positive impact on lifestyle modification, which was highlighted in the cluster of CMOCs relating to strategies to promote social connectedness and fun (CMOCs 24–26; Table 3). Peer involvement or group-based activities can foster a sense of sticking together and social connectedness while increasing motivation to actively engage with the intervention. Additionally, explicit strategies that promote fun, through humour or music, increases motivation and enjoyment.

*Programme theory: Broader behavioural processes.* Wider influences not specific to lifestyle modification were included in the overarching programme theory (CMOCs 27–33; Table 3). Although the broader behavioural processes are not explicitly tied to interventions, they must be considered as they will exert a strong influence on the lifestyles of adults with intellectual disabilities. For adults with intellectual disabilities, the physical environment can impact on motivation and confidence. Safety concerns can be caused by poor weather conditions and darkness reducing outdoor activities. The wider community may also reduce perceived safety and can reduce confidence or motivation to engage in lifestyle behaviours that are based in the community. The socio-environment also relates to financial limitations, and a lack of resources reduces the capacity and confidence directly through an inability to afford healthy options and indirectly through the ability of caregivers to pay for healthy lifestyle options (e.g. healthy food and physical activity resources). For adults with intellectual disabilities, the lifestyles of others may both enable or hinder healthy

lifestyles, as the behaviours of others modelled and observed, impacting on motivation and confidence.

Unhealthy lifestyle behaviours may be used as a maladaptive coping mechanism to deal with mental health concerns, stress and low mood. The physical and mental health exert a direct influence by reducing perceived capacity, confidence and motivation. Additionally, demographic factors tie into this, with individual-level influences, such as older age, associated with greater risk of health conditions, making it imperative to consider the individual characteristics of the people targeted by an intervention. Reflecting this, it is essential for researchers to consider the level of intellectual disabilities of participants involved in the study. The lived experiences, support needs and abilities of a person with mild intellectual disabilities will be different from an individual with severe or profound intellectual disabilities. It is important that the support available, intervention strategies and materials and delivery method are designed to respect this and the wider socio-environment.

*Programme theory: Involvement of people with lived experiences.* Individuals developing lifestyle modification interventions for adults with intellectual disabilities should involve people with lived experiences in the process (CMOC 23; Table 3). As already outlined, across the literature there were numerous challenges to active engagement ranging from ability of caregivers to support lifestyle change, to the accessibility and suitability of the intervention strategies and delivery. Most importantly, when developing the programme theory for this study, the input and feedback of people with intellectual disabilities helped to prioritise and interpret the emerging CMOCs.

As a result of working with adults with intellectual disabilities, the programme theory gave attention to the broader behavioural pathways, that is, the wider contexts impacting on the lifestyles of adults with intellectual disabilities that may not be specific to lifestyle modification interventions. These included issues relating to underlying physical and mental health conditions and financial limitations along with other individual, social and environmental-level influences. These were prioritised based on PPI experiences. Involving adults with intellectual disabilities and other relevant stakeholders in the

intervention development and implementation can alleviate some of the challenges to engagement by ensuring the intervention reflects their needs, abilities and wants.

#### *Simplified model to guide intervention development*

The initial iteration of the overarching programme theory was a simplified version. It highlighted the core contexts and mechanisms that contribute to active engagement with an intervention. However, it was not presented in a comprehensive realist format and was designed to emphasise the many complex and interacting influences of lifestyle modification for this population (Fig. 3).

The outer ring in the model (yellow) represents the broader behavioural processes that impact on the lifestyles of adults with intellectual disabilities and the ability of caregivers to provide support. This outer layer also includes 'lived experiences', which represents the importance of including people with lived experiences when making decisions about the intervention design and delivery.

The second layer (blue) represents the intervention specific contexts, such as support involvement (i.e. caregiver support), intervention strategies and delivery. Support involvement includes additional arrows, which display that caregiver support impacts on other aspects of the intervention. The outer ring of broader behavioural processes exerts an influence on the intervention specific contexts, for example, the level of intellectual disabilities impacts on intervention strategy accessibility and suitability, support involvement, autonomy and choice.

The third ring (green) represents the mechanisms and the behavioural and emotional responses that are triggered by the contexts and contribute to the intervention outcomes. The outcome of the centre of this model relates to active engagement with the intervention (orange), as the contexts directly relate to the ability of adults with intellectual disabilities to engage with, participate and process the intervention delivered.

## **Discussion**

A programme theory can facilitate the development and evaluation of complex interventions (Skivington

*et al.* 2021). This study aimed to understand what works, for whom and in what circumstances in relation to lifestyle modification interventions for adults with intellectual disabilities. The synthesis of the literature and input from people with lived experiences highlighted the many challenges to lifestyle modification for adults with intellectual disabilities. These challenges contributed to the ability of people to actively engage with an intervention and subsequently interact with and process the intervention as delivered. As a result, the decision was made to further focus the programme theory by having active engagement with lifestyle modification interventions as the central outcome. The core contexts and mechanisms contributing to this related to caregiver involvement, autonomy and freedom of choice, the accessibility and suitability of intervention strategies and delivery, the importance of social connectedness and enjoyment and the broader behavioural pathways to lifestyle change. The programme theory ultimately emphasises complexity of lifestyle change in this population and how important it is to work directly with people with lived experiences (e.g. adults with intellectual disabilities, family members and paid caregivers).

Adults with intellectual disabilities experience impairments in conceptual, social and practical skills, which can result in a need for additional support (AAIDD 2021; APA 2013). Across the literature, social support from paid and/or family caregivers was a core contributor to lifestyle modification. Nevertheless, the ability of caregivers to provide social support was impacted by multiple interacting contexts and mechanisms. For example, heavy workloads and looking after multiple of people can reduce the ability of paid support staff to facilitate lifestyle change. Therefore, directly involving family or paid caregivers in the development and evaluation of interventions is crucial to their success.

Research with adults with intellectual disabilities also requires careful consideration of autonomy and freedom of choice. The results suggest that adults with intellectual disabilities may have limited control over their lives, and lifestyles, with this being more pronounced for people with severe or profound intellectual disabilities (Table 3; CMOCs 8–12). The programme theory also covers the careful negotiation caregivers experience between balancing behaviour change and respecting freedom of choice and

personal decisions. Although this can have implications for capacity to achieve lifestyle change, this raises greater concerns over consent. Within studies included in the synthesis, researchers described participants feeling 'nagged and pestered' to take part (Matthews *et al.* 2016). It is essential that researchers administering interventions consider capacity for consent, produce accessible easy read materials and develop strategies to ensure informed consent is achieved.

Accessible materials also tie into the intervention strategies and delivery, as careful consideration should be made by researchers when choosing behaviour change techniques, measurement methods and any materials used, along with flexibility, support and fitting into the routines of people with intellectual disabilities. Past systematic reviews have raised concerns over measurement methods and behaviour change techniques with adults with intellectual disabilities, with reflection on suitability in relation to cognitive and adaptive skills of adults with intellectual disabilities (Melville *et al.* 2017; Pitchford *et al.* 2018; Willems *et al.* 2017). Researchers should consider adapting existing methods or developing new population specific methods that may facilitate lifestyle modification for adults with intellectual disabilities.

The individual lives and experiences of adults with intellectual disabilities should also be considered when thinking of the benefits of potential interventions. The programme theory highlighted that peer involvement and having a social element can increase motivation and confidence while fostering social connectedness and a sense of sticking together. It has been reported that adults with intellectual disabilities have reduced social networks, which reduces opportunities for social interaction (Harrison *et al.* 2021). Broadening the focus of lifestyle modification interventions to consider social and psychological outcome can better promote improved health and well-being.

The findings of the programme theory support guidelines for health promotion for people with disabilities (Drum *et al.* 2009) and recommendations for lifestyle interventions for people with disabilities living in supported accommodation (Hatzikiriakidis *et al.* 2023). The recommendations were not developed for people with intellectual disabilities; however, there was consistent focus on the

importance of having disability appropriate measures for intervention outcomes, having family caregivers and people with disabilities involved in the development and evaluation processes and ensuring the accessibility of programmes (Drum *et al.* 2009; Hatzikiriakidis *et al.* 2023). Additionally, Drum *et al.* (2009) highlighted the importance of supporting personal choice and making sure programmes were affordable, backing recommendations outlined in the overarching programme theory. Hatzikiriakidis *et al.* (2023) also stressed the importance of organisational influences, social support and involvement of support staff, which corroborate the findings outlined in this study that paid support staff facilitate active engagement.

One realist synthesis has previously explored lifestyle interventions relating to obesity among adults with intellectual disabilities, with a focus on physical activity and diet (Taggart *et al.* 2021). However, the synthesis included studies identified from reference lists of six review articles, and only included 14 studies, which all reported on intervention effectiveness (Taggart *et al.* 2021). Failure to incorporate broader qualitative and mixed-methods literature potentially reduced understanding of complex CMOCs. Additionally, there was no involvement of people with intellectual disabilities in the development of the programme theory, which can provide insight of what is meaningful and important from the perspective of individuals with lived experiences.

The involvement of adults with intellectual disabilities in this realist synthesis through the PPI group and steering committee, and as an active member of the research team, was a core strength of this study. Having input from people with intellectual disabilities in the programme theory accurately reflected the lived experiences of adults with intellectual disabilities, and the most relevant and important CMOCs included the overarching programme theory. The member of the research team with lived experience of having intellectual disabilities was involved in the project from the start. This is further recommended by recent research on co-creating a physical activity intervention for adolescents with intellectual disabilities (Maenhout *et al.* 2023). Having consistent involvement helped to ultimately increase confidence and integrity when making decisions for the direction of the project.



Certain limitations, which may have impacted on the generalisability of the programme theory, need to be acknowledged and discussed. The synthesis also mainly included studies related to adults with mild to moderate intellectual disabilities, with limited research available focusing on people with severe and profound intellectual disabilities. People with severe and profound impairments in intellectual and adaptive functioning contributing to challenges in collecting data. However, this contributes to a major gap in the evidence base, as the lived experiences of a person with mild intellectual disabilities will be different from a person with profound intellectual disabilities requiring 24-h care and support. Therefore, it is important to acknowledge that the PPI group did not include people with severe or profound intellectual disabilities, which must be considered when applying the programme theory.

There may also be a potential impact of sex/gender on lifestyle behaviours; however, it was not possible to comment on this, as many studies did not report the sex/gender of participants, which has been reported previously for physical activity and sedentary behaviour research (Westrop *et al.* 2019). Additionally, it was not possible to comment on the impact of ethnicity and wider cultural implications, as studies either having minimal reporting on important demographic factors or reported that most of the participants as being from White/Caucasian ethnic groups.

There was also less focus within the literature on alcohol, smoking and sedentary behaviour, which prevented a meaningful comparison between lifestyle behaviours. This highlights a need for more research addressing sedentary behaviour, alcohol and smoking behaviour of adults with intellectual disabilities. Additionally, the diverse study design, outcomes and outcome measures prevented discussion of how specific contexts and mechanisms contributed to explicit intervention outcomes. Nevertheless, the programme theory developed focused on active engagement with lifestyle modification interventions in general; therefore, the contexts and mechanisms covered are applicable across various lifestyle behaviours.

### Recommendations for future research

Future research should be participatory, including relevant stakeholders to ensure research reflects the

needs, wants and abilities of adults with intellectual disabilities. There should also be increased research relating to measurement methods and BCTs that are suitable for use with adults with intellectual disabilities. Additionally, research would benefit from developing population specific taxonomies that are relevant and accessible for adults with intellectual disabilities. There is also a need for more research including people with severe and profound intellectual disabilities; the first step towards this is through considering novel and accessible data collection methods. The realist synthesis also greatly benefited from the inclusion of qualitative and mixed methods literature. Collecting more qualitative or mixed-methods data relating to the lifestyles of adults with intellectual disabilities will further enhance the understanding of how to promote a healthy lifestyle.

### Conclusions

The programme theory of lifestyle modification for adults with intellectual disabilities provides the first evidence-informed framework to be used by researchers, policymakers and other stakeholders hoping to improve the lifestyles of adults with intellectual disabilities. It emphasises the complexity of lifestyle change in this population and how important it is to work directly with people with lived experiences (e.g. adults with intellectual disabilities, family members and paid caregivers). This helps ensure the intervention reflects the lives, needs, wants and abilities of adults with intellectual disabilities, which can improve active engagement with the intervention delivered. Those developing interventions should also reflect on the wider benefits to well-being, with opportunities for social connectedness and peer involvement improving motivation to take part.

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### Conflict of interest

No conflict of interest to declare.

### Data availability statement

Data is available from the corresponding author upon reasonable request.

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## Appendix I

### Example search strategy—Medline

1	((development* or learn*) adj2 disorder*).tw.
2	exp intellectual disability/
3	((learn* or development* or mental* or intellect* or cognitv*) adj2 (deficien* or disab*or disorder* or deficien* or difficult* or impair* or handicap* or retard* or sub?normal* or challenge*).tw.
4	(cretin* or feeble minded* or imbecil* or moron*).tw.
5	exp smoking/or exp cigarette smoking/
6	((smok* adj2 (behavio?r or habit* or us* or consum*) or (tobacco or cigarette)).tw.
7	exp binge drinking/or exp alcohol consumption/
8	((alcohol or ethanol or drink*) adj2 (problem* or harm* or hazard* or depend* or binge or us* or consum* or misuse* or behavio?r or habit*).tw.
9	(unhealth* adj2 (food or diet*) adj2 (habit* or consum*).tw.
10	exp sedentary time/or exp sedentary lifestyle/
11	((sedentary or passive or inactive or physical*) adj2 (life? style* or behavio?r* or liv* or li?e or time)).tw.
12	exp obesity/

(Continued)

13	((over or excess) adj2 weight).tw.
14	exp behavior therapy/ or exp cognitive behavioral therapy/ or exp psychotherapy/ or exp family therapy/or exp counseling/
15	((life?style* or behavio?r*) adj2 (modif* or interven* or change* or program*).tw.
16	((behavio?r* or cogniti* or CBT or psycho?therap* or psycho?educat or psycho?social or counsel*) adj2 (session* or therap* or technique* or modif* or interven* or change*).tw.
17	(health* adj2 (promot* or educat* or life?style*).tw.
18	exp health promotion/or exp health education/
19	exp smoking cessation/
20	((tobacco or smok* or nicotine or replace* or relapse) adj2 (cessat* or stop or reduc* or prevent* or therap*).tw.
21	exp diet therapy/ or exp caloric restriction/ or exp low fat diet/ or exp low carbohydrate diet/ or exp portion size/ or exp nutritional support/
22	(health* adj2 (diet* or weight)).tw.
23	((calorie* or portion* or serv* or size*) adj2 (control* or reduc* or restrict*).tw.
24	((diet* or nutri* or food or carb* or protein* or fat*) adj2 (educat* or guide* or habit* or intake)).tw.
25	exp physical activity/or exp exercise/
26	(interven* adj2 (physic* or exercise*).tw.
27	((moderat* or vigo?r*) adj2 (activit* or exercise* or train*).tw.
28	((exercise* or physic*) adj2 (aerobic* or train* or fit* or active* or endur*).tw.
29	((gym* or circuit* or aqua* or walk* or jog* or run* or swim* or weight* lift* or (strength or resist* or circuit* or aerobic*) adj2 train*).tw.
30	((fat or body or weight) adj2 loss).tw.
31	((health or weight or obes*) adj2 (loss or reduc* or manage*).tw.
32	or/1-4
33	or/5-13
34	or/14-31
35	32 and 33 and 34
36	limit 35 to humans

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