

What works in community health education for adults with learning disabilities: A scoping review of the literature

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Abstract

Background: Research suggests there is insufficient good quality information regarding the effectiveness of health education aimed at adults with intellectual disabilities. By analysing the literature, this review aimed to identify what constituted effectiveness in this context.

Method: Relevant evaluations were extracted from bibliographic databases according to pre-specified criteria. Papers were analysed using QSR NVivo 11 by developing a narrative synthesis and analytic framework that identified and explored text addressing the research question.

Results: Twenty-two studies were included. The review identified two broad components of effective health education: mechanisms and context. Mechanisms included embedded programme flexibility, appropriate and accessible resources, and motivational delivery. An effective context included an accessible and supportive environment and longer term opportunities for reinforcement of learning.

Conclusions: Important gaps in the literature highlighted a need for further research addressing community learning experiences of adults with intellectual disabilities as well as the effectiveness of infection prevention programmes.

KEYWORDS

community, health education, intellectual disability, self-care

1 | INTRODUCTION

The poorer health experienced by people with intellectual disabilities is well documented in the literature and includes higher rates of adverse health conditions, greater health inequalities and higher mortality (Emerson & Baines, 2011; Hatton, 2016; Krahn & Fox, 2014; Kuijken et al., 2016; Learning Disabilities Observatory, 2016; Northway, 2017). Authors report that these issues are compounded by disparities in preventative care and in engaging in healthy behaviours such as good oral hygiene, diet and physical exercise (Naaldenberg, Kuijken, van Dooren, van Schroyen, & de Valk, 2013; Scott & Haverkamp, 2016).

Research suggests that these health inequalities are a result of the social and economic determinants of health rather than intellectual disability per se (Emerson et al., 2016; Krahn & Fox, 2014). In this respect, access to effective health education, good quality health care, social support networks, housing and employment can affect health and potential health behaviours. Inadequate health education and promotion can inhibit an ability to make good decisions about health. However, some health concepts are difficult to convey to the general public and potentially even more so to people with cognitive impairments (Feldman et al., 2012); understanding the concept of antibiotic resistance, for example, is challenging (Pinder et al., 2015).

The literature suggests that there is insufficient good quality information regarding the effectiveness of health education interventions

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aimed at adults with intellectual disabilities (Bergström, Elinder, & Wihlman, 2014; Naaldenberg et al., 2013). Studies are diverse and explore a range of health issues but many have methodological weaknesses (Frankena, Naaldenberg, Cardol, Linehan, & Valk, 2015; Gerber et al., 2012; Scott & Haverkamp, 2016). There is currently no overall analysis of these weaknesses in a health education context nor synthesis of the ways in which programmes are effective.

Research suggests that adults with intellectual disabilities bring different abilities and motivations to a learning environment and effective education needs to account for this (Bergström et al., 2014; Scott & Haverkamp, 2016). However, there is currently no analysis of the ways in which this had been addressed in health education programmes nor in subsequent evaluation findings.

To address these issues, the focus of this review is effectiveness in health education for adults with intellectual disabilities particularly regarding self-care, infection prevention and the ongoing management of good health. Specifically, it aims to review and synthesize findings in the literature in this context, and answer the research question: What are the components of effective health education for adults with intellectual disabilities?

2 | METHOD

The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews, PRISMA-ScR (Tricco et al., 2018), was used to guide this review. The PRISMA-ScR is a checklist of items specifically developed to ensure effective reporting within a scoping review. An initial review of the literature suggested that the papers relevant to the research topic were dispersed in terms of database location, methods and results. The search strategy (applied in February 2019) therefore involved searching 11 different bibliographic databases and sources of grey literature, citation tracking and a manual search of reference lists from included articles.

A search of the Cochrane Database of Systematic Reviews, the Database of Abstracts of Reviews, the International Register of Prospective Systematic Reviews (PROSPERO) and JBI Evidence Synthesis confirmed that there was no published systematic review of education/training evaluations for people with intellectual disabilities. Naaldenberg et al.'s (2013) review focuses on health promotion but it does not explore in depth the process of improving knowledge and behaviour, which is fundamental to the questions of the current review.

Databases were selected for relevancy and scope after consultation with a university librarian. Databases included: MEDLINE (Figure 1), PubMed, Social Care Online, Social Sciences Citation Index, Scopus, CINAHL, Cochrane Central Register of Randomised Controlled Trials (CENTRAL), TRIP (Turning Research into Practice) and PsycINFO. A search of OpenGrey, EThos and Google provided links to unpublished studies, reports and national guidelines.

Citation tracking and manual searching of reference lists enabled a search for additional papers that were excluded in the bibliographic search results.

Studies were included in the search if they:

- evaluated a health education, training or health promotion intervention for adults with intellectual disabilities aged 16 + that aims to address a change in health behaviour;
- appeared as peer-reviewed articles in academic databases published in the English language between database inception and January 2019. International studies were included if they were published in English; or
- included people with mild, moderate or profound intellectual disabilities and included papers with an additional focus on learning difficulties such as dyslexia, autism and Asperger's syndrome. These were included to ensure full coverage of potential components of effective health education.

Studies were excluded if they:

- focused on children (under 16 years) because the focus of the present review is adults or young adults learning in community settings;
- focused solely on caregivers, supporters or staff because the research questions of the present review focus on adults with intellectual disabilities; or
- only used physical outcome measures because physical outcome measures alone do not give an indication of education effectiveness.

2.1 | Data extraction and analysis

Figure 2 illustrates the search and selection process. All included papers were imported into QSR NVivo 11 for narrative synthesis of the literature (Popay et al., 2006). Narrative synthesis uses words

MEDLINE search 11th February 2019

"learning disabilit*" OR "intellectual disabilit*" OR "developmental disabilit*" OR "mental retardation" OR "learning difficult*" OR "special needs"

AND "health"

AND "training" OR "education" OR "development" OR "learning" OR "promotion"

AND "effectiveness" OR "efficacy" OR "effective" OR "success" OR "outcome" OR "evaluation" OR "intervention"

From database inception to January 2019

FIGURE 1 Database search example

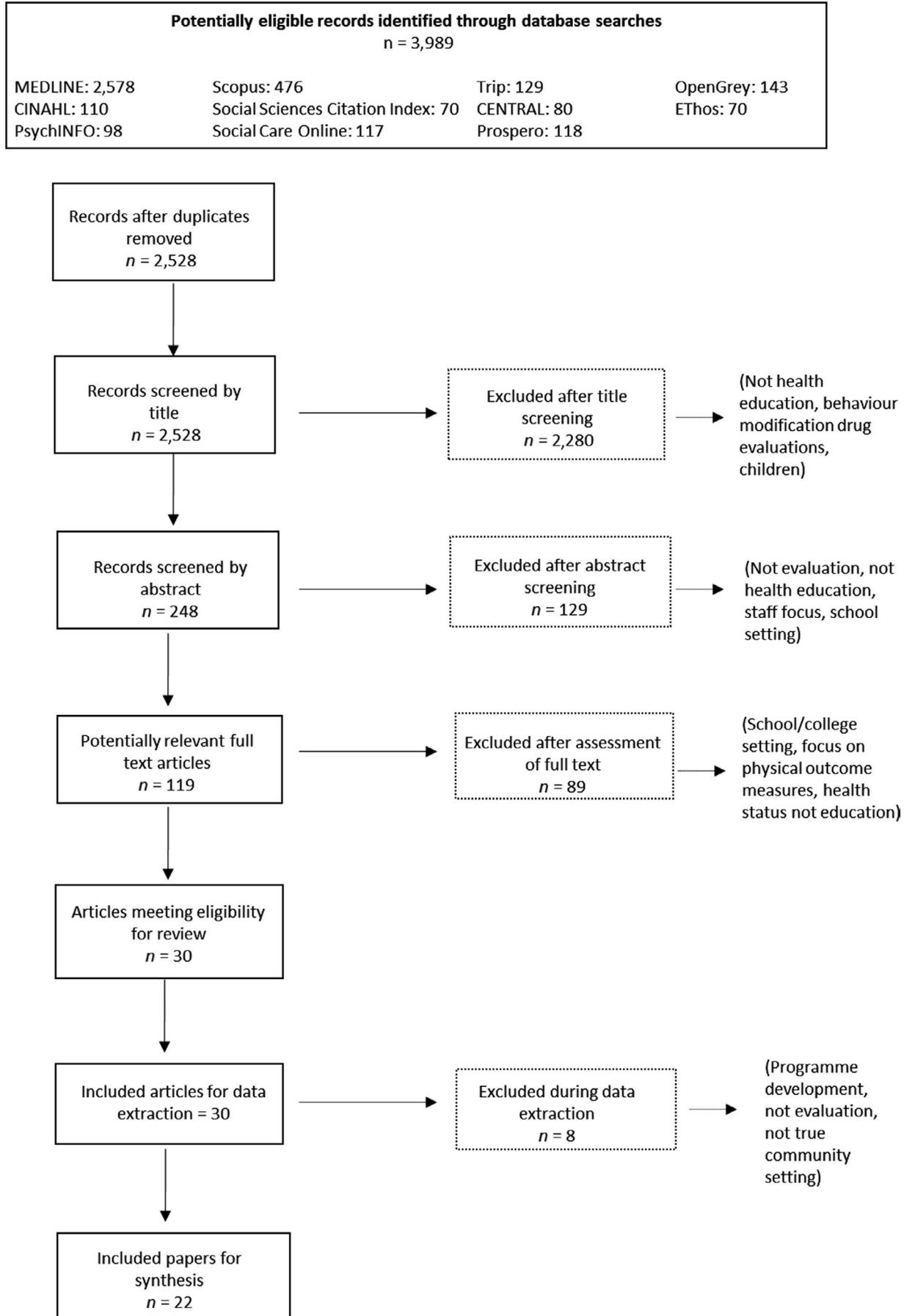


FIGURE 2 Flow diagram of literature search

and text to explore findings and can be an effective approach when meta-analysis is inappropriate (Campbell, Katikireddi, Sowden, & Thomson, 2019; Noyes et al., 2019). A meta-analysis is often used for reviewing groups of intervention studies (Higgins & Green, 2011) and usually includes randomized controlled trials. The body of literature on health education relating to intellectual disability is not developed enough to conduct this type of analysis. Therefore, this review includes non-randomized studies and by using narrative synthesis evaluates the evidence for each intervention individually.

Narrative synthesis was conducted using the research question as the basis of the analysis; the whole of each paper was analysed. First, text was identified that addressed the research question and therefore related to the delivery, experience and outcomes of the interventions undergoing evaluation. Secondly, themes in this text were identified inductively by reviewing findings in the studies that were relevant to the research question. Ongoing review and refinement of the analytic framework was conducted to ensure that earlier papers were further analysed in the light of new themes arising from subsequent articles. This thematic analysis provided insight into the educational experience of participants as reported by the authors, and reviewed in detail the context of the intervention and of the study results.

The included studies were also summarized (see Table 1), and the following data were extracted into a Microsoft Excel spreadsheet: general study characteristics and evaluation results; intervention characteristics; quality assessment scores; and evaluation findings.

2.2 | Quality assessment

The Cochrane Centre acknowledges the difficulty in assessing the quality of public health and health promotion studies (Higgins & Green, 2011). This is largely due to the range of designs used and the complexity of appraising qualitative studies that often form part of such evaluations. As Higgins and Green (2011) suggest, appraisal criteria will depend on the type of study undergoing review. Since different types of study were included in this review, two methods of quality assessment were used:

2.2.1 | Eight criteria of quality assessment developed by Naaldenberg et al. (2013)

Using this method, studies were scored according to the following characteristics: clear description of aim(s) and research question(s); description and discussion of rationale for sample size chosen, research population, attrition rate and measurements used; discussion of study limitations; and description of intervention development and content. In total, 16 points can be assigned to each paper, two points per criteria if information was provided and elaborated, one point if marginal information was provided and discussion or elaboration was lacking and zero points if no information was provided.

2.2.2 | The quality assessment tool for quantitative studies (Effective Public Health Practice Project, 2007)

This tool was developed to appraise any quantitative study design and involves assessment of selection bias, study design, confounders, blinding, data collection methods and withdrawals/dropouts.

3 | RESULTS

3.1 | Main study characteristics

Table 1 outlines the main characteristics of the 22 studies included in the review. The studies address a range of health areas including physical activity and diet; general health and health advocacy; women's health; hygiene, infection prevention and oral health; and diabetes. Studies covered a range of different geographical areas: nine were conducted in the United States, seven in the UK and the remainder geographically dispersed across the world. Programme participants represented a wide range of demographic characteristics.

Most studies accepted a definition of intellectual disability that was used by the service provider from which the participant was recruited. This is defined in most papers as "mild to moderate intellectual disability," and further detail is generally not provided. However, Clark, Espie, and Paul (2001) assessed intellectual disability according to specific tests administered by the researchers. Dunkley et al. (2017) and Taggart et al. (2018) used clinical notes directly from general practitioners to record intellectual disability and other health conditions. Bergström, Hagströmer, Hagberg, and Elinder (2013) also applied broader inclusion criteria asserting that participants should be able to understand basic concepts of the programme. Sample sizes ranged from five to 198 participants. Eleven studies used a sample of between 11 and 50 participants, four of between 51 and 100, and a further four studies had a sample size of over 100. One article did not specify the sample size. The differences in sample size reflect the diverse set of studies in this review.

Two papers about the same study authored by Dixon-Ibarra, Driver, VanVolkenburg, and Humphries (2017), Dixon-Ibarra, Driver, Nery-Hurwit, and VanVolkenburg (2018), two by Feldman et al. (2012, 2016) and two by Bergström et al. (2013), Bergström et al. (2014) were included in the review because they presented different but relevant study characteristics, measures and findings.

Eleven programmes focused specifically on health education. The remainder included a health education component as part of a wider programme, which also included behaviour change techniques. Sixteen papers described community settings, four a group home environment and two educational establishments. Most were small-group interventions, although one programme (Wells, Clark, & Sarno, 2012) was delivered in one-to-one instructional sessions. Two programmes (Feldman et al., 2016; Sandjojo et al., 2019) offered one-to-one additional support or booster sessions alongside group activity. Five of the interventions also included specific components for caregivers (Bergström et al.,

TABLE 1 Main study characteristics

Authors	Study topic	Methodology	Sample size
Physical activity (PA) and nutrition studies			
1. Bergström et al. (2013)	Diet and PA in group home setting. HE and BC	Cluster RCT; pre-, post- and follow-up.	139
2. Bergström et al. (2014)	Diet and PA in group home setting. HE and BC	Qualitative component of above study.	83
3. Dixon-Ibarra et al. (2017)	PA in group home setting. HE and BC	Formative and process evaluation; one-month follow-up,	54
4. Dixon-Ibarra et al. (2018)	PA in group home setting. HE and BC	Qualitative component of above study.	12
5. Bodde et al. (2012)	Community PA scheme with education component. HE and BC	Formative and process evaluation; short follow-up.	42
6. Melville et al. (2015)	Community walking programme with education component. HE and BC	Cluster RCT; pre-, post- and follow-up.	102
7. Heller et al. (2004)	Community fitness and HE programme. HE and BC	RCT; pre-, post- and follow-up.	53
8. Marks et al. (2013)	Community health programme. BC	RCT; pre-, post- and follow-up.	67
General health and health advocacy studies			
9. Sandjojo et al. (2019)	Community self-management. BC	Cohort; pre-, post- and follow-up.	17
10. Feldman et al. (2016)	Health self-advocacy training. HE	RCT; pre-, post- and follow-up	31
11. Feldman et al. (2012)	Health knowledge training programme. HE*	RCT; pre-, post- and follow-up.	22
12. Codling (2015)	Community health knowledge and management programme. HE	Unclear.	12
Hygiene, infection prevention and oral health studies			
13. Hartwig et al. (2017)	Oral health programme. Rehabilitation centre setting. HE and BC	Quasi-experimental with follow-up.	61
14. Eley et al. (2018)	Community hygiene and self-care course. HE and BC	Cohort; pre-, post- and follow-up.	9
15. Witton et al. (2017)	Peer dental ambassador programme. Community setting. HE and BC	Cohort study; interviews. No follow-up.	Not specified.
Women's health studies			
16. Swaine et al. (2014)	Education on cervical and breast cancer screening. Community setting. HE	RCT with follow-up.	198
17. Lunsy et al. (2003)	Women's health programme. University setting. HE and BC	Cohort; pre-, post- and follow-up.	22
18. Parish et al. (2012)	Breast and cancer screening info programme. Community establishment setting. HE	RCT; pre-, post- and follow-up.	170

Measurement of effectiveness	Successful outcomes	Quality assessment ^a	
		Qualitative	Quantitative
Pre-, post- and follow-up assessments—dietary quality (photographs), physical measures, life satisfaction.	Positive effect on PA ($p = .045$), work routines and waist circumference.	15	Moderate
Thematic identification of barriers and facilitators of effectiveness.	Programme provided opportunities for increased health literacy and autonomy.	16	N/A
PA knowledge via questionnaire, PA via activity sheets, BMI and pedometer, use of training tools, behaviour risk questionnaire for staff.	(No change in knowledge or body weight). Staff gained understanding of motivational techniques.	12	Weak
Thematic analysis of programme training, implementation, physical activity, barriers and facilitators.	Study confirmed that supporting context can empower individual health decision-making.	16	N/A
Assessment of knowledge gain. PA effectiveness assessed using accelerometer.	Knowledge gain in nutrition ($p < .05$) and PA ($p < .001$).	15	Weak
Standardized assessment tools and measurements—physical, QoL, self-efficacy. Accelerometer to assess PA and questionnaire to assess self-reported PA.	Programme provided choice, good self-esteem but no significant effect on PA.	15	Strong
Scales of activity, cognitive–emotional barriers, exercise perceptions, community integration, depression, life satisfaction.	Programme enabled more positive perception of the benefits of exercise and self-efficacy ($p < .05$).	16	Weak
Standardized measures of psychosocial and physiological health status; knowledge and skills; and fitness level.	Significant improvements in health status, knowledge, self-efficacy and fitness; psychosocial measures; and increase in healthy behaviours.	15	Weak
Assessments of goal attainment, social functioning, work support needs and quality of life.	Attainment of self-management goals and reduction in support needs ($p < .01$).	14	Strong
Scenario assessments, satisfaction questionnaire and health interview.	Training group had higher post-test ($p < .001$) and follow-up scores ($p < .01$).	15	Moderate
Health interview, satisfaction questionnaire.	Training group made more correct responses on post-training ($p < .001$) and follow-up tests ($p < .01$).	15	Moderate
Assessment of knowledge gain.	Study suggests that health promotion more effective if psychosocial approach adopted and adapted to different levels of ability.	7	N/A
Gingivitis and debris measurement.	Significant decrease in dental debris index ($p < .05$).	15	Weak
Knowledge change, reported behaviour change and trainer views.	Significant improvement in knowledge ($p < .05$) in every session except food bugs ($p < .06$). Some behavioural change (handwashing, toothbrushing).	14	Weak
Qualitative interviews and knowledge quiz.	Increase in dental knowledge, knowledge retention and skills.	7	N/A
Validated assessments via computer-assisted interviews including National Core Indicators and the Socio-Sexual Knowledge and Assessment Tool-Revised. Both measures have been tested with adults with intellectual disabilities.	Knowledge gain on one breast knowledge measure ($p < .036$) and one cervical knowledge measure ($p < .045$).	16	Moderate
Results of interview addressing women's health knowledge, healthy behaviour beliefs, problem-solving and coping strategies regarding medical procedures.	Significant gains in health knowledge and behaviour beliefs ($p < .05$). Retained some of these at follow-up ($p < .01$).	15	Weak
Questions from various established instruments used to measure knowledge. Tested and refined standardized tools with two women with intellectual disabilities.	Moderate knowledge gain regarding breast cancer screening ($p < .05$).	16	Moderate

(Continues)

TABLE 1 (Continued)

Authors	Study topic	Methodology	Sample size
Diabetes studies			
19. Taggart et al. (2018)	Diabetes education programme. Community setting. HE	Pilot RCT with pre- and follow-up. Also process evaluation	39
20. Dunkley et al. (2017)	Diabetes screening and education programme. Community setting. HE	Qualitative—two phases.	11
Other studies			
21. Wells et al. (2012)	Computer education programme. Academic setting. HE	Quasi-experimental design; pre- and post-assessments but no follow-up.	46
22. Clark et al. (2001)	Epilepsy education programme. Training centre setting. HE	Experimental design; pre-, post- and follow-up.	18

Abbreviations: BC, behaviour change; HE, health education.

^aQualitative score: Naaldenberg et al. (2013). Quantitative score: Effective Public Health Practice Project (2007).

2013; Dunkley et al., 2017; Hartwig et al., 2017; Taggart et al., 2018; Witton, Potterton, & Smith, 2017). One programme (Witton et al., 2017) used a peer-led approach, and another (Heller, Hsieh, & Rimmer, 2004) involved one peer trainer working alongside other trainers.

Fourteen papers describe the application of learning or behavioural theory in the development of the programme. Theories included social cognitive theory, goal setting and diffusion theory, the transtheoretical model or a combination of several theories. Eight studies did not mention the use of theory in programme development, and only three (Dixon-Ibarra et al., 2017; Eley et al., 2018; Marks, Sisirak, & Chang, 2013) referred to theoretical underpinning in their analysis, albeit briefly.

Thirteen studies adopted an experimental design; 10 of these conducted a randomized controlled trial. Two papers focused on a qualitative component of a wider experimental study. The remaining nine studies adopted various cohort designs, most of which included a pre-/post-/follow-up approach. Three studies were feasibility trials or pilot evaluations (Dunkley et al., 2017; Eley et al., 2018; Taggart et al., 2018), and authors had plans to extend the scope of their research.

Seventeen studies reported a follow-up measurement of outcomes. The follow-up period varied considerably: eight studies assessed outcomes within one month after completion of the programme (Table 1, studies 3, 5, 7, 13, 16, 18, 20 and 22), and a further five contacted participants between one and six months after completion (Table 1, studies 6, 10, 11, 14, 17 and 19). Two studies contacted participants 12 months after completion of the programme (Table 1, studies 1 and 8). One study (Sandjojo et al., 2019) conducted several follow-up assessments.

The methods used to measure outcome within the studies included in this review are outlined briefly in Table 1. Most researchers used more than one outcome measure, and a combination of

standardized and specifically developed tools. One paper did not specify how it measured outcome (Codling, 2015). Measures used include knowledge gain, quality of life, psychosocial, reported behaviour change and measures specific to the topic of study, for example physical outcomes for physical activity studies. Most of these measures do not reflect the learning experience of the participant nor the ways in which the education was effective. For example, Heller et al. (2004) found that a centre-based programme provided an appropriate learning context, changed attitudes towards exercise resulting in increased self-efficacy and improved life satisfaction. However, we do not know in depth how participants' experience of the learning environment (internal and external to the programme) influenced a change in behaviours.

These measures, however, provided some insight into the outcomes of the programmes evaluated (Tables 1, 3 and 4), and quality assessment indicated that most outcome measurement tools were valid and reliable. Nevertheless, sample sizes were small and several authors commented that further research was needed with larger samples.

3.2 | Research quality

Overall, the quality of the research is mixed. Table 2 shows that only two studies rated as "strong" on The Quality Assessment Tool for Quantitative Studies (Effective Public Health Practice Project, 2007). Seven were "moderate" and eight "weak." Five studies were not appropriate for this measure because they used qualitative methods or did not provide sufficient information to assess adequately. Those that rated as moderate or weak often did not provide sufficient information relating to key assessment criteria and therefore scored as "can't tell" which equated to a weak rating. Studies that are not randomized controlled trials (RCTs) are also at

Measurement of effectiveness	Successful outcomes	Quality assessment ^a	
		Qualitative	Quantitative
Standardized questionnaires administered by interview, focus groups. Educator reflection after each session	Feasibility study—concluded programme was feasible. Showed reduced HbA1c ($p < .04$) Increase in psychosocial scores.	16	Weak
Qualitative themes.	Feasibility study—concluded study was feasible. Participant compliance improved regarding use of accelerometers. Programme was cost-effective in some scenarios.	16	N/A
Qualitative interviews and computerized assessments. Survey for staff.	Significant increase in knowledge in all domains (facts $p < .01$, worry $p < .10$, V1 $p < .01$, V2 $p < .1$, risk perception $p < .01$, condom use intention $p < .05$).	15	Weak
Results of knowledge questionnaire (intellectual disability), EY-Checklist, evaluation questionnaire.	Increased knowledge at follow-up ($p < .04$).	12	Weak

a disadvantage on this assessment tool because they automatically score less due to the study design. A RCT is not always appropriate for evaluations with people with intellectual disabilities (Mulhall, Taggart, Coates, McAlloon, & Hassiotis, 2018; Oliver, Done, Regan, Cooray, & Tyrer, 2002), and assessment results should therefore be interpreted with caution.

Naaldenberg et al.'s (2013) assessment approach supports a more qualitative assessment of studies. Most performed well on this assessment; the average score was 13.9 out of a total of 16. Seven studies scored the maximum 16. The lowest score was seven.

No studies were excluded on the basis of quality. There are two reasons for this. First, even those that rated as weak on the quality assessment displayed some interesting methodological issues or relevant intervention development. Secondly, some papers performed well on Naaldenberg et al.'s (2013) assessment but not so well on the quantitative tool. These studies are included because of the qualitative component.

Many of the authors described limitations in their research, notably small sample sizes (Bodde, Seo, Frey, Van Puymbroeck, & Lohrmann, 2012; Clark et al., 2001; Dixon-Ibarra et al., 2017; Feldman et al., 2012; Hartwig et al., 2017; Heller et al., 2004; Lunsy et al., 2003; Sandjojo et al., 2019; Swaine, Parish, Luken, Son, & Dickens, 2014; Wells, Clark, & Sarno, 2012). Convenience samples were also often listed as a limitation of the studies included in this review because they could not guarantee generalizability. The issue of convenience sampling is also a strength of many studies because it enables us to establish what works for whom in what circumstances. This is particularly important with a diverse group of people that have different learning styles and abilities.

A limitation of many studies in this review is the lack of long-term follow-up. Evidence suggests that people with intellectual disabilities learn best through regular reinforcement and repetition (Dunkley et al., 2017). None of the studies followed up participants beyond a year, and therefore, evidence of longer term effectiveness

is not available. There is also little evidence in the papers about the process and experience of education from perspectives of the participants. This is addressed further in the *Discussion*.

Few of the studies included in this review involved people with intellectual disabilities in the research process. Involving the public in intervention design and evaluation helps to ensure validity, accuracy and appropriateness (National Institute for Health Research INVOLVE, 2018; Walmsley, Strnadová, & Johnson, 2018). Taggart et al. (2018) developed a reference group of adults with intellectual disabilities with type 2 diabetes. The group commented on the scales used for data collection, and these were amended during the process to include pictures and symbols. Feldman et al. (2016) worked with a group of five self-advocates who reviewed initial research ideas and together agreed on the focus of the evaluation. The researchers adopted a "rights-based" approach to the implementation of the programme although little further detail is provided regarding participation of people with intellectual disabilities on the evaluation.

3.3 | The components of effective health education for adults with intellectual disabilities

A purpose of this review is to generate an understanding of what works well in health education for adults with intellectual disabilities, particularly the ways in which health concepts are effectively conveyed and healthy behaviours subsequently adopted. The narrative synthesis approach described in *Method* enabled identification and analysis of text that referred to components of effective health education. All of the studies reported some effectiveness in this respect, although the extent of this varied considerably. Reported outcomes of effective programmes include the following:

- Knowledge and skills gain

TABLE 2 Quality assessment

			Qualitative assessment (Naaldenberg et al., 2013)
Authors	Study topic	Methodology	score
Physical activity (PA) and nutrition studies			
Bergström et al. (2013)	Diet and PA in group home setting. HE and BC	Cluster RCT; pre-, post- and follow-up.	15
Bergström et al. (2014)	Diet and PA in group home setting. HE and BC	Qualitative component of above study.	16
Dixon-Ibarra et al. (2017)	PA in group home setting. HE and BC	Formative and process evaluation; one-month follow-up.	12
Dixon-Ibarra et al. (2018)	PA in group home setting. HE and BC	Qualitative component of above study.	16
Bodde et al. (2012)	Community PA scheme with education component. HE and BC	Formative and process evaluation; short follow-up.	15
Melville et al. (2015)	Community walking programme with education component. HE and BC	Cluster RCT; pre-, post- and follow-up.	15
Heller et al. (2004)	Community fitness and HE programme. HE and BC	RCT; pre-, post- and follow-up.	16
Marks et al. (2013)	Community health programme. BC	RCT; pre-, post- and follow-up.	15
General health and health advocacy studies			
Sandjojo et al. (2019)	Community self-management. BC	Cohort; pre-, post- and follow-up.	14
Feldman et al. (2016)	Health self-advocacy training. HE	RCT; pre-, post- and follow-up	15
Feldman et al. (2012)	Health knowledge training programme. HE*	RCT; pre-, post- and follow-up.	15
Codling (2015)	Community health knowledge and management programme. HE	Unclear.	7
Hygiene, infection prevention and oral health studies			
Hartwig et al. (2017)	Oral health programme. Rehabilitation centre setting. HE and BC	Quasi-experimental with follow-up.	15
Eley et al. (2018)	Community hygiene and self-care course. HE and BC	Cohort; pre-, post- and follow-up.	14
Witton et al. (2017)	Peer dental ambassador programme. Community setting. HE and BC	Cohort study; interviews. No follow-up.	7
Women's health studies			
Swaine et al. (2014)	Education on cervical and breast cancer screening. Community setting. HE	RCT with follow-up.	16
Lunsky et al. (2003)	Women's health programme. University setting. HE and BC	Cohort; pre-, post- and follow-up.	15
Parish et al. (2012)	Breast and cancer screening info programme. Community establishment setting. HE	RCT; pre-, post- and follow-up.	16
Diabetes studies			
Taggart et al. (2018)	Diabetes education programme. Community setting. HE	Pilot RCT with pre- and follow-up. Also process evaluation	16
Dunkley et al. (2017)	Diabetes screening and education programme. Community setting. HE	Qualitative—two phases.	16
Other studies			
Wells et al. (2012)	Computer education programme. Academic setting. HE	Quasi-experimental design; pre- and post-assessments but no follow-up.	15
Clark et al. (2001)	Epilepsy education programme. Training centre setting. HE	Experimental design; pre-, post- and follow-up.	12

Abbreviations: BC, behaviour change; HE, health education.

Quantitative assessment score

(Effective Public Health Practice Project 2007)

Global score	Component scores: 1 = strong, 2 = moderate, 3 = weak					
	A: Selection bias	B: Study design	C: Confounders	D: Blinding	E: Data collection	F: Withdrawals and dropouts
Moderate (2)	2	1	3	2	1	1
N/A—qualitative	N/A	N/A	N/A	N/A	N/A	N/A
Weak (3)	3	1	3	2	1	3
N/A—qualitative	N/A	N/A	N/A	N/A	N/A	N/A
Weak (3)	2	1	1	3	1	2
Strong (1)	2	1	1	2	1	2
Weak (3)	2	1	3	3	1	1
Weak (3)	2	1	1	2	1	1
Strong (1)	2	2	1	2	1	N/A
Moderate (2)	1	1	1	2	1	1
Moderate (2)	2	1	1	3	2	2
N/A—insufficient detail	N/A	N/A	N/A	N/A	N/A	N/A
Weak (3)	3	2	1	3	1	3
Weak (3)	3	2	1	3	1	3
N/A—qualitative	N/A	N/A	N/A	N/A	N/A	N/A
Moderate (2)	2	1	1	3	2	1
Weak (3)	2	2	1	3	3	3
Moderate (2)	2	1	1	3	2	1
Weak (3)	3	1	3	3	2	1
N/A—qualitative	N/A	N/A	N/A	N/A	N/A	N/A
Weak (3)	3	2	3	3	2	1
Weak (3)	3	1	3	3	3	3

TABLE 3 Mechanisms of effective health education accessible to adults with intellectual disabilities

Mechanism	Identified in study index number (see Table 1)	Why/how it facilitates effective health education for adults with intellectual disabilities
Education planning and development		
Appropriate theoretical basis.	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 14, 20, 21	Creates a sound basis for education programme development.
Built-in flexibility and adaptability of course.	1, 2, 6, 7, 9, 15, 19	Support meeting of individual needs.
Participatory methods in course development.	1, 2, 3, 5, 10, 12, 19, 20	Ensure the education is appropriate and most likely to succeed.
Combination of accessible resources and techniques.	1, 2, 9, 16, 17	Facilitates understanding, involvement and learning.
Goal setting and action planning.	2, 6, 9, 14, 15, 19	Are motivational and reinforce learning.
Integrated reinforcement and repetition.	1, 2, 9, 11, 13, 14, 15, 20	Embed learning and behaviour change.
Education delivery		
Motivational, sensitive and perceptive delivery.	1, 2, 3, 20	Participants enjoy learning and get the best out of it.
Appropriate methods and techniques of delivery.	1, 2, 5, 9, 11, 16, 20	Support positive individual learning outcomes.
Course fidelity (but a need for flexibility too).	1, 3, 5, 8, 11, 13, 18, 19	Ensures programme is delivered as planned.
Visual and interactive mechanisms (including tools to take away).	3, 5, 9, 11, 16, 20	Generate interest, motivate and illustrate learning concepts. Opportunity to practise what is learnt.
Small-group or one-to-one learning.	2, 3, 7, 11, 15, 21	Enable achievement of learning goals and reinforcement of behaviour change steps.
Education follow-up		
Long-term need to reinforce learning.	19, 20	Embeds learning and behaviour change.

- Healthier behaviours—handwashing, toothbrushing, exercise, nutrition
- Enjoyment of healthier behaviours
- Acquisition and application of skills to manage health more independently
- Reduction in specific support needs
- Better health (healthier teeth, healthier weight, increased fitness, general health)
- Feelings of self-efficacy and life satisfaction
- Development and use of coping strategies to address health issues

Most of the studies in this review provide data on learning outcomes without reflecting on the *process* of education and learning that produced this outcome. It is therefore difficult to fully evaluate the education and its effect. However, the studies do provide some interesting information regarding components of effective health education. These are presented as mechanisms for education delivery and the preferred contextual issues that accompany these mechanisms. Table 3 shows that mechanisms include an appropriate theoretical basis, built-in flexibility and adaptability, goal setting and action planning and motivational, sensitive and perceptive delivery.

The studies also highlight the importance of achieving the right context for effective health education to encourage and reinforce

learning. Table 4 illustrates the important components here, which include a social and supportive learning environment, contextual adaptation appropriate to the course and participants, and opportunities for post-learning support.

4 | DISCUSSION

4.1 | Mechanisms for effective health education accessible to adults with intellectual disabilities

Cognitive models are recognized as being important for education and behaviour change interventions (Naaldenberg et al., 2013). Many of the health education programmes in this review were developed using learning or cognitive development theories. However, most authors did not refer to theoretical underpinnings in the analysis of results and it is therefore difficult to determine the role of theory in the evaluation of these studies. It is possible to make some inferences. For example, the activity programme in Heller et al.'s (2004) study was based on a social learning model. Group activities were reported to be enjoyable. Relating health to participants' feelings led to better understanding of their health conditions, and the implication is that a social model can support health learning in this context.

The literature suggests that an effective health education programme for adults with intellectual disabilities needs to be either specifically developed or carefully adapted to meet learning needs (Heller et al., 2004; Taggart et al., 2018; Witton et al., 2017). Most of the programmes were specifically developed to address the needs of adults with intellectual disabilities although some were adapted from existing programmes aimed at a wider population. Adaptations included accessible resources such as easy read materials, videos and scenario-based role playing.

Flexibility is also required in terms of both the learning and the support environment. Taggart et al. (2018) and Witton et al. (2017) identified the importance of delivery and timing of sessions to meet individual concentration levels and learning needs. In these programmes, the adaptation of resources, structure, curriculum, length of sessions and use of health action plans were effective. A health self-management training programme evaluated by Sandjojo et al. (2019) focused on addressing individual needs through flexible support regarding the transfer of learned skills to daily life. This was a relatively intensive programme that involved on average two trainers guiding four participants but was effective in decreasing support needs and attaining self-management goals.

The concept of adaptation helped to illustrate reasons why the Walk Well programme (Melville et al., 2015) was not effective; challenges in adapting complex behaviour change interventions for adults with intellectual disabilities partially explained the lack of effectiveness of the programme.

Several papers refer to the importance of working with people with intellectual disabilities on the development of the educational intervention (Bergström et al., 2013; Bodde et al., 2012; Dixon-Ibarra et al., 2017; Dunkley et al., 2017; Feldman et al., 2012; Taggart et al., 2018). In this context, participatory methods can support the development of effective resources by ensuring they are appropriate to the needs of people with intellectual disabilities.

Dixon-Ibarra et al. (2017) described stakeholder involvement in the development and implementation of the programme. The researchers worked with an advisory group to obtain community feedback regarding barriers, facilitators and critical feedback for the programme design. In Bodde et al. (2012), people with intellectual disabilities met twice, piloted two lessons and commented on the readability of visual materials. They were involved in the second draft of curriculum development and developing the process measures for the evaluation. Staff in Bergström et al. (2013) also tried to involve participants in planning content although the success of this varied. Codling (2015) briefly described working with a steering group of eight people including one with intellectual disabilities and one carer to discuss course development.

Goal setting enabled participants to remove or remediate access barriers such as lack of support, motivation and access. Eley et al. (2018), Sandjojo et al. (2019), Taggart et al. (2018) and Witton et al. (2017) found that setting, monitoring and reporting on goals could be motivational and could enhance learning. For example, Eley et al. (2018) reported that action planning to pledge behaviour change supported an increase in appropriate health behaviours such as handwashing and toothbrushing. Sandjojo et al. (2019) found that goal setting alongside training contributed to attainment of self-management goals. However, the participants in Melville et al.'s (2015) study experienced difficulties conceptualizing and adhering to self-monitoring and goal setting. The authors suggested this was partially a result of the behaviour change techniques involved.

Learning reinforcement mechanisms such as certificates of attendance or completion (Dunkley et al., 2017; Eley et al., 2018), action planning and goal setting (Dunkley et al., 2017; Eley et al., 2018; Sandjojo et al., 2019), self-monitoring opportunities and activities such as diary-keeping (Dunkley et al., 2017) were effective in supporting knowledge retention and behaviour change. Use of repetition and recapping on sessions were also effectively applied (Dunkley et al., 2017; Eley et al., 2018; Feldman et al., 2016). For

TABLE 4 Components of an effective learning context for adults with intellectual disabilities

Context	Identified in study index number (see Table 1)	Why/how context supports effective health education for adults with intellectual disabilities
A positive physical environment—comfortable and opportunities for refreshments and breaks.	2, 5, 7, 15, 20	Encourages a good frame of mind and physical comfort for learning.
A social and supportive learning environment.	1, 2, 7, 9, 15, 19, 20	Encourages a good frame of mind and mutual support for learning, sharing ideas and asking questions.
Opportunity to practise autonomy but also access appropriate levels of support.	1, 6, 8, 9, 15, 19, 20	Meets the needs of individuals.
Participatory and interactive ethos but not be intimidating.	1, 2, 3, 15, 20	Enhances learning by encouraging debate and input of ideas.
Contextual adaptation appropriate to the course and to the participants—understanding of each participant's personal context and learning needs.	1, 2, 3, 9, 15, 19	Enhances learning at an individual level.
Accessibility (physically, mentally and in terms of resources and materials).	1, 2, 3, 7, 15	Ensures physical needs are met, supports well-being and appropriate learning.
Opportunities for post-learning support and reinforcement of learning.	2, 19, 20	Embeds learning and behaviour change.

example, Hartwig et al. (2017) maintained weekly motivation to ensure oral hygiene was part of daily routines in four sequential sessions. Witton et al. (2017) found that regular demonstration and repetition enabled effective toothbrushing and therefore supported independent oral hygiene practice. Tools to take away, including diaries and homework, were also effective in embedding learning because they provided the opportunity to practise what was learnt (Dixon-Ibarra et al., 2017).

Mechanisms of effective education delivery include small-group sessions, one-to-one support, a computer-assisted learning approach and various combinations of taught sessions with additional individual support. The programme evaluated by Wells et al. (2012) used a computer programme to teach about HIV/AIDS key concepts. The authors concluded that teaching these concepts via interactive technology was effective because it was not dependent on literacy levels and could be undertaken in different locations and environments. After this programme, participants' knowledge and avoidance skills improved. Feldman et al.'s (2016) sample learned health self-advocacy skills through small-group training that used PowerPoint slides, interactive videos and games. Dixon-Ibarra et al. (2017) found that visual and interactive mechanisms such as video games, pictures and role play in small-group learning sessions (three to four people) with optional one-to-one support were effective.

Some health topics may need a more specific approach. Whilst role play worked well for participants in Lunskey et al.'s (2003) study of a women's health education programme, Swaine et al. (2014) found that some concepts taught in education of breast and cervical cancer screening were not appropriate for role play. Instead, a "Building Skills" activity worked better, which involved scenario-based questioning. Lunskey et al. (2003) suggested that role play would not suit women with profound and multiple disabilities however, and staff intervention combined with small-group or individual therapy would be more appropriate.

Many of the papers in this review illustrate that a combination of resources such as videos, pictorial instructions, worksheets, role play, games and other interactive activities could increase health knowledge gain (Bodde et al., 2012; Dunkley et al., 2017; Feldman et al., 2016; Sandjojo et al., 2019; Swaine et al., 2014). Dunkley et al. (2017) used multiple practical and participatory methods including models, images, visual memory aids, bingo and storytelling along with regular breaks. The educators also used materials developed by the participants themselves to support behavioural and lifestyle changes. They found these effective although also established that it was important not to overwhelm with too many resources.

The literature suggests that a motivational educator, interactive sessions, and a comfortable and safe learning environment can lead to high levels of engagement and enjoyment and thereby contribute to good acquisition of skill and knowledge. The programme evaluated by Dixon-Ibarra et al. (2017) included a focus on personal choice and enabled participants to develop and use their own materials. In this context, motivational learning/interviewing was effective in terms of both an educational technique and the presence of a good educator who engaged well with participants. In Dunkley et al.'s (2017)

programme, educators identified challenges and motivated participants to make behavioural changes.

Facilitators in the programme evaluated by Sandjojo et al. (2019) ensured that each participant's training was tailored to their abilities and preferences. They achieved this by continuously consulting with participants about how they would like to be trained. For example, if a participant was unable to read, sessions were presented more orally or visually with demonstrations, role play or video material.

Witton et al. (2017) and Heller et al. (2004) included a peer approach to learning in their programmes. Peers were considered effective because participants could relate to them. In this context, Witton et al. (2017) described high levels of engagement and enjoyment and good acquisition of skills and knowledge.

The extent to which caregivers and supporters are effective facilitators in health education for people with intellectual disabilities can vary considerably. Some studies reported they had a positive effect on acquiring and embedding learning (Bergström et al., 2013; Dunkley et al., 2017; Hartwig et al., 2017; Sandjojo et al., 2019). Dunkley et al. (2017) found that care workers had a key role in helping to motivate and support participants to make and sustain changes to their diet and physical activity. Hartwig et al. (2017) reported that targeting caregivers could be a successful strategy to improve oral health.

However, supporters can also impede progress. Course leaders in Bergström et al. (2013) suggested that a course without caregivers' presence provided an opportunity for the participants to increase autonomy. The authors identified several instances where caregivers did not support participants in the programme. They suggested that more frequent communication about how best to support participants would have improved this. Bergström et al. (2013) also suggested that good collaboration with caregivers was important, however. This is also illustrated by findings in Dixon-Ibarra et al. (2017). Here, the authors refer to the importance of obtaining "buy-in" from staff and caregivers and suggested this was critical for behaviour change in the context of the programme they evaluated. Achieving this is often difficult however; Lunskey et al. (2003) found that support workers offered an opportunity to support and embed learning but there were often challenges regarding regular staff turnover and shift work.

It appears that with commitment, good communication and an appropriate programme, it is possible to achieve a good balance between participant support and autonomy. For example, Marks et al. (2013) reported on the unique role of staff in a train the trainer model to improve health and health behaviours of people with intellectual disabilities. Trained staff worked closely with participants to support them in developing goals, targeting specific behaviours and improving knowledge, skills and fitness. The evaluation showed significant improvements in psychosocial and physiological health status and an increase in healthy behaviours.

Several studies identified fidelity as an important mechanism in supporting a consistent and effective programme (Bodde et al., 2012; Dixon-Ibarra et al., 2017; Feldman et al., 2016; Hartwig et al., 2017; Marks et al., 2013; Parish et al., 2012; Taggart

et al., 2018). Fidelity is the extent to which a course is delivered as planned and adheres to its theory. In the context of health education, it is important because it enables consistent delivery as well as understanding of the causal mechanisms regarding behaviour change.

Educational follow-up was identified by Dunkley et al. (2017) and Taggart et al. (2018) as a mechanism that could support longer term embedding of learning although most of the interventions evaluated within this review only included follow-up for research purposes.

4.2 | A context for effective health education

A participant's personal context affects the knowledge, experience and motivation they bring to a learning environment (Bergström et al., 2014). Additionally, the learning environment provides context that influences participants' experience (Bergström et al., 2014; Bodde et al., 2012). In a study of barriers and facilitators in health education for adults with intellectual disabilities, Bergström et al. (2014) found that support from within *and* outside the formal learning environment was important, and supportive post-education context was subsequently important in embedding learning. In this respect, context can also support the reinforcement of learning and behaviour change.

Individual motivations and abilities are another important contextual component of successful learning, and this is reflected in the learning theory used by some of the programmes in this review. Several studies suggested that the motivations, abilities and interests of participants can affect learning outcomes (Bergström et al., 2013; Dixon-Ibarra et al., 2017, 2018; Witton et al., 2017). In a review of a dental ambassador programme, Witton et al. (2017) concluded that it was critical to design a programme that was realistic about the abilities and skills of the participants and could account for diverse needs.

Other important contextual components included a comfortable and safe learning environment, an ethos of participation, collaborative working and enjoyment (Heller et al., 2004; Witton et al., 2017). These generated high levels of engagement and subsequent acquisition of knowledge and skills. Additionally, familiarity and consistency can support effective learning (Dunkley et al., 2017). Dunkley et al. (2017) found that combining use of the same venue with a core group of educators ensured continuity and developed rapport. The authors suggested that educators should also gain an understanding of each participant prior to starting a course. This enables familiarization and development of plans to meet individual needs. It also enables the establishment of mutually agreed guidelines to support group functioning.

5 | CONCLUSIONS

This review aims to identify the effective components of health education for adults with intellectual disabilities that are raised in the

existing literature in the context of self-care, infection prevention and the ongoing management of good health. Although the range of studies in this review is broad, authors identified similar conclusions regarding the components of effective health education. These include fidelity alongside flexibility of delivery, accessibility of materials, and a supportive and motivational learning context. The means of measuring the effectiveness of these components varied considerably however, and the focus tended to be on outcome evaluation. Further research is needed to explore the learning context as experienced by people with intellectual disabilities, particularly the education environment, the personal context of course participants and how this relates to their learning outcomes and behaviour change. Whilst the studies included in this review described some components of effectiveness and outcomes, few addressed in depth the learning experience of participants and its effect on outcomes. Further research is needed in health education evaluation to explore the learning context as experienced by adults with intellectual disabilities, particularly the education environment, the personal context of course participants and how this relates to their learning outcomes and behaviour change.

In this review, only Eley et al.'s (2018) pilot study addresses the substantive issues of self-care, infection prevention and antibiotic use. In order to ensure adults with intellectual disabilities can understand and address these concepts, more evidence is needed on the effectiveness of health education in improving knowledge and behaviour in this respect. This includes evidence on whether such programmes work in the short, medium and longer term and on the development of appropriate outcome measures. Additionally, the fact that few of the studies in this review used collaborative, inclusive or participatory research methods highlights a need for a better understanding of how such methods can shape good quality health education evaluation.

5.1 | Strengths and limitations

A major strength of this review is that it systematically analyses important issues in public health education accessible to adults with intellectual disabilities. By objectively selecting papers and analysing narrative text, it has been possible to identify what is effective in this context. This review also enabled comprehensive understanding of methods of measuring outcome, their strengths and limitations.

A potential limitation is that the data extraction and analysis was conducted by just one person. Whilst every effort was made to search for and include all relevant studies, the volume of papers was large and it is possible that a relevant study may have been overlooked.

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